



Infected Blood Inquiry

# The Report

People's Experiences  
Treloar's

2 of 7

20 May 2024  
HC 569-II

Infected Blood Inquiry

# **The Report**

Presented to the House of Commons pursuant to section 26 of the Inquiries Act 2005.

20 May 2024  
HC 569-II



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## 2.1 People's Experiences

### Introduction

*“Hopefully, the public will get a glimpse of what we have had to suffer for decades. For that’s all it will be, a glimpse. The public will never see the true pain and anguish that we and our loved ones have had to suffer.”* Pete Burney.<sup>1</sup>

Some disasters are seared into the national memory, when they happen on one day or in one place. But there has been no particular day, no one-off event, that our nation will for decades associate with the deaths of men, women and children as a result of infected blood and blood products. It is too rarely acknowledged that suffering continues to this day. This disaster happened – and continues to happen – in every part of England, Northern Ireland, Wales and Scotland, and often has had to happen largely behind closed doors as people and their families lived and live with the consequences of the treatment they received, not able to realise the lives they hoped to live. The weight of unfulfilled hopes and imagined lives, or opportunities in life made unattainable, is almost unbearable.

For so many people, the blood – or the blood products they received – that was meant to help them, or their loved ones destroyed much of what life should be. What followed was life-changing, in many cases soul-destroying. It had all-encompassing effects on their day to day life: on marriages, family life, work, finances and homes. It has damaged relationships. Many have died and continue to die.<sup>2</sup> Children faced the loss of parents and parents faced the loss of children. The failure of government to take responsibility for what has happened has compounded the psychological burden.

This chapter addresses the impact of infected blood and blood products on people who have been infected and affected. The Inquiry received over four thousand statements from people infected and affected. Each of them has been read carefully. Some who gave those statements are known to the Inquiry, but have decided to remain anonymous to the public. Many feel a need to protect their identity and way of life since their experience is that stigma remains all too real. There are those who want their voices to be heard, but after decades of being unable to speak out, do not wish even to make a statement protected by anonymity. To help them give their accounts, the Inquiry appointed three experienced social workers as “intermediaries” to meet them for a confidential conversation, and report on their collective experiences. These accounts have echoed the evidence given anonymously, which itself has echoed the named witness statements received.

The stories shared so powerfully in each statement and in the two intermediaries’ reports were amplified, illustrated and confirmed by the oral evidence, often assisted by the presence

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1 Pete Burney Transcript 26 September 2018 p53 INQY0000000\_004. Pete died in December 2019.

2 The Inquiry has endeavoured to recognise where people infected have died after giving a written statement quoted in this Report.

of partners, family members, or friends sitting alongside; or as part of a panel of people with certain experiences in common.

For a large number it was the first time they had spoken in public about their ordeal. It takes real courage to break silence after so many years, and I would like to pay a personal tribute to all those who were prepared to do so – in a written statement; in private to an intermediary; in the hearing room; or by video link. From so many different perspectives and backgrounds they have painted such a compelling overall picture that, taken together, some conclusions have become overwhelmingly obvious.

Behind each statement there is a deeply personal story that has been laid bare in public, usually addressing painful and distressing matters. It is not possible to refer to each of those statements in this part of the Report. The statements themselves will remain publicly available and this chapter provides an overview of the broad themes expressed by the people infected and affected.

I need to recognise, however, that it is simply not possible in the account which follows to capture the full scale of the horror, and tragedy, that has been caused by this disaster. Nor is it possible to convey the resilience of each person who has been infected and affected by infected blood. Though this chapter highlights only some of the pieces of a complex jigsaw puzzle, every individual story has made a valuable contribution to the findings, conclusions and recommendations of this Report.

## Communication of risk

### Blood products: what were people told?

#### *Haemophilia A and Factor 8*

Factor 8 was understood to be “a miracle drug to the haemophilia community.”<sup>3</sup> Paula Bateman describes how Factor 8 treatment “was thought to be a godsend. It gave [her brother] Michael more freedom.”<sup>4</sup> One mother was not advised of any risks with the treatment and it “was considered to be a ‘wonder drug’ because it allowed us to go out and play and ‘be boys again’.”<sup>5</sup>

Factor 8 was not a miracle drug. The infections it transmitted catastrophically affected an entire community. As Adrian Goodyear describes “The ‘wonder drug’ ... moulded and shaped my future but not in the way it was intended to. For me, my half-brothers and so many friends, it was our death call and remains so.”<sup>6</sup>

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3 Written Statement of ANON para 11 WITN1428001x

4 Written Statement of Paula Bateman para 5 WITN7118001

5 Written Statement of ANON para 5 WITN1310001

6 Written Statement of Adrian Goodyear para 142 WITN1243001

The risks of infection were not discussed with people receiving Factor 8 or, in the case of children, their parents. For some, the emphasis of the advice they received was firmly on the positive benefits of Factor 8 without any discussion of the risks. One woman recalls that *“We were never informed of any risks inherent in the taking of Factor VIII ... We were told that it was wonderful and that with the treatment, [my son] would be able to live a normal life. My daughter remembers finding a Miffi-esque book which we were given about it with the line ‘with just a little prick you’ll feel better’.”*<sup>7</sup> One man had an adverse reaction to cryoprecipitate and his father asked his doctor what could be done if he had a bleed and he replied: *“we have this new fantastic and revolutionary treatment called Factor VIII, it will change your life”*.<sup>8</sup> He was treated with Factor 8 from then on and was infected with HIV.

The parents of a boy with mild Haemophilia A were told that he would only be given British blood products *“but this didn’t happen and I was given American products for some reason.”* His parents were not given any information before he received Factor 8 about any risks of infection.<sup>9</sup> He was infected with HIV, Hepatitis B and Hepatitis C.

For most people there was simply a lack of knowledge of there being any risks. One man with severe Haemophilia A has described being given Factor 8 treatment from a young age and injecting it himself by the age of seven. Risks of infection were not discussed with his parents before Factor 8 was administered and his *“parents didn’t know that blood products could be dirty.”*<sup>10</sup> He was infected with HIV, Hepatitis B and Hepatitis C. Julie Fletcher describes neither her parents or her brother Kevin ever being advised of any risks of Factor 8, rather she says: *“The impression that we got from the medical staff was that if we wanted him to stay alive then he had to have it.”*<sup>11</sup> Kevin was infected with HIV and Hepatitis C and died in 2018.

Others, both adult patients and the parents of children with bleeding disorders, placed their trust in doctors and accepted the shift away from cryoprecipitate without question. Terry White, a man with mild haemophilia, was first treated consistently with Factor 8 at age 16. He explains that *“I was old enough for the doctors to discuss all health issues that affected me. However, they never gave me or my parents any or any proper advice. It did not occur to us to question the doctors on how best they felt I should be treated. We took it for granted that the FVIII products had been properly screened and were safe to use. Like any other reasonable family, we placed utmost faith in the doctors”*. He remembers Factor 8 being described as the *“new wonder drug”* and as *“good stuff”*.<sup>12</sup> He was infected with Hepatitis C. One man, infected with HIV and Hepatitis C, says *“No one ever warned me or my parents about the risk of infection through FVIII concentrate before treatment. I am from a good,*

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7 Written Statement of ANON para 37 WITN3123001

8 Written Statement of ANON para 7 WITN2734001

9 Written Statement of ANON para 7, para 9 WITN1297001

10 Written Statement of ANON para 14 WITN0008001

11 Written Statement of Julie Fletcher para 14 WITN7459001

12 Written Statement of Terry White para 10, para 22 WITN1724001

*upstanding, traditional Indian Sikh family. My parents trusted my doctors implicitly and [our doctor] could do no wrong in our eyes.*"<sup>13</sup>

Neil Weller has Haemophilia A: *"No advice was given to my parents at any time about the use of or risks associated with blood products. I was diagnosed with haemophilia at infancy because of recurrent bruising. Patients and their parents put their trust in the doctors and we were all led to believe that they would give you factor which would make you better and help our bleeds. My mother and I trusted the doctors and medical staff. As a mother, when you see your child in agony, you just want them treated and for them to be eventually free of pain. You did not question them, you had no reason to. No advice was given to me subsequently. I was never offered a choice of product or recall being aware that there was a choice for the patient."*<sup>14</sup> Neil was infected with Hepatitis C.

Nicola Jones, a symptomatic carrier of Haemophilia A, received Factor 8 when she had a tonsillectomy at age nine, as a result of which she was infected with Hepatitis C. No advice was given about the use of, or risks associated with, blood products. She and her parents were not even aware that her treatment had changed from cryoprecipitate until *"later in life."*<sup>15</sup>

Other witnesses were positively told that the risks were tiny or that the products were safe. One man, treated with Factor 8 concentrate from the age of 13 months and infected with Hepatitis C in consequence, recalls that *"As a child I was unaware of the dangers of Factor VIII. My parents trusted my doctors implicitly and took everything they said as gospel. My parents' recollection is that they were told the risks were so small ... that it was no different from the small risk of side-effects from taking any off the shelf medicine."*<sup>16</sup> Stephen Martin-Hanley's mother *"had heard rumours that the Factor VIII treatment was potentially dangerous and therefore didn't want me put on it; however Dr Hill and Sister Marion assured her that the product was completely safe."*<sup>17</sup> Stephen was infected with HIV and Hepatitis C. Lynda and James Heatlie describe being told that the Factor 8 their late son Brian was receiving came from America and was *"refined like fine wine not like British rough plonk."*<sup>18</sup> Brian was infected with HIV. Steven Newby says *"my parents raised the question of the risk of infection and Dr Ludlam described the risk of me contracting an infection from the treatment for my haemophilia as 'infinitesimally small'."*<sup>19</sup>

### *Haemophilia B and Factor 9*

Much the same pattern is apparent from the evidence in relation to Factor 9. John Morrissy states that his mother and father were *"told that the Factor IX treatment was a 'wonder drug'*

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13 Written Statement of ANON para 8 WITN3845001

14 Written Statement of Neil Weller para 9 WITN1598001

15 Written Statement of Nicola Jones para 9 WITN1756001, Nicola Jones Transcript 28 October 2019 p125 INQY1000045

16 Written Statement of ANON para 10 WITN1436001

17 Written Statement of Stephen Martin-Hanley para 7 WITN1376001

18 Written Statement of Lynda Heatlie para 8 WITN0833001, Written Statement of James Heatlie para 8 WITN0832001

19 Written Statement of Steven Newby para 6 WITN2233001



*for haemophiliacs, she was given the impression that treatment was improving at the time ... The Factor IX treatment seemed very positive, nothing concerning was discussed with my mother nor were any side effects discussed. There was no reason for my mother to object to the new treatment and, as a result, I was treated with Factor IX.*<sup>20</sup> He was infected with Hepatitis C.

Cain Squires notes that he and his mother were not given any advice about the risks of receiving Factor 9, which infected him with Hepatitis C: *“At that time we trusted the doctors implicitly and we only attended hospital if it was serious and therefore we would be unlikely to question any of their decisions.”*<sup>21</sup> David Whistler was infected with Hepatitis C as a result of receiving Factor 9: *“Prior to receiving FIX [Factor 9] I was never informed that the treatment carried a risk of infection/s. I spoke to my mother about this but she was of an era where she would not question the doctor’s advice or authority and believed that anything they said or did was for my wellbeing. When questioning my mother earlier this year about what was mentioned to her at the time with regard to infected blood risk, she said nothing was ever mentioned to her by Dr Scott or his team.”*<sup>22</sup>

Shirley Smith recalls attending a pre-operative assessment with her father, who had moderate Haemophilia B, in 1980 or 1981 for dental extractions and says that whilst the dangers of experiencing a severe bleed were explained to him, *“My father was not provided with any information surrounding the risk of being exposed to blood borne infection associated with the use of Factor treatment. I was present in the room during the pre-operation assessment, and this information was not discussed.”*<sup>23</sup> He was infected with Hepatitis C.

One man with severe Haemophilia B received home treatment and weekly prophylactic treatment with Factor 9. He was *“given no advice regarding the risks involved ... I knew that FIX was made from human blood products but no other information was provided about the risks involved. I was told that the treatment was a step in the right direction and it would give me a better quality of life.”*<sup>24</sup> He was infected with HIV and Hepatitis C and has now died.

Barrie Dennis, who had mild/moderate Haemophilia B, was treated with Factor 9 concentrate on seven occasions between 1977 and 1989, often for dental work. He was *“only ever told that my Factor IX was £1,000 per shot and was made up of blood plasma from hundreds of people. I was not given any other information about the product or told of any potential risks of the treatment.”*<sup>25</sup> He was infected with Hepatitis C and died in 2022.

John Shackleton confirms that there was *“no discussion surrounding any risks associated with taking Factor IX.”* His mother was a single parent *“and I was her only child which meant that she was very protective of me. She always told me she was informed that Factor IX was*

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20 Written Statement of John Morrissy para 9 WITN1409001

21 Written Statement of Cain Squires para 7 WITN1538001

22 Written Statement of David Whistler para 8 WITN1603001

23 Written Statement of Shirley Smith paras 21-22 WITN6875001

24 Written Statement of ANON para 10 WITN1158001

25 Written Statement of Barrie Dennis para 6 WITN1185001

*safe to use and that it would allow me to lead a 'normal' life.*" He was infected with Hepatitis C and in turn his mother was infected following an accident when he was 11. *"Given that we had no idea that I had any kind of infection my mother didn't take any precautions and helped me exposing her to my blood."*<sup>26</sup>

One man with Haemophilia B recalled discussing the "new treatment of factor IX" with Dr Forbes at Glasgow Royal Infirmary: *"I remember I asked him if there were any risks ... He said 'Not really'. He did explain that I could get an allergic reaction. He also said that there was a risk of a type of hepatitis ... He said the effects of the type of hepatitis we might develop would be the equivalent of a stomach upset."*<sup>27</sup> He was infected with Hepatitis C.

### *Von Willebrand disorder*

People with von Willebrand disorder received a variety of treatments including cryoprecipitate, Factor 8 and blood transfusion, but the risks of infection were not discussed. One woman describes that she and her parents were *"never advised of the risk of blood products or given any treatment options"* for the treatment of her von Willebrand disorder and that it made *"no sense why the Hospital Authorities switched my treatment from Cryoprecipitate to Factor VIII concentrate. I just recall being told by the registrar that there will be a switch. The matter was never discussed with my parents and no options were given."*<sup>28</sup> She went on to be infected with HIV and Hepatitis C. Another woman recalls that her son received transfusions and cryoprecipitate on different occasions and *"No information was given to us beforehand about the risk of [our son] being exposed to infection or becoming infected. It was a completely uninformed decision."*<sup>29</sup> He was infected with Hepatitis C.

When Kevin Roberts was treated for von Willebrand disorder: *"Neither I nor my parents were given any information what so ever about there being any risk of infection from blood products the doctor just said 'We've got something that will slow your bleeding, it's a concentrate and it will sort out any bleeding problems'. That is all we were told."*<sup>30</sup> He contracted Hepatitis A, Hepatitis B and Hepatitis C. Michael Leimanis, whose diagnosis of von Willebrand disorder has since been questioned, was treated with Factor 8 when he injured his hand and was infected with Hepatitis C. He recalls that *"At no stage was anything mentioned to me about the potential risks of infection from using blood and blood products."*<sup>31</sup>

Lesley Brownless has mild von Willebrand disorder. As a child she was treated with blood products for minor surgery such as tooth extraction and removal of a mole. Her mother *"was never given any advice or told of any potential risks involved in receiving this treatment. I was never asked for my consent. Had I been made aware of any risk involved I would never have consented to this form of treatment, unless of course it was a life saving necessity*

26 Written Statement of John Shackleton para 15, para 18 WITN1705001

27 Written Statement of ANON para 5 WITN2294001

28 Written Statement of ANON paras 39-40 WITN5696001

29 Written Statement of ANON para 8 WITN2151001

30 Written Statement of Kevin Roberts para 9 WITN1492001

31 Written Statement of Michael Leimanis para 6 WITN6363001

*which of course it was not.*” When Lesley became an adult, she was “*never*” given any advice or warnings about the risks.<sup>32</sup> In the mid 1990s she learned that she had been infected with Hepatitis C.

Rosamund Cooper has severe von Willebrand disorder and received multiple treatments; her parents were “*never told of the potential risks of having the blood products or undergoing the blood transfusions.*”<sup>33</sup> Susan Chadwick was treated with Factor 8 “*on a number of occasions as and when needed to treat cuts and bleeds and also ahead of surgical procedures to include dental treatment.*” She was “*not provided with any information or advice beforehand about the risk of being exposed to infection*”. Nor were her parents warned of the potential risk: “*I was simply told if I did not have treatment, I would bleed to death. I thought I had no choice in the matter.*”<sup>34</sup>

### *Other factor deficiencies*

Denisia Gray had deficiencies of Factors 5, 7 and 10 but particularly Factor 10. She was initially treated with cryoprecipitate and subsequently with Factor 8. She said: “*Prior to being treated with it, I was told nothing of Factor VIII. The only thing I knew was that each phial of the concentrate had been created using approximately fifty units of blood ... I had no reason to believe that the Factor VIII I was taking was in any manner or form ‘unsafe’.*”<sup>35</sup> She was infected with Hepatitis C and has now died. Greg Stokes has severe Factor 10 deficiency and received Factor 9 products, which at the time contained Factor 10 as well; he was infected with Hepatitis C. His parents were not informed of the risk of being exposed to infection from blood products.<sup>36</sup>

Wayne Johnson received both whole blood transfusions and Factor 7 concentrate to treat his Factor 7 deficiency. He says “*I seem to recall when the first Factor concentrate was made available to haemophiliacs it was promoted as a brilliant and life changing product which was 96% safe. As a figures oriented person, I felt positive about those odds and I was persuaded by them. It was all very much good news that Factor VII was available and there was absolutely no advice given about the risks of this treatment.*”<sup>37</sup> He was infected with Hepatitis C.

### *Factor products given to people misdiagnosed with bleeding disorders*

One woman’s son was misdiagnosed with mild Haemophilia A and received factor concentrates on two occasions. She says “*My husband ... and I were not told beforehand*

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- 32 Letter from Dorothy Ryan discussing her daughter Lesley’s treatment with blood products 15 November 2018 WITN1111004. Emphasis in original. Lesley Brownless Transcript 2 May 2019 pp138-139 INQY1000003
  - 33 Written Statement of Juliet Batten para 22 WITN0343001, Rosamund Cooper and Juliet Batten Transcript 18 October 2019 p89 INQY1000044
  - 34 Written Statement of Susan Chadwick paras 5-6 WITN1148001
  - 35 Written Statement of Denisia Gray para 26, para 28 WITN0404001
  - 36 Written Statement of Greg Stokes para 16 WITN2041001
  - 37 Written Statement of Wayne Johnson para 11 WITN1311001

*about the risk to [our son] of infection from FVIII concentrates.” It was subsequently discovered that he did not have haemophilia.<sup>38</sup> He was infected with Hepatitis C. Fiona Rennie, who was infected with Hepatitis C, was misdiagnosed as having von Willebrand disorder as a child. At sixteen, she had an operation to straighten her teeth and was “informed that the procedure would need to be supported by Factor VIII. I did not know what this was at the time, but I was desperate to have my teeth done. I was told that everything would be fine and at no point was I made aware that the blood product may put me at risk of infection. If my mother had been told of any such risk, she would have withdrawn consent from the operation immediately.”<sup>39</sup>*

### *Immunoglobulins*

One woman received both intravenous immunoglobulin (“IVIG”) and transfusions to treat her severe idiopathic thrombocytopenia purpura.<sup>40</sup> She says “I did not know in 1984 when I first had IVIG that it was a blood product. I assumed it was a drug product to raise my platelets. I don’t think I realised that it was a blood product until more recently (in the last ten years or even less).”<sup>41</sup> She was infected with Hepatitis C.

Peter Warner was treated with IVIG to treat a deficiency of immunoglobulin from May 1985. Peter’s GP wrote to his treating clinician to explore alternative treatment when he had bad reactions to his regular intramuscular immunoglobulin injections. The letters discussed the costs of Sandoglobulin, a new commercial IVIG treatment and noted that “they are not entirely free of side effects” but these were “usually negligible”. There was no discussion in the correspondence about the risks of viral infection and “he was not given full information about the risks of being treated intravenously with commercial product sourced from human plasma and so did not consent to this.”<sup>42</sup> He was infected with Hepatitis C.

Ronald Cooper Ebbrell was treated with gamma globulin injections and then fresh frozen plasma on a regular basis for hypogammaglobulinaemia,<sup>43</sup> before starting treatment with Sandoglobulin. His wife said: “At no time was my husband advised as to the risks of contracting infections through blood product infusions.”<sup>44</sup> He was infected with Hepatitis C and died in 2000.

### **Blood transfusions: what were people told?**

The evidence of people infected through transfusions, and their families, consistently shows that patients were not warned of the risks of infection to inform their decision about whether

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38 Written Statement of ANON para 7 WITN4722001

39 Written Statement of Fiona Rennie para 7 WITN2933001

40 A bleeding disorder characterised by low platelet count.

41 Written Statement of ANON para 5 WITN4176001

42 Written Statement of Patricia Warner para 9, para 26 WITN1994001, Letter from Dr R Thompson to Consultant Haematologist 2 April 1985 WITN1994002

43 An immune deficiency disorder characterised by low level antibodies (immunoglobulins).

44 Written Statement of ANON para 13 WITN0102001

or not to have a transfusion. In cases where the transfusion was a necessity, people did not receive adequate information about the risks involved so they could be alert for symptoms and seek testing when it became available. One woman describes receiving blood after post-natal haemorrhages and miscarriages: *“I was never told that there was a risk of being infected with anything when I was given the blood transfusions. It was just a case of being told the nurse was coming to give me blood and that was it. There was no explanation.”*<sup>45</sup> She was infected with Hepatitis C.

Jayne Young, who received transfusions when she had an ectopic pregnancy and contracted Hepatitis C states that *“the risks of being exposed to infection through blood transfusion were not explained to me at any stage, nor did my ex-partner receive any such explanation that he subsequently relayed to me.”*<sup>46</sup> One man recalls his wife being given a transfusion in 1991 after a caesarean section to deliver their twins who were born six weeks premature due to pre-eclampsia. He recalls: *“No one advised us as to the risk of infection through the blood transfusion. I find it astonishing that unscreened units of blood (with a limited shelf life of weeks) were still being used as late as 1991.”*<sup>47</sup> She was infected with Hepatitis C.

Information and advice regarding the risks of infection were not provided to one woman receiving antenatal care in hospital. She was left physically weakened by a haemorrhage and had become anaemic *“but her life was not in danger and she did not need the transfusion. She needed to rebuild her iron reserves instead.”* Her husband, who was a GP, described a consultant who would *“not let up about the transfusion”* which took place in the husband’s absence. She was infected with HIV, as was her son, and died some years later, leaving five children.<sup>48</sup>

Blood transfusions were generally presented as beneficial without any reference to risks. One woman was advised to have a blood transfusion after giving birth to a daughter in 1984. When she refused, saying *“No, I don’t want someone else’s blood in my body”*, the nurse said she would get better more quickly if she had a transfusion. She asked *“Can’t you give me tablets instead?”* but the following day, when her sister visited, she was *“crying in bed whilst being transfused.”* She was infected with HIV which was transmitted to her infant son.<sup>49</sup> She died in 1995 and her son died in 2007.<sup>50</sup>

Many of those who received transfusions and were infected with Hepatitis C simply trusted the doctors. Another woman had an emergency Caesarean section and while in theatre, she recalls *“there was panic in the theatre, they were saying, ‘Have we got the blood?’, ‘Have we got the blood?’. I received the transfusion. I didn’t have a say as to whether I consented to this, from memory they just did it. I trusted the hospital staff.”*<sup>51</sup> Another woman

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45 Written Statement of ANON para 14 WITN0018001

46 Written Statement of Jayne Young para 4 WITN0948001

47 Written Statement of ANON para 8 WITN7546001, Written Statement of ANON para 9 WITN7545001

48 Written Statement of ANON paras 5-7 WITN5657001

49 Written Statement of ANON paras 3-5 WITN0822002

50 Written Statement of ANON para 10, para 36 WITN0603001

51 Written Statement of ANON para 2.9 WITN0031001

who was given a transfusion during a caesarean section says: *“After the delivery, I was informed I had been given four pints of blood. I cannot remember why but I assume this was due to blood loss. I trusted the doctors, and it was one of those instances where I was grateful to be alive, and my baby was healthy. No one ever warned me about any potential risks associated with receiving blood or a blood transfusion. In hindsight, if they had been aware of such risks, they should have informed me.”*<sup>52</sup>

Many witnesses acknowledge that the transfusion saved their lives. However, the lack of information about the risks of transfusion took away their ability to make an informed decision and give informed consent, if they were in a position to do so, and in all cases to know that infection was a possibility. Stephen Smith was unconscious when he was given blood and says: *“[the blood] most likely saved my life. Nevertheless, in an ideal situation, I should have been told of the potential risks ... after I had regained consciousness. At least then I would have been aware and known of the risks associated and been able to live my life accordingly.”*<sup>53</sup> Joan Lewis’ son Damian was given platelets, whole blood and plasma transfusions prior to and after a bone marrow transplant in 1983. She and her husband were not provided with *“any information or advice beforehand about the risk of Damian being exposed to HIV through contaminated blood.”* Four years later they were told that he had HIV. He died, aged 20, in 1995.<sup>54</sup> A man infected with Hepatitis C is grateful for the blood transfusion which may have saved his life, but thinks it *“unforgivable that I was not thereafter informed of the risks. If I had been informed of the risks that would have made such a difference; at least I could have dealt with the fact that I had been infected before my liver was damaged irreparably.”*<sup>55</sup>

Other people were positively reassured that the transfusions were safe. Lesley McEvoy’s evidence on this was particularly stark and is discussed in the *Commentary on the Government Response*. There were other examples of positive assurances as to safety being given. One woman received a transfusion in 1987 before she had a caesarean section: *“When the nurse was putting the transfusion up I asked her if the blood was ok, and she said yes, it was fine and told me it had been treated with gamma rays.”*<sup>56</sup> She contracted Hepatitis C. Jacky Barber received a blood transfusion in September 1990 in the days leading up to major abdominal surgery because of colitis. She and her husband were concerned about the need for blood transfusions:

*“HIV and infected blood was quite a topical conversation at the time that I received the transfusion and my husband and I did have concerns. My impression from everything I read and heard through media coverage over the years was that since the 1970s and 1980s, a transfusion was safe. I remember being concerned about it and wanting to have these conversations with the medical team. When*

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52 Written Statement of ANON paras 10-11 WITN7600001

53 Written Statement of Stephen Smith para 79 WITN6605001

54 Written Statement of Joan Lewis para 10 WITN2768001

55 Written Statement of ANON para 34 WITN1889001

56 Written Statement of ANON para 3 WITN1987001

*I was first told that I needed the blood transfusion, the surgeon ... assured me that the blood was safe. On the day of receiving the blood transfusion, I had an in depth conversation with the surgical registrar and was reassured by him that I was lucky to have the blood as it was now safe. I recall the registrar saying that if it was a couple of years earlier, they would not have been giving me the blood as it would not have been safe. Both those statements made me feel like the blood was safe and that I did not need to get tested for HIV or hepatitis.”<sup>57</sup>*

In 2018 she learned that she had been infected with Hepatitis C.

### *Thalassaemia*

There was a similar lack of information for people requiring frequent blood transfusions to treat thalassaemia.<sup>58</sup> One woman with beta thalassaemia infected with Hepatitis C explains that *“Nobody warned me that the blood I was being given, carried risks of viral infection. I’ve grown up in National Health care. In the 1970s and 1980s, the culture was very paternalistic. As a patient, I didn’t have any agency in my medical care. I was just told that I needed the blood and so I took it. My consent was never obtained. It was very much a ‘doctor knows best’ mentality and I just did what I was told.”<sup>59</sup>*

Georgia Halwani talks about her brother, Costas, who had thalassaemia and died of Hepatitis C: *“Unfortunately, my parents’ knowledge and use of the English language was something of a barrier to their being able to fully engage with the clinicians treating Costas, so they were unaware of specific details such as where the blood he may have been given had come from, or of any risks it may have posed ... They had to accept what was being offered, as without intervention Costas would have been placed in greater jeopardy.”* Costas also had a blood transfusion during surgery in 1987: *“no mention of any risk associated with the blood he was given was mentioned at this time.”<sup>60</sup>*

Andre Andreou’s husband Mario, who had beta thalassaemia major and died of liver cancer in 2017, *“was never given any information or advice about there being a risk of being exposed to an infection by receiving blood; he had no clue that he could be infected by the contaminated blood. This was so even though he had many transfusions throughout his life. The knowledge of the fact he had become infected with hepatitis C came as a massive shock to him.”<sup>61</sup>*

### *Sickle cell disorder*

Sarah Akoni was a student nurse when she met her future husband, Omololu, in 1992. He had sickle cell anaemia and was in and out of hospital on a regular basis. He required

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57 Written Statement of Jacky Barber para 10 WITN0715001

58 A bleeding disorder characterised by reduced levels of hemoglobin.

59 Written Statement of ANON para 16 WITN7079001

60 Written Statement of Georgia Halwani paras 12-13, para 29 WITN0956001

61 Written Statement of Andre Andreou para 12 WITN1821001

blood transfusions frequently when he had a sickle cell crisis. In relation to consenting to a transfusion, Sarah is “*not sure whether he was asked each and every time he had a blood transfusion ... Omololu had sickle cell anaemia and therefore, he had to undergo regular blood transfusions.*” She does not “*believe Omololu was told of any risk of contamination from blood during the late 80s.*” Certainly when she was training as a nurse from 1992, after screening was introduced, she says that nurses “*didn’t gain consent or talk about contaminated blood when giving blood transfusions, only the risk of having a reaction to the blood.*” Omololu was diagnosed with Hepatitis C during the lookback process.<sup>62</sup>

When one woman’s daughter was five years old, she had her first sickle cell crisis:

*“[My daughter] was given oxygen and monitored for several days. After about three days, she began to get better. The doctors informed me that she could have a blood transfusion in order to speed up her recovery. I discussed this with my family, and my sister told me that I should not allow her to have a blood transfusion. My sister is a Jehovah’s Witness and medical interventions like transfusions are against her religion, so she thought I should not allow [my daughter] to have one if it was not medically necessary. I told the doctors that I did not want [my daughter] to have a transfusion, and noted that it should not be necessary because she was getting better. The following day when I was at work, [my daughter] was given a blood transfusion without my consent. No one informed me that she would be having one, and it wasn’t until I arrived at the hospital after work that I realised she was connected to a bag of blood ... I also did not understand why it had to be done while I was away, without any warning. The doctors laughed at me, and seemed to think I didn’t know what I was talking about.”<sup>63</sup>*

### **Organ transplantation: what were people told?**

Mr W’s wife was infected with HIV from a donor kidney. “*We were told that there is a danger with any operation but there was no mention whatsoever about HIV or the possibility of any infection arising from the donor kidney.*” The kidney donor had been involved in a road traffic accident and received “*massive blood transfusions*”, including a unit which was infected with HIV. The transplant went well but after a week or two, his wife “*began to get high temperatures and was extremely fatigued ... She was losing weight rapidly.*” She had numerous chest infections and pneumonia and died aged 33, three years after the transplant. At the inquest, Mr W asked the doctor how long his wife would have survived with dialysis if she hadn’t had the transplant and was told that “*she could have gone on for a few more years.*”<sup>64</sup>

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62 Written Statement of Sarah Akoni para 11 WITN1817001

63 Written Statement of ANON paras 7-8 WITN1823001

64 Written Statement of ANON para 2, para 8, para 10, paras 14-15, para 37 WITN2781001, ANON Transcript 9 July 2019 pp3-29 INQY1000030



In 1981, Louise Veale had a kidney transplant. She says: *“Before my kidney transplant, no one ever informed me that the procedure carried a risk of contracting a blood borne virus.”* She was informed that she was infected with Hepatitis C in 1992.<sup>65</sup>

For others it is unclear whether the infection arose from blood transfusions at the time of transplant or from the donor organ. Lesley Mason’s husband Chris had three kidney transplants between 1975 and 1984: *“He was infected with Hepatitis C following his third failed kidney transplant in 1984, around this time he was given many transfusions of whole blood and blood products. It is impossible to say which one gave him the infection.”* There was no indication given to her that the blood products he received could be contaminated, although she was unaware whether any information was given to him before he was placed in a medically induced coma.<sup>66</sup> Janis Dickson says *“Dad was diagnosed with Hepatitis C in 1992. Eight years earlier, in 1984 he received a kidney transplant, and my family believe that either the transplant or a blood transfusion that he received during the operation was the source of the Hepatitis C infection.”* As far as she was aware, her father was never informed of any risk of infection from the transplant or transfusion.<sup>67</sup>

### **What were people told about the risk of infecting or being infected by others?**

A number of people were infected by others, whether through sexual transmission, in utero transmission or other blood to blood contact.

Clair Walton was infected through her husband, Bryan. She says that he was not given any information or advice about the risks of infection associated with factor products. In early 1985, when they had been married for less than two years, Bryan was told he had tested positive for HTLV-3. Clair was handed a box of rubber gloves and they were advised that if they were to have sex they should use condoms and Clair says: *“and then that was it. That really was it ... we were left completely isolated ... we were just left to sort of work it out for ourselves.”* Clair was not tested until 1987. She says she was told she had probably seroconverted and had to await a second test: *“I went numb and floated through the next few weeks in a strangely numb state. The hospital told Bryan that my second test had come back HIV positive when he attended his own appointment but they did not tell me directly.”*<sup>68</sup>

Jill Cunnington describes her husband Robert being *“told there was something wrong with his blood”* in 1985. Both she and Robert were *“called in for testing ... Robert’s test came back HIV positive ... He was not given any advice on precautions to take and there was no warning about the possibility of passing the virus onto me”*. Her blood sample was initially lost and so she had to have another test done: *“I was advised I was not infected and would most likely be okay. However, six weeks later I was also told ... that I was HIV positive and*

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65 Written Statement of Louise Veale para 27 WITN5212001

66 Written Statement of Lesley Mason para 2, para 20 WITN0667001

67 Written Statement of Janis Dickson para 4, para 9 WITN3626001

68 Written Statement of Clair Walton paras 8-10 WITN1589001, Clair Walton Transcript 2 May 2019 pp1-18 INQY1000003

*that it was a death sentence.*” Jill and Robert had a five-year-old child and three-year-old twins at the time.<sup>69</sup>

Gaynor Lewis was infected with HIV through her husband Haydn. He was told in 1985 that he had been infected with HIV from blood products and from that point onwards they used protective measures. But prior to that they had had no reason to do so, Haydn having been given no information about the risks of infection (other than *“he may get jaundice but it was underplayed I think. It was nothing but, you know, he might feel ill for a short time.”*) Learning that Gaynor had been infected absolutely devastated Haydn: *“I saw a change in him from that day on. He felt guilty. He felt awful.”*<sup>70</sup>

Robert Derek-Ryan was infected in the womb. His mother was given several transfusions for anaemia when she was pregnant with him and Robert was born with high alanine transaminase levels. He was tested at age 18 when it was discovered that he had a chronic Hepatitis B infection. He says *“It came to light when my mother changed her GP, who noticed from her records that she had been given contaminated blood back in the 1980s and he advised I should have a test to see whether I had also been infected.”* His mother, Megan Ryan, says *“No one had ever mentioned to us that there was a possibility that Robert could have been infected. None of my previous GPs had picked up on it.”* She was given no information at the hospital when he was born about any risks of transmission.<sup>71</sup>

Keith Lloyd was advised that Hepatitis C could not be transmitted sexually but that blood spillages should be cleared up and toothbrushes should not be shared. When his wife Tracy was infected, he was *“utterly devastated”* and this led to a further decline in his mental health. Tracy was *“in total shock”* because they had *“religiously followed”* the advice given to Keith.<sup>72</sup>

The partner of a man infected with Hepatitis C from Factor 9 discovered that she had been infected too in 2017: she had never suspected it because they were aware that the main form of transmission was from blood to blood contact, they had been really careful and *“had never shared any razors or the like”* and her partner had been told that the risk of transmission through sexual intercourse was almost non-existent.<sup>73</sup>

One woman explained that she, her son and daughter were all infected with Hepatitis B. She was jaundiced but her doctor did not make the link to her son’s cryoprecipitate and after three months she was referred to a liver specialist who diagnosed Hepatitis B and the link was established to her son’s treatment.<sup>74</sup> She has since died.

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69 Written Statement of Jill Cunnington paras 4-6 WITN0154001

70 Gaynor Lewis Transcript 26 July 2019 pp4-10 INQY1000036

71 Written Statement of Robert Derek-Ryan pp1-3 WITN2608001, Written Statement of Laura Megan Ryan para 1, para 18 WITN0648001. Laura Megan Ryan and Robert Derek-Ryan Transcript 14 June 2019 p120 INQY1000020

72 Written Statement of Keith Lloyd para 7, para 12-13 WITN1683001, Written Statement of Tracy Lloyd para 7, para 9 WITN1351001

73 Written Statement of ANON para 13 WITN3668001

74 Written Statement of ANON para 15 WITN0353001

Mrs AU gave oral evidence anonymously and described how her daughter was infected with Hepatitis B at age nine months after she received plasma following an accident. Her daughter had another accident when she was aged four and *“was covered in blood and still bleeding.”* Mrs AU kissed and hugged her daughter and it was subsequently found that she had contracted Hepatitis B. She says that when her daughter received plasma *“we were given no information or advice about the risk of being exposed to infection through infected blood products.”*<sup>75</sup>

## Diagnosis

### HIV

The way in which people were told of their diagnosis of HIV varied widely. The impact was understandably devastating. For some, it was also a rollercoaster of emotion because initially some clinicians thought that people who were testing positive for HIV antibodies were not at risk, but they were subsequently told that they were. Daniel Hancox’s father was told at a routine appointment that he was HTLV-3 positive: *“Dr Peter Jones ... said to my father ‘If you have the antibody it means that you won’t get AIDS, you will be fine’. He told him that he must practise safe sex. My father had attended this appointment alone and had taken the bus. Upon his return he said to my mother ‘Peter has told me that I have the AIDS antibody’.”*<sup>76</sup> Andrew Hearne was told the same thing in Oxford: that he had AIDS antibodies *“which meant that I would probably not contract AIDS”* and then he was told *“I had, in fact, been infected with AIDS.”*<sup>77</sup>

#### *Informed at appointments*

A large number of people were called into appointments where they were told of their infection. The diagnosis came as a shock to many because they were not aware that they had been tested for HIV. One woman recalls that her husband, who was infected with HIV and Hepatitis C through Factor 8, *“had no knowledge that he was being tested for the above infections. He was just called in to be told about the test results which was when he found out he was tested.”*<sup>78</sup> Ian Cobbledick recalls that his mother was told she was HIV positive in 1986. She was called into an appointment for a blood test. After her diagnosis, when she asked why her blood had been tested in the first place *“she was told they were checking people like her who they knew had been given the HIV infected blood through transfusions.”* She had been infected by a blood transfusion that she received after surgery for an ectopic pregnancy.<sup>79</sup>

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75 Written Statement of ANON paras 6-7, para 12 WITN2590001. ANON Transcript 31 October 2019 p150 INQY1000048

76 Written Statement of Daniel Hancox para 10 WITN1270001

77 Written Statement of Andrew Hearne paras 7-8 WITN1281001

78 Written Statement of ANON para 17 WITN1474001

79 Written Statement of Ian Cobbledick para 4, para 8 WITN2103001

Other people were told in the corridor or told almost as an afterthought: one mother was told about her sons' HIV infection as one of the boys was going home after knee surgery. As she handed her son's notes into the haemophilia centre: *"a sister stuck her head through a window and asked 'would you like to know the boys' HIV test results?' She walked past us and said 'they are both positive, see you soon'. I didn't even know they had been tested. Many people were around us and overheard it."*<sup>80</sup> Maria Burke was told by Dr Geoffrey Savidge of her 14-year-old son's diagnosis with HIV as she was walking down the corridor in front of other people.<sup>81</sup> Stuart Gregg explains that *"Nobody sat me down and told me about my infections; it all transpired in a piecemeal fashion. The medical professionals knew about my infections years before they spoke to my mother or I about them. My mother received this information from talking to other mothers and from the Ward Sister who said 'Isn't it sad about the boys?'"*<sup>82</sup>

A number of witnesses made appointments after they watched something on TV that worried them. Mr M describes his mother receiving a phone call from someone they knew from the Haemophilia Society telling them to watch a documentary and being puzzled when watching it: *"After 20 minutes the penny dropped when it was reported that haemophiliacs were 'now falling victims to the mysterious disease' ... The programme was a bombshell."* When they spoke to their clinicians, the programme was *"dismissed ... as unscientific, exaggerated, melodramatic and just 'TV' stuff"*. Both he and his late brother were infected with HIV.<sup>83</sup> Robert Hodgkins was told of his diagnosis at an appointment with his parents at about 15 years old shortly after they watched something on TV: *"At the consultation, Dr Howes said that I had been exposed to HIV. My mother who was in the room with me did not understand what that meant. Dr Howes and another doctor attempted to explain that little was known about blood products and HIV and that we should not believe all what we watched on TV. This caused problems with my parents as for a year they did not realise that I was infected. I understood that I had it, but did not understand what it meant."*<sup>84</sup>

Many witnesses describe the diagnosis being delivered in a way that was blunt and dispassionate, with little empathy or kindness. One man recalls that he attended the haemophilia centre *"for a general appointment and at the end of this appointment he just mentioned, in a very matter of fact way, that I was HIV positive. I was totally stunned. [The doctor] then told me that I had only two or three years to live. He did not give me any information other than this; no advice, empathy or sympathy. I walked out of this appointment a very different man."*<sup>85</sup> A woman attended a *"routine appointment"* with her husband in

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80 Written Statement of ANON para 22 WITN1792001

81 Written Statement of Maria Burke para 12 WITN1123001

82 Written Statement of Stuart Gregg para 19 WITN1252001

83 Written Statement of ANON paras 9-10 WITN1291001. ANON Transcript 14 June 2019 pp12-15 INQY1000020. Dr Layinka Swinburne has responded to the statement and said *"I do not recall the conversation ... I do not, however, seek to challenge his account. What I will say, however, is that at no time did I tell him or any other patient anything that I did not believe to be true."* Written Statement of Dr Swinburne para 12 WITN3447001

84 Written Statement of Robert Hodgkins para 25 WITN0009001, Robert Hodgkins Transcript 15 October 2019 pp132-134 INQY1000041

85 Written Statement of ANON para 9 WITN1310001

relation to his haemophilia two days after their wedding when they were told that he was HIV positive: *“We were supposed to be starting a wonderful new life together but after the news, our world fell completely apart ... What was most worrying was that they did not refer us to an HIV specialist who could give us accurate information. We were just sent home with 2 condoms and that was it. There was no respect or empathy shown to us at all.”*<sup>86</sup>

Another woman’s daughter had been unwell since receiving a blood transfusion after a riding accident. Four years later in 1986 her daughter (now 19) had a serious thrush infection and was admitted into hospital as her white blood cell levels were concerning. Her mother then received a phone call to attend the hospital:

*“When I arrived at [the consultant’s] office, [my daughter] was already sitting there. [The consultant] addressed [my daughter] saying ‘Do you want to tell her or shall I?’ [My daughter] replied that [she] would rather he tell me. Then he blurted out she had AIDS. His manner of delivery was so awful. [My daughter] was upset and went on to say she was stepping out to have a cigarette. He said ‘you shouldn’t do that ... but I suppose it doesn’t matter now.’ It was just horrible the way it was put. I was devastated.”*<sup>87</sup>

One man was told that he was HIV positive, from receiving blood products, after being requested to attend an appointment at his treating hospital. He says: *“My wife and I duly attended and he told me that I was HIV positive. He conveyed this information to me in a very matter of fact way; I likened it to being told that I had the flu or measles. I was given no practical information about HIV and no information regarding the risks of transmission.”*<sup>88</sup>

By contrast, Derek Martindale describes seeking out testing for HIV in 1985 after the media started to report that people with haemophilia were a high-risk group in relation to HIV infections. Until then, no one from the hospital had contacted him about being tested. *“On Friday the 13th September 1985 I took a long lunch break from work and went to hospital to see Dr Wylie and find out the results of the test. Dr Wylie informed me, in a matter of fact way, that the test results had come back and that I was HIV positive. I was told that I would be dead within 12 months, I was 23 years old. Dr Wylie was very upset when he told me; he had been treating me and my brother since we were very small.”*<sup>89</sup>

One mother discovering that her four-year-old son was infected with HIV describes remembering *“the pictures of the old man and the scythe that gave the indication that a diagnosis like that meant death.”* She describes a meeting with Dr Evans at Great Ormond Street Hospital (“GOSH”): *“She was the doctor that usually treated the boys and told us what we already knew from the news. There was no available treatment and this infection was more or less a death sentence. We came away feeling numb and did not know what*

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86 Written Statements of ANON para 11, para 14 WITN0145001, para 2 WITN0145003

87 Written Statement of ANON paras 21-22 WITN7308001

88 Written Statement of ANON para 6 WITN1408001

89 Written Statement of Derek Martindale paras 13-14 WITN1688001

to do.”<sup>90</sup> Another person describes their “overriding memory” of when they were told of their HIV positive diagnosis as “feeling utterly alone and being unable to discuss how I was feeling with anyone.”<sup>91</sup> A mother describes being told that her son had HIV when he was on the ward being treated for a bleed. She recalls “I had to ask what it meant as I didn’t know what it was. I was told it could develop into AIDS. I wasn’t really listening; I was in shock so couldn’t take it all in.”<sup>92</sup> When one father and his wife were told of their son’s infection with HIV, their “world imploded with this news not least because of the stigma attached to the condition as well as our concern for [our son’s] long-term health.”<sup>93</sup>

### *Informed by letter or phone*

Some people received their diagnosis by letter. Dorothy Metcalfe recalls that her mother opened a letter from her father’s treating hospital, the Churchill Hospital, which “advised that my father was HIV positive. It also enclosed raffle tickets for purchase.”<sup>94</sup> Another woman’s husband was told by letter – “a terrible and inappropriate way to tell someone such serious news” – that he was HIV positive. She recalls that the letter “came on a weekend so we couldn’t get into contact with anyone to talk about it and had to worry the whole weekend.” As her daughter points out, being informed by letter was not secure: “We lived on a busy housing estate [where] mail was delivered to the wrong addresses regularly. Should this letter have been opened by someone other than my mother or father, the resulting social stigma for my family would have been catastrophic.”<sup>95</sup> Brenda Dibnah’s 17-year-old son, David “received a letter addressed to him, marked private, asking him to attend the North Stafford Hospital as his blood tests for HIV had come back positive.” She describes it as “a horrible way for us to be told.” Just before he died, David was told that he had also been infected with Hepatitis C and Hepatitis B.<sup>96</sup>

Carol Osborne’s late husband Jeffrey was telephoned at work by the sister at the hospital and informed that he had tested positive for HIV: “This was a terrible shock to us both and the manner in which he was told of the infection by the Sister over the telephone was appalling.”<sup>97</sup> Mavis Slater’s late husband Edward was telephoned and told he was HIV positive, something that she describes as “absolutely terrible” and “completely unforgivable.” She considers that they should have been called in to the hospital and told in person. He had not known that he was being tested for HIV “and therefore his diagnosis came as a complete shock to him.”<sup>98</sup>

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90 Written Statement of ANON paras 18-19 WITN0040001

91 Written Statement of ANON para 14 WITN1691001

92 Written Statement of ANON para 11 WITN7446001

93 Written Statement of ANON para 9 WITN7283001

94 Written Statement of Dorothy Metcalfe para 9 WITN1391001

95 Written Statement of ANON para 12 WITN1330001, Written Statement of ANON para 7 WITN1452001

96 Written Statement of Brenda Dibnah para 11, para 16 WITN1188001

97 Written Statement of Carol Osborne para 10 WITN1445001

98 Written Statement of Mavis Slater para 8, para 14 WITN1710001

### *Informed indirectly*

Some people were told about their infections indirectly. Michael Mason recalls discovering he was HIV positive when he received a diet sheet through the post about what to do if you had HIV or AIDS. He took it to his GP who told him he had been informed of his HIV positive status when he was 16 but, he says, *“they did not; it is not something you would forget.”*<sup>99</sup> Jennifer Beddoes’ father was informed that he had contracted HIV when he *“applied for a letter so that he could take his Haemophilia treatment and associated paraphernalia out of the country.”* He duly received the letter ... and it was stamped with a warning stating *“This person is infected with HIV”*. She describes this as *“utterly soul destroying for my father and mother; the news was exacerbated by the way in which it was delivered.”*<sup>100</sup> Another woman found out that her son was HIV positive when they were at the haemophilia unit at the Children’s Hospital. She recalls his *“notes were out of the filing cabinet and were open on the desk in the unit. There was a white sheet of paper stapled to the inside of [his] file with some results on it. As I was nosey and inquisitive I read this sheet of paper and felt numb. It showed that [he] was HIV positive.”*<sup>101</sup>

Steven Carroll found out that he was HIV positive when he was 13: initially he overheard a conversation between his mother and a doctor, *“and then a few weeks later I was reading an article in the newspaper and there was a TV personality’s son who had died from AIDS and I said to my Mum, ‘That’s what I’ve got, isn’t it’, and she went, ‘Yeah, yeah’.”*<sup>102</sup>

The Merry family were not told of their sons’ diagnoses by doctors. Matthew Merry describes what happened: *“My parents were waiting for a train ... one day and bumped into this other mother. She asked my parents if they had had any letters from the hospital and my parents said they hadn’t. She then told them that me and my brother were HIV+ then, as any Haemophiliacs that had tested negative were receiving letters confirming this ... At no point did the [hospital] ever ask my parents to attend the Haemophilia centre to inform them of our diagnosis.”*<sup>103</sup>

### *Informed in group meetings*

In a number of haemophilia centres, including Treloar’s,<sup>104</sup> group meetings were held to inform people about HIV – either before or after people were told about their diagnosis. One woman recalls her son’s diagnosis: *“I cannot remember the specific date when we were told about HIV but I do recall that there was a meeting I was asked to attend ... I think it was at the Children’s Hospital. It was in a big room and there were quite a few parents there. We were told that some of the children had been infected with HIV and some had*

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99 Written Statement of Michael Mason para 6 WITN1377001

100 Written Statement of Jennifer Beddoes para 6 WITN1087001

101 Written Statement of ANON para 15 WITN1586001

102 Steven Carroll Transcript 9 May 2019 pp57-58 INQY1000007

103 Written Statement of Matthew Merry para 16 WITN1389001, Written Statement of Simon Merry para 12 WITN1390001

104 See the chapter on *Treloar’s*.

*not. We were told that if we wanted to find out if our child had then we would have to ask for the information individually.*<sup>105</sup> A woman recalls her late husband attending a meeting in Edinburgh Royal Infirmary: *“From what my husband told me I believe that they were quite cagey with information and divulging anything. He certainly left with the impression that he was ok.”* In fact he had been infected with HIV, which he subsequently learned about in December 1986.<sup>106</sup>

Nigel Hamilton recalls a similar meeting in Belfast where

*“as haemophiliacs in the community of haemophiliacs ... we were asked to attend one of a number of group meetings that were being held ... There were several elements of that meeting that I found strange ... one of those was that ... gave us the choice ... that she wanted to know, and medical staff would take our bloods and test us, but it was up to us to decide whether individually or as families to be told [about whether we had HIV] ... If somebody chose not to be told, they were a potential time bomb or hand grenade. They could have infected a number of other people.”*<sup>107</sup>

Trevor and Louise Marsden attended the same meeting and Trevor decided that he did not want to know his test results. Louise says: *“She then passed over me to the next gentleman to my left ... I then put my hand up and said, a bit like Oliver, ‘I have a problem. I want to know’ ... even though I was known to Dr Mayne, she turned to her secretary and said ‘Put that down, Trevor doesn’t want to know but Mrs Marsden wants to know.’ To me, it was the touch of sarcasm because she referred to me as Mrs Marsden rather than Louise.”*<sup>108</sup>

One woman’s husband was told about his HIV infection, transmitted by Factor 8, in private by Professor Bloom and *“then as a part of a group of HIV sufferers from across Wales. I was present at this meeting. There were about 40 patients present in all. They were given very little advice. The majority formed the opinion that even Professor Bloom and his staff did not know very much at this initial stage”*; *“we were told ‘the ladies do not need to worry, they cannot catch it’. There was no warning about sexual transmission between partners.”*<sup>109</sup> The recollection of Jonny Evans was that the group meeting held in the lecture theatre *“wasn’t all that helpful as we all had more questions than we would ever have been able to receive answers to in the time available, but very few people spoke as like me they were all in a state of shock – each of us having been told that we had HIV.”*<sup>110</sup>

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105 Written Statement of ANON para 13 WITN1586001

106 Witness Statement of ANON para 15 WITN2202001

107 Nigel Hamilton Transcript 23 May 2019 p7-9 INQY1000011

108 Louise and Trevor Marsden Transcript 9 October 2019 pp4-5 INQY1000038

109 Written Statement of ANON pp8-9 WITN0047001

110 Written Statement of Jonny Evans para 69 WITN0362001



## Delayed communication of diagnosis

Other witnesses were not told of their diagnosis for some time, despite doctors being aware that they had tested positive. Martin Beard discovered he was HIV positive when, as an adult, he had to transfer from Birmingham Children’s Hospital to Staffordshire North Infirmary for his haemophilia treatment. He attended an appointment where the doctor said to him, with the office door open so others could hear the conversation, “*Good morning. I see you are HIV positive*”. Martin’s response was “*well that’s life*” and the doctor responded “*that is your life for the next two years*”. Martin subsequently discovered that clinical staff at Birmingham had known of his HIV status over a year earlier, and had deliberately hidden it from him. This emerges from a letter written on 11 October 1985 when he had received some treatment at Leicester Royal Infirmary, having been referred there from Birmingham Children’s Hospital. It was written by the doctor at Leicester to Dr Perry, a Senior Registrar in haematology at the Birmingham Children’s Hospital. “*We note that he (Martin) is HTLV 3 antibody positive, but is not aware of this and that you do not wish this to be divulged to him. We shall make every effort to comply with your wishes.*”<sup>111</sup>

William Dewdney was tested for HIV in September 1985, but for four months the hospital failed to inform him that he was HIV positive. His daughters point out that he should have been informed as soon as the hospital had the results because during this time he was unknowingly putting their mother’s life at risk.<sup>112</sup>

In early August 1985 a clinical review of Mrs AJ’s husband identified a low white blood count and neutropenia and referred to “*the possibility of the HTLVIII virus being present in this gentleman and causing this problem. We have therefore arranged for him to have viral titres and an HTLVIII titre assay. This was not mentioned to him, purely that we were looking for some underlying viral infection. We have taken the necessary precautions here and do not think that the patient should be alerted until we have evidence that this is necessary.*” In late August the consultant wrote to Dr Charles Rizza in Oxford informing him of the positive test result, yet Mrs AJ’s husband was not told of the result until October 1985. At that time they had been trying for a baby.<sup>113</sup>

111 Written Statement of Martin Beard paras 21-22, para 31 WITN0012001. Letter from Dr Vivian Mitchell to Dr David Perry 11 October 1985 WITN0012002. Dr Mitchell, of Leicester, explained that his understanding was that Birmingham Children’s Hospital “*were asking that he should not be told by a doctor he had never met before and would never see again*” and complying with the request “*refers to making sure Mr Beard was not informed inappropriately by an inadvertent ‘out of the blue’ remark perhaps when attending out of hours for treatment ... Had Mr Beard’s care been transferred from Birmingham to Leicester and he was unaware of his HTLVIII result, I would have arranged to see him and his mother with the Haemophilia Sister with time allowed for full counselling*”. Written Statement of Dr Vivian Mitchell paras 10-11, para 14 WITN3174001. Dr David Perry has responded and stated that at the time he was a trainee under close supervision by his consultant and “*The letter stating that I did not wish the HTLV3 antibody status to be divulged to Mr Beard would have been the instructions I had received from my senior consultant colleagues and not a decision I would have made independently.*” Written Statement of Dr David Perry paras 8-9 WITN3173002

112 Written Statement of William Dewdney p2 WITN1596002, Written Statement of Janet Webb para 11 WITN1596001, Written Statement of Sabrina Hayward para 10 WITN1280001

113 Letter from Dr C Cobb 6 August 1985 WITN1303011, ANON Transcript 11 October 2019 pp85-86 INQY1000040, Written Statement of ANON para 26 WITN1303001

### *Informing children of infections*

When parents were told of a child's diagnosis, they faced an agonising decision about whether, when and what to tell their child. A mother explains:

*“My husband and I had decided not to tell [my son] about his HIV, we wanted him to have a good childhood. I think this would have helped [my son] as he knew nothing about it and so when the boys at school were calling him ‘AIDS boy’ it washed off him like water off a duck ... [My son] was getting more independent by this time. He continued using the Factor 8 and when he was 16 I told him about the Hepatitis C and he said that he was going to beat it. When [he] was 18 I told him about the HIV and he was devastated. He was angry. He nearly threw his sister out of the house.”*

Her son died around the age of 20.<sup>114</sup> Another mother says that her son, then aged 11, *“always wanted complete honesty and therefore [Anon] explained to him the anxiety within the medical profession about blood products and the need for him to be tested for HIV ... [the test] confirmed that he was HIV positive. I recall [my son] saying ‘so those who save my life will also kill me’.”*<sup>115</sup> He died in 1995 at age 22. Alan and Christine decided not to tell their nine year old son, Christopher, when he was diagnosed with HIV. They waited until he was 15. Christine says: *“He was becoming a young man and you had the obvious dangers of becoming a young man, and it was time for him to realise his responsibilities, really, you know, and how dangerous things were, so I told him the situation. He seemed to take it very well ... He went out that night with some friends and he did come home and said ‘You know Mum, I was looking round and thinking I’m different, I’m not like these people’ and immediately separated himself out in [his head].”*<sup>116</sup>

One man did not find out about his diagnosis until his early teens when he discovered a letter to his father from his late mother, who had died of HIV contracted through a blood transfusion. He read the letter and showed it to his brother who *“thought that the contents of the letter suggested that I had also been infected with the condition. On the back of this, I think I went to the doctor and had a test which confirmed that I had the condition. Finding out that I had been infected completely messed up my head and led me to become an incredibly disturbed teenager.”*<sup>117</sup>

Other children worked it out for themselves: Roger Newman recalls *“when I was about 15/16 years old watching television when Haemophilia and AIDS were mentioned. I asked my mum whether that was about me and she said yes it was.”*<sup>118</sup>

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114 Written Statement of ANON para 32, para 43 WITN6924001

115 Written Statement of ANON paras 11-12 WITN3116001

116 Alan and Christine Fowle Transcript 8 May 2019 p17 INQY1000006

117 Written Statement of ANON paras 16-17 WITN4452001

118 Written Statement of Roger Newman para 14 WITN1431001

Some parents were deprived of making the decision when and how to tell their children of their infection because the child was told directly. In Brenda Haddock's case, she was not even told that her son Andrew had been told of his diagnosis:

*“When Andrew was around 12 years old, I took him to the Hospital for a tooth extraction. I was given his records to hold whilst we waited. Right at the front of his records it said that Andrew was HIV positive. We knew there was a possibility of infection as it had been in the news but the fact that I simply read it in Andrew's medical records was a complete shock to me. When I discussed this with Andrew, he informed me that Dr Hill had already told him about his diagnosis. He was only 12 at the time and Dr Hill had spoken to him without either parent being present.”*<sup>119</sup>

Another mother was told by phone that her son, aged 13, was infected with HIV and then *“The next day, [my son] heard nurses saying he was HIV positive as he was wheeled into theatre ... I did not know [my son] had heard in this terribly cruel way he was infected until he told me himself when I started to talk to him. This was heartbreaking for me that I was not with him.”*<sup>120</sup> One man was also told of his HTLV-3 diagnosis when he attended the haemophilia centre alone for the first time, aged 14 or 15. He was told that he must not tell anyone. He then saw a programme on TV that made clear that HTLV-3 was HIV and says: *“The realisation that I had a serious condition suddenly hit me. I felt like I had been given a death sentence and everything changed. It was crushing.”* He says he took the advice *“quite literally. I didn't even tell my parents.”* When his parents subsequently attended the centre about his younger brother's results, they were asked in passing if they knew of their older son's results as well, which they did not.<sup>121</sup> Another mother explains that her late son, who had Haemophilia A, *“became noticeably quieter and more reserved”* from the age of about 14. She says:

*“As a mother, I was concerned that something was wrong; however, staff [at the hospital] usually kept parents well-informed about what was going on with their children. [My son] finally told me what was wrong when he was 17 years old. He explained that he had been informed by staff around the age of 14 that he was HIV positive, having received infected blood products from America. He was told by staff not to tell anyone about his diagnosis, not even his parents. [My son] told me that he did not want to die. As a mother, his words still haunt me to this day.”*<sup>122</sup>

Tina Barton's son Daniel was twice treated with US factor concentrates in the first two years of his life. In 1985, when he was around four years old, she and her husband were informed that Daniel had tested positive for the presence of HIV. They decided not to tell him about

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119 Written Statement of Brenda Haddock paras 10-12 WITN1260001

120 Written Statement of ANON para 19 WITN3062001. The Trust have responded and apologised for the insensitivity shown in their care of her and her son. Letter from the Chief Executive of the University Hospitals of Derby and Burton NHS Foundation Trust 19 June 2020 p1 WITN4480001

121 Written Statement of ANON paras 18-21 WITN6478001

122 Written Statement of ANON para 4 WITN7220001

his HIV, given his age, but when he was eight they reluctantly agreed to him being informed by a health worker at the Churchill Hospital.

*“Around the time that he had found out about his infection, HIV was all over the news so he had found out quite a lot of information. At one point, he had asked me whether he was going to get very ill and die, to which I replied stating something along the lines of ‘you are not going to die for a very long time. Everyone on the earth dies, it is a natural cycle.’ At that moment, I knew that was the biggest lie I had ever told him. However, you did not tell kids things such as the truth in this case. I wanted to protect him. As a mum this was and remains very upsetting. Can you imagine having that conversation with your young child?”*

Daniel died in 1993, aged 11. At his request – because “he knew that he was going to die like grandad did” – his ashes were scattered with those of his grandfather, Tina’s dad, Philip Pugsley, who had also been infected with HIV from factor concentrates and who had died in 1991.<sup>123</sup>

### *Children being informed of their parents’ infections*

Children were deeply affected when they were told about their parents’ infections. Samuel Rushby’s father died of HIV through infected blood products. His mother died having been infected with HIV by his father. His younger sister died at four months old from HIV, passed down from mother to baby. He was brought up by his paternal grandparents: “My parents were very rarely mentioned. Midway through my primary school years I asked my grandparents what had happened to them ... I was told by my grandparents that my Dad had had a stroke and that my Mum had died of cancer ... I stopped asking (more) questions about my parents after a while because they were so visibly upset.” He was told that his sister had been born with a hole in her heart. He did not find out the truth until 27 years later when he reconnected with his mother’s siblings.<sup>124</sup>

Matthew Northwood says: “I will never forget the day [my dad] shared his diagnosis of HIV with me, it is burned in my memory. I could see how devastating it was for him to tell me. I was 25 years old at the time and I saw the fear in his eyes when he told me; this is something that plays on my mind to this day, the thought that my father believed that I would reject him because of his HIV infection.” His father had waited many years before telling him about his infection and died shortly afterwards.<sup>125</sup>

### *Impact of the diagnosis*

Helen Northwood recalls the day her husband Gary learned that he had been diagnosed with HIV:

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123 Written Statement of Tina Barton paras 22-61 WITN5492001

124 Written Statement of Samuel Rushby para 13 WITN7122001

125 Written Statement of Matthew Northwood para 14 WITN6611001

*“He went to the appointment and it transpired that he received devastating and life altering news of his HIV diagnosis. Nobody was with Gary at the time of that diagnosis. I was at home with a young baby, Gary arrived home to tell me his awful news. He was absolutely distraught, devastated and indicated that ‘they have given me a slow sentence of death.’ I cannot convey the sentiment in that room on that day where we were a young couple with two very young children and the impact and consequence of that diagnosis couldn’t be more significant in relation to our lives.”*<sup>126</sup>

In 1994, when she was 15 years old, Melanie McKay was told that when she was a baby and had surgery, *“something went wrong and I was infected with something called HIV.”* She had had open heart surgery in 1983, aged four, when she received blood transfusions, and was treated with Factor 8 concentrates in 1984 following a tonsillectomy. She was *“upset, angry and wished I was dead. I wanted to kill the person that did this to me. I often asked, why me? Why has this happened to me? ... I felt like my whole life came crumbling down.”*<sup>127</sup>

One man, having been told by his mother of the HIV diagnosis at the age of 15, went to the Royal Free soon after *“and they gave me a very basic explanation of what happened. I do not remember much about the conversation as I was not in an entirely stable frame of mind at the time and I was trying to process everything that had been said to me. I do remember that the appointment did not take very long and it was very matter-of-fact. It struck me as odd that they did not appear to be sorry for what had happened. I came away feeling that it was my fault for being ill in the first place.”*<sup>128</sup>

Another man said *“I lost all interest in going to the hospital. It was like watching Titanic; you knew what was coming; I just didn’t want to put myself through going to clinics. I wanted to live what little life I had left as normally as possible.”*<sup>129</sup>

Robert James says: *“It is difficult to think of any words that are adequate to describe the situation of being diagnosed with a terminal illness that was subject to such extraordinary stigma at the age of 18 and then to survive when so many of my friends – with or without haemophilia – died with AIDS or liver failure.”*<sup>130</sup>

### *Sharing the diagnosis with family and friends*

Michael O’Driscoll said that after he was diagnosed with HIV:

*“I would’ve been travelling on the tube, probably coming home in a state of shock. Not – you know, knowing how I was going to tell [my wife] Yvonne. Given that she was pregnant, given that. – I mean, they didn’t tell me – they didn’t*

126 Written Statement of Helen Northwood para 18 WITN1046001. Her children were both under three – one was a baby of less than three months.

127 Written Statement of Melanie McKay para 13, paras 5-6, para 22 WITN3587001

128 Written Statement of ANON para 9 WITN1442001

129 Written Statement of ANON para 16 WITN1791001

130 Written Statement of Robert James para 93 WITN1004001

*tell me then when I'd – when I'd become positive, I had no idea whether it's something that had happened just recently or had happened two or three years ago, so, you know, we'd been having a normal sexual relationship, so – and I knew ... there was every chance that I might have infected Yvonne. So I think I was almost panicking.”<sup>131</sup>*

Christopher Bradley was told of his diagnosis while at university and on the same day took the train home: *“on the train on the way home the big issue I considered was whether to tell my parents or not. That was a very worrying aspect. I had an ‘old school’ relationship with my parents so I wrestled about how to tell them in a matter of fact way. I did tell them later that day. I told them being HIV positive was not AIDS and it probably would not become active. I told them in a very lackadaisical way as I did not want them to be overly upset.”<sup>132</sup>* Another man had not told his children that he had HIV but when he became unwell with gallstones *“when the paramedics turned up they asked me for my medical history. My daughters were standing there and I had to give them the information; it was an awful way for them to find out. The truth is, had that situation not occurred, they still wouldn't know to this day.”<sup>133</sup>* Janet Stuart says that telling her mother that her brother had HIV *“was the worst thing I have ever had to do. It was like telling her that Paul had died. It felt like a bereavement. I saw the sorrow and the guilt wash over her and settle there and there was nothing I could do except be there for her.”<sup>134</sup>* Lyndsey Calder met her late husband when she was 17 and recalls: *“It was a long time before he could bring himself to tell me of his HIV and HCV infections and it was only later on that I learned how difficult it had been for him and how he had struggled for a long time to find the courage to tell me ... as he later told me, he was scared that I might break off the relationship or tell others.”<sup>135</sup>*

Some of those infected were simply unable to tell their loved ones about their diagnosis. One man who was told he was HIV positive as a teenager at Treloar's says *“I never spoke to my parents about this, I thought it was a death sentence and my mind has blocked out the conversation.”<sup>136</sup>* He has never told them of his diagnosis. When Shirley MacRae's husband Peter was told he had HIV, contracted through blood products, he did not tell her:

*“I only found out because I wanted another baby and Peter's response was that he did not think his doctors would be very happy. I asked him what it had to do with them and it was then that he told me that he had been diagnosed with HIV some months earlier. He was very upset ... He had not wanted to tell me of the diagnosis as he was so upset and worried about what it would mean for me and*

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131 Michael O'Driscoll Transcript pp116-117 INQY1000047, Written Statement of Michael O'Driscoll p5 WITN2384001

132 Written Statement of Christopher Bradley para 15 WITN3665001

133 Written Statement of ANON p4 WITN2520001

134 Written Statement of Janet Stuart para 13 WITN5241001

135 Written Statement of Lyndsey Calder para 25 WITN4450001

136 Written Statement of ANON para 16 WITN3044001

*our daughters. He was very worried that I would leave him and also other people finding out. He was very scared of what might happen to him and us.”*<sup>137</sup>

Sheila Ford only discovered that her brother, Alan, was infected with HIV and Hepatitis C from blood products from his death certificate. She says: “*Alan did not tell anyone about his infections and became more secretive before he died. He went out with his friends and I think he wanted to keep everything as normal as possible. After he died, nobody seemed to have been aware of Alan’s infections ... We did exactly the same as Alan did after he died, we didn’t tell anybody outside the family about Alan’s infections, as the stigma associated with the infections at the time was so bad.*”<sup>138</sup>

## Hepatitis C

### *Delays in diagnosis*

A very significant number of people have told the Inquiry that they were ill for many years before being diagnosed with Hepatitis C. This was particularly prevalent amongst women who received a transfusion during childbirth, where assumptions were made that they were exhausted from their childcaring responsibilities rather than recognising the incipient symptoms of Hepatitis C.

Karen Pearce contracted Hepatitis C through a blood transfusion after childbirth in April 1989. She was not diagnosed until February 2017. After the birth she “*kept having to go to the doctor’s, I felt tired all of the time. They told me I had depression. I felt tired and because I kept going to the doctor’s I felt like a hypochondriac. Every time I went to a new doctor I felt full of hope, but no one believed me; I felt so ill and I knew that I was ill. That was so frustrating*”. In February 2017 the doctor “*examined my blotchy hands, the spider veins on my skin, my itchy palms and my stomach*” and ordered tests that revealed Hepatitis C.<sup>139</sup>

One woman was transfused with two units of blood after an emergency caesarean section in 1978. Following her discharge from hospital, she was unwell and jaundiced and was diagnosed with non-A non-B Hepatitis. She gradually recovered during 1978. However, ten years later she began to have “*various intermittent episodes of extreme lethargy, vague gastro intestinal symptoms, almost permanent left sided abdominal pain, nausea, joint pains, very dry eyes and sometimes feeling as if [she] had the flu.*” She developed food intolerances. She explains that “*various investigations were carried out but my symptoms were explained away as stress incurred due to my marriage breakdown, bringing up my children alone and the stress of my beginning to work again in the NHS from 1984*”. She was diagnosed with Hepatitis C in 1997/98 after a battery of investigations to understand her liver pain, nausea and “*other vague symptoms*”.<sup>140</sup>

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137 Written Statement of Shirley MacRae paras 11-12 WITN1363001

138 Written Statement of Sheila Ford para 26, para 30 WITN1221001

139 Written Statement of Karen Pearce para 15, para 17 WITN0235001

140 Written Statement of ANON paras 10-11, para 18 WITN0558001

Another woman's mother was infected with Hepatitis C through a blood transfusion after childbirth in 1985. She was not diagnosed until 2017. Her mother had had *"a number of persistent health issues for decades following the blood transfusion. Between 2014 and 2017 her health problems seemed to be getting much worse but even after various organ scans, blood tests, colonoscopy and endoscopy, nothing significant was diagnosed. Nothing seemed to explain why she was having continual health problems."* In 2017 a scan identified *"a section of her liver which appeared abnormal"* and she was also tested for Hepatitis C. Thereafter, *"Further testing discovered extensive liver cirrhosis, kidney and spleen damage and a tumour in her liver"*. Her mother died a few months later.<sup>141</sup>

Lynn Foster contracted Hepatitis C from a transfusion after childbirth but the transfusion was not identified as the source of her infection for about 27 years: *"Before I was diagnosed, I had felt that there was something wrong with me for a long time ... I knew that I was always very tired, but I was not in a happy marriage at the time, so I thought that was the cause of my exhaustion ... I kept going to see doctors during this time ... However, the doctors just thought that I was depressed and kept trying to give me antidepressants."* Lynn was diagnosed with gallstones and had her gallbladder removed. After nodules were found on her liver, she was asked how much she drank: *"My impression was that [the doctor] did not believe me about my true alcohol consumption and put the state of my liver down to me drinking more than I should. I was shocked and I felt like I was being labelled an alcoholic."* Lynn had her liver function checked by her GP and was told it was fine, she was diagnosed as diabetic, then with breast cancer and after that cancer treatment, she was diagnosed with Large B-cell Non-Hodgkin Lymphoma. Only after this diagnosis was she tested for HIV and hepatitis and was diagnosed with Hepatitis C. Her consultant was able to identify the batch numbers of the transfusions she had received during her maternity care.<sup>142</sup>

One woman, who was given blood due to postnatal haemorrhage in 1986 and again on other occasions when she gave birth or miscarried, started feeling unwell in 1999. Although in 2000 she *"had a scan and was told I had pigments on my liver"* the doctors did not explore it further. They treated her numerous symptoms – of nosebleeds, hyperventilating on exertion, fainting, itchy skin, jaundice, weight loss and chronic fatigue – but did not look *"for the core issue"*. In October 2016, Hepatitis C was diagnosed by the GP who *"said it had been in my system for quite a while and that my liver had already been badly affected"*.<sup>143</sup> Anna Fothergill said *"I experienced various symptoms such as tiredness, headaches, aching limbs and depression. After seeking medical attention I was told that I was depressed and was prescribed anti-depressants."* Some ten years later she was diagnosed with Hepatitis C, which by then was 20 years after she had given birth and experienced blood loss.<sup>144</sup>

Dawn Zerbinati only found out that she had been infected with Hepatitis C in 2018, following a transfusion in 1984. The doctor *"told me that the type of damage I had was usually seen*

141 Written Statement of ANON para 5, paras 9-10 WITN1819001

142 Written Statement of Lynn Foster paras 6-9, paras 14-18, paras 21-27 WITN0094001

143 Written Statement of ANON paras 17-20 WITN0018001

144 Written Statement of Anna Fothergill paras 5-6 WITN3221001



*in a prolific cocaine user. I said I didn't take any drugs and hardly drank. He explained it's a blood to blood virus and I told him that I didn't take drugs, hardly drank, had no tattoos, botox, fillers etc ... I then told him I had had a blood transfusion in 1984. He told me the blood was probably screened at that time ... I left the building and cried and cried.*"<sup>145</sup> Universal screening of blood for Hepatitis C was not introduced until September 1991.

One woman discovered she had been infected with Hepatitis C during cancer treatment as a child: *"Life went on as normal, but from my mid teens and particularly in my 20s, I had periods of ill health. I would periodically go back to the GP with headaches, chronic fatigue, skin rashes and itching".* The GP was dismissive of a homeopath raising concerns about her liver levels. She then attended a sexual health clinic and had a full screening and says: *"They phoned back the next day to say not to drink alcohol as my liver levels were extremely bad and I had HCV. Incidentally this was left as a voicemail message, and my then to be husband picked it up."* She returned to the GP asking to be referred and *"He refused to make a referral to a specialist for a liver biopsy, and said the infection was my own fault. He also laughed when I explained I had none of the risk factors."*<sup>146</sup> Another woman was infected through a transfusion in 1981 and the following year started feeling ill. Despite going to the doctor many times and having to stop working because of how ill she felt, it was many years before she was diagnosed. She is now in her eighties and says: *"It took so long for me to be diagnosed ... [my husband] died before I was told I had Hepatitis C ... I could have passed the virus on to him without even knowing."*<sup>147</sup>

Karisa Jones' husband Geraint had a number of blood transfusions in June 1990 following an accident at work. In April 2012 he became suddenly unwell, vomiting blood, and was admitted to hospital, where he was told that he had a huge tumour on his liver, likely to have been caused by Hepatitis C. It was too late to do anything and Geraint died *"an horrific death"* in September 2012. Geraint had transmitted the infection to Karisa too. Looking back subsequently at her medical records, she identified various earlier occasions when she had reported symptoms of Hepatitis C to clinicians but had not been tested:

*"I am concerned that I ought to have been tested for HCV in 2000, 12 years before I was diagnosed, if not in 1993 at my antenatal booking appointment, 19 years before I was diagnosed. If I had been diagnosed with HCV all those years earlier then I could have been treated at that time, preventing years of damage to my body, particularly my liver, from HCV. Much, much more upsetting is that had I been diagnosed earlier then Geraint would also have been tested, his HCV diagnosed sooner and treatment offered. This might have saved his life."*<sup>148</sup>

Even people attending haemophilia centres experienced late diagnoses. A woman with von Willebrand disorder was not diagnosed with Hepatitis C until early 2011 when she went to

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145 Written Statement of Dawn Zerbinati para 11 WITN0394001

146 Written Statement of ANON paras 14-23 WITN0020001

147 Written Statement of ANON para 26 WITN0398001

148 Karisa Jones Transcript 23 July 2019 pp10-18, pp25-28 INQY1000033, Written Statement of Karisa Jones para 27 WITN2019003,

her doctor because she had been feeling unwell: *“I strongly believe that I should have been tested and told earlier that I had Hepatitis C, particularly in light of the fact that I attended the Haemophilia Centre ... on a regular basis.”*<sup>149</sup>

Other people dismissed their own symptoms and did not seek help because they were explicable from other factors in their life. One woman who received a blood transfusion in 1986 during childbirth started feeling unwell in around 2006 or 2007: *“I was extremely tired and achy. I had awful aches and pains in my arms and my neck, I had stomach problems and felt very low. I had always been very active and suddenly I couldn’t do much at all. I was working a lot and had two children and I just put how I was feeling down to daily life.”* She went to see her GP a little later and was referred to a rheumatologist. After scans, tests and endoscopies over two or three years, she was diagnosed with lupus. She had blood tests every four months. In 2012, her rheumatologist said *“she wanted to test for something, she did not tell me what.”* She was then diagnosed with Hepatitis C.<sup>150</sup> James Pepperell was treated with Factor 9 in 1979 and 1983. In 1998, he says

*“I had been feeling increasingly unwell and unusually tired for a considerable period of time, probably 5 or 6 years. I initially put this fatigue down to my lifestyle circumstances. I was in my mid 50s and I held a senior position as operations director of a company. My job involved lots of travelling, commuting and meetings. I was also going through a very lengthy divorce and financial settlement ... I initially assumed that my symptoms were related to all of the stress I was under. My symptoms did not improve and I ended up going to my doctor who referred me to the Royal Bournemouth Hospital for tests.”*

He was told that he had been infected with Hepatitis C.<sup>151</sup>

### *Delayed communication of diagnosis*

Some people were not informed of their diagnosis for a number of years after they had tested positive. John Lister, who has moderate Haemophilia A, was not told that he had been infected with Hepatitis C until the mid 1990s. He had been living with fatigue for thirty years but was told it was *“just a symptom of [his] thin blood and haemophilia”*. He saw something on television about Hepatitis C and the links to haemophilia and approached his haematologist: *“She initially told me that I did not have it, but when she checked my notes she discovered that I had actually contracted Hepatitis C. If I had not contacted her and specifically asked about Hepatitis C, I would not have been told about the infection at all.”* Despite his fatigue, he was reassured it was nothing serious.<sup>152</sup>

Judith Howell’s son, Sam was told of his Hepatitis C infection at his first appointment at a new haemophilia centre after transferring for university. Since he had had no blood tests at

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149 Written Statement of ANON paras 8-12 WITN1502001

150 Written Statement of ANON paras 6-9 WITN1847001

151 Written Statement of James Pepperell paras 16-17 WITN1008001

152 Written Statement of John Lister paras 17-19 WITN1350001

the new centre, he must have been tested for Hepatitis C at his previous centre but was not told of the result.<sup>153</sup> There was a delay of 21 months before Andrew March was informed of his Hepatitis C positive test. He was informed that he had been infected with Hepatitis C, in addition to the HIV he knew about and also Hepatitis B, when he moved haemophilia centre after he started studying at the Royal College of Music.<sup>154</sup>

Simon Merry describes attending appointments at the haemophilia centre without his parents at the age of 18 and, during a routine consultation with Dr Maurice Strevens, discussing his HIV infection. He says:

*“Towards the end of the meeting he very casually uttered the words ‘and of course you have Hepatitis C.’ My reactions very clearly illustrated that I had no idea of this. This was a completely new discovery to me. Nonetheless, Dr Strevens allowed me to leave and drive home. He would’ve known I was in complete shock by the emotions I displayed. Neither did he contact my parents. My parents came to greet me at the door on my return. They had heard a car engine revving and came out to investigate. My car had lost traction on the hill due to snow and ice. I was erratic and my driving was not controlled. I approached the front door screaming and shouting at my mother. I was angry and upset at the thought of her not telling me! It took a while for my mother to calm me down and bring me inside, where she explained that she knew nothing of this news either.”*

Dr Strevens subsequently apologised to Simon that he was not told the result until 1996.<sup>155</sup>

There was a two year delay between Pe Rae’s husband, Paul, being diagnosed with Hepatitis C and being told about it:

*“I think that Paul should have been informed of his diagnosis as soon as the medical professionals found out about it. It was shocking to me that his GP was told about it in 1997 and did not tell him about it until 1999, even writing to the hospital to say he didn’t tell Paul so as not to worry him. We found out about Paul’s diagnosis entirely by accident because Paul was being tested to see if he could have a lung transplant. If he had not needed the transplant we may never have found out about his infection as the GP did not tell us until we raised it to him. I find this unbelievable.”*<sup>156</sup>

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153 Written Statement of Judith Howells paras 15-16 WITN0344001, Written Statement of Sam McMahon para 8 WITN1386001

154 Written Statement of Andrew March paras 20-22 WITN1369001

155 Written Statement of Simon Merry para 13 WITN1390001. Dr Strevens said *“It should not have happened and I apologised.”* He also said he did not believe he would have advised a patient casually. Written Statement of Dr Maurice Strevens para 2.4 WITN3808006, Written Statement of Dr Maurice Strevens para 2.1 WITN3808007

156 Written Statement of Pe Rae paras 25-26 WITN1962001. Paul’s GP has explained that the letter from the consultant with the result came out of the blue and he knew very little about Hepatitis C. He thinks it is likely that he decided to tell Paul about his infection when he next attended, knowing him to be a regular attendee: *“With hindsight I accept that this was a bad decision which I very much regret, as Mr Le Bourn did not in fact attend again for nearly a year. He had not been informed by the Papworth hospital that there was an outstanding blood test result or that he should arrange to see his General*

Others received the diagnosis of Hepatitis C when the infection was already very advanced. Alasdair Cameron was diagnosed with Hepatitis C when he developed oesophageal varices (potentially fatal enlarged veins).<sup>157</sup> Another man had minor haemorrhoid surgery but complications were followed by a severe chest infection in October 2016. When he returned to hospital to receive the results of a CT scan for his chest infection, he was told that he had a liver tumour. Hepatitis C was subsequently diagnosed.<sup>158</sup> Dawn Mobey describes the day when she and her late husband, Christopher, realised “*something was seriously wrong*”. She says: “*It was the school summer holidays and Christopher had returned home from a day out in the sun with friends ... He was having hot and cold sweats and he then began vomiting buckets of blood. I rushed him to PMH A&E. He vomited four pints of blood in the space of six hours ... He was in a terrible state, suffering with his first bout of encephalopathy ... It was at the QEH [Queen Elizabeth Hospital] during Christopher’s stay in hospital that August that we learned that Christopher had HCV and a problem with his liver.*”<sup>159</sup>

In some cases the diagnosis of Hepatitis C was not communicated in a person’s lifetime. Suzanne Archer discovered that her father had Hepatitis C after he died from liver cancer and the undertakers refused to dress him in his wedding day suit. The undertakers informed Suzanne’s uncle that her father had been placed in a closed casket that could not be opened due to an infection risk. Suzanne spoke with the Coroner and was told that her father had been infected with Hepatitis C. She believes he had not been told.<sup>160</sup>

Diagnosis was also delayed because people were asked to attend appointments at which they now think Hepatitis C was to be discussed and tested for but because the request to attend seemed low-key, they did not appreciate the importance of attending. Graham Manning has mild haemophilia and in August 1992 he received a letter asking him to attend hospital so that his present condition could be assessed. It referred to being vaccinated for Hepatitis B and being tested for infections. Graham considers with hindsight that it hints at Hepatitis C. However, at the time: “*I felt that the letter was a standard letter sent out to all haemophiliacs and that it was not really aimed at me. I was a mild haemophiliac who had only received treatment with concentrate on two occasions at that point and had not visited the haemophilia centre for years. I thought the letter was really aimed at severe haemophiliacs who received regular treatment. At the end of the letter there was a slip which was to be returned to the hospital to indicate whether you wanted to attend for testing or not – it did not suggest that it was a big deal or that patients should attend for testing because it was something serious.*” He did not attend. He attended the clinic in 1995 and tested positive for Hepatitis C.<sup>161</sup>

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*Practitioner to discuss it ... In retrospect I should have asked Mr Le Bourn to make an appointment, and sought guidance from the Transplant Unit at that stage in relation to the causes, prognosis and management of Hepatitis C.”* Written Statement of Dr Peter May paras 14-22 WITN3177001

157 Written Statement of Alasdair Cameron paras 8-10 WITN0090001

158 Written Statement of ANON paras 11-13 WITN0056001

159 Written Statement of Dawn Mobey paras 7-8 WITN1402001

160 Written Statement of Suzanne Archer para 6 WITN1417001

161 Written Statement of Graham Manning paras 18-22 WITN1367001, Graham Manning Transcript 7 June 2019 pp74-76 INQY1000016

One woman describes what happened with her partner who had received letters for general appointments: *“he generally felt well and had no haemophilia issues ... It had been agreed previously with his consultant that as he was only a mild haemophiliac he only really needed to see him when he had an issue and he could just make an appointment. Several appointments had been made by the hospital for him to attend. However they sent no explanation as to why and as [he] felt alright he did not attend.”* He attended in 1995 when they wrote to him explaining that the non-A non-B Hepatitis he had was in fact Hepatitis C. He attended an appointment immediately, had a liver biopsy and attempted treatment which he was unable to tolerate. About eight years later, her partner became very unwell and deteriorated rapidly with liver cancer. He died four weeks after the cancer diagnosis.<sup>162</sup>

### *Informed by letter or phone*

Some people were told by phone, others by letter and others were asked to attend an appointment. There was no right way of telling people given the devastating nature of the news. However, it is clear that for many people it came out of the blue or was conveyed in a fashion that was insufficiently confidential, in circumstances where the communication of the diagnosis could and should have been given greater thought.

Lee Simpson, who was infected with Hepatitis C following blood transfusions after a road traffic accident, was informed of his infection by phone: *“we were on a family day out at a farm. They told me that they had received the results of my blood test and they showed that I had Hepatitis C. They did not ask me to come in so they could tell me in private. They just told me over the telephone. It came as such a shock and I had a panic attack upon receiving the news.”*<sup>163</sup> Another woman was also phoned with her Hepatitis C results which she contracted from blood transfusions, and was informed of her results by the secretary of the GP surgery. She says: *“I felt my condition should have been treated more confidentially and not shared with the receptionists at the surgery.”*<sup>164</sup> Another woman, infected with Hepatitis C during a caesarean section in 1975, was told of her infection by phone out of the blue a few days after the tests in 2011. She says: *“I was stunned. I thought she had made a mistake and I told her that she was mistaken; it wasn’t me, I was waiting for the results of my ultrasound. She confirmed that it was me. In an instant, my world was turned upside down ... I should have been asked to attend the surgery or hospital and been told in person, not by a stranger I had never met before over the phone.”*<sup>165</sup> Shelagh O’Shea received a letter about her son, Luke saying *“you will remember that Luke has acquired Hepatitis C infection at some time in the past”* and that it should be kept under review. She had no recollection of being told about his infection but says: *“You have such high regard for a consultant that I*

162 Written Statement of ANON paras 23-26, paras 42-43 WITN1240001

163 Written Statement of Lee Simpson para 12 WITN0323001

164 Written Statement of ANON para 8 WITN0177001

165 Written Statement of ANON paras 2.42-2.43 WITN0031001

*completely doubted myself and thought I must have forgotten. But I knew I would not have known about Luke's infection and then not told my partner.*"<sup>166</sup>

### *Informed indirectly*

One man, who contracted Hepatitis C through blood products, was going on holiday to France and says: *"my parents had asked for a letter about my haemophilia treatment to make it easier for us to get through customs. The letter came a few days before our holiday and it also stated on it that I had HCV."*<sup>167</sup>

Jo-Anne Cohrs and her husband, Keith, discovered that he had non-A non-B Hepatitis *"by reading a note that a Haematologist had left out on his desk during a routine check up"*. She says: *"We did not question the doctor further on it, as we believed that if it was concerning then the doctors would have spoken to us about it."* Keith had previously learned that he was HIV positive by a letter that arrived just after Christmas 1984.<sup>168</sup> Mark Stewart discovered that he was Hepatitis C positive when following his usual practice of collecting his records from the haemophilia centre to take them to whichever department he was attending. He says:

*"In November 2006 I was having some treatment in hospital and as usual had my medical records with me. As I was waiting to be seen I decided to have a look through my records and found some old blood test results from the Virology Department at the Royal Free Hospital. These included the results of testing for HCV antibodies by EIA [enzyme-linked immunosorbent assay] and by RIBA [recombinant immunoblot assay]. I carefully looked through them and realised that these results did not state that I was 'negative'. In particular I found two early results, one dated 2 June 1992 that read **"\*POSITIVE\*** for HCV antibodies by EIA and **'INDETERMINATE RESULT'** for HCV antibodies by RIBA ... and another dated 25 November 1994 that stated **"\*POSITIVE\*** for HCV antibodies by EIA and **'REACTIVE'** for HCV antibodies by RIBA".*<sup>169</sup>

He went to speak to clinicians in the haemophilia centre and was re-tested for Hepatitis C.<sup>170</sup>

Mr AH, who contracted HIV and Hepatitis C from blood products, was told that he was HIV positive by a play specialist at the hospital: *"I found this shocking because surely if anyone should tell me it should be my parents or a doctor ... I didn't know what to think, I was shocked and disturbed. I was 12 years old. I couldn't process that information correctly."*

166 Written Statement of Shelagh O'Shea paras 2.4-2.6 WITN0043001, Written Statement of Luke O'Shea Philipps para 15 WITN1696001. Professor Samuel Machin responded to Shelagh's statement and said: *"all Luke's blood tests from 1984 onwards would have been obtained with parental approval. However I recognise that the standard level of consent process in the 1980s may not have involved specifically discussing the precise laboratory tests to be conducted on the blood sample obtained."* Written Statement of Professor Machin para 14 WITN3090001

167 Written Statement of ANON para 7 WITN1294001

168 Written Statement of Jo-Anne Cohrs para 15 WITN1162001, Jo-Anne Cohrs Transcript 11 June 2019 pp68-69 INQY1000017

169 Written Statement of Mark Stewart paras 9-10 WITN1000001

170 Written Statement of Mark Stewart paras 13-14 WITN1000001

A few years later he *“was staying in Lewisham hospital at the time due to having an AIDS related illness and a nurse came to my bed and told me that I had Hepatitis C. The nurse went on to say that I shouldn’t worry too much about it because I wouldn’t be affected by it for around 12 years ... She then left me on my own, no one was present with me in the room not even my parents were with me.”*<sup>171</sup>

The infection of one woman came to light when her mother tested positive in 1997 and was advised to have the whole family tested. Her mother had received blood transfusions after the birth of her sister in 1966. When she told her mother of her own diagnosis she says: *“she became very upset and blamed herself for my diagnosis as she felt that it was her fault for passing it on to me.”*<sup>172</sup> A man discovered he was Hepatitis C positive when his wife, who was pregnant with their second child, was told she had contracted Hepatitis C. It was identified that he was the source of her infection, having been infected through blood products.<sup>173</sup>

#### *Tested for Hepatitis C – but not told*

A number of people, particularly those who were attending medical appointments for pre-existing conditions, were not told they were being tested for Hepatitis C. In March 2018, Jacky Barber had tests prior to starting new medication for rheumatoid arthritis. She was not advised what type of blood tests she was having *“and I certainly was not informed the tests included the hepatitis C virus test.”* She had further tests and was told by phone that she had contracted Hepatitis C:

*“The phone call from the rheumatologist nurse advising me of my diagnosis came late on a Friday. This meant I did not have an opportunity to obtain further information ... Despite this diagnosis, no one had tried to contact me to provide me with any further information. I emailed the rheumatologist nurse and she said there were no appointments available to talk about my infection with the hepatitis C virus ... I had first been told I had hepatitis C, then that I had cleared the virus, only to be told I did actually have it. All in such a short period of time.”*<sup>174</sup>

Another woman, who has beta thalassaemia major and requires very regular transfusions, was diagnosed with Hepatitis C in 1991. She says, given the frequency of her transfusions, *“I know the colours of the bottles [for blood tests] and how much, so it was strange to me when around 1989 the nurses would take more blood ... But, instead of two bottles they would take five so I am sure they were testing without my knowing what for. I remember asking the nurses and they would just say the doctor needs it.”*<sup>175</sup>

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171 ANON Transcript 10 October 2019 pp94-96 INQY1000039, Written Statement of ANON para 9 WITN1006001

172 Written Statement of ANON para 4, paras 9-10, para 42 WITN0390001

173 Written Statement of ANON para 11 WITN1317001

174 Written Statement of Jacky Barber para 18, paras 21-24 WITN0715001

175 Written Statement of ANON para 2, para 8 WITN0554001

Another woman, who has Haemophilia A, was given factor concentrates before and after a sterilisation operation. About ten years later she went for an appointment that she understood to be a factor level check. In fact, she was tested for Hepatitis C but was not informed of this. Two years later she was sent a letter which stated she had “*been infected with a virus but it would pass.*” She was not told which virus this was.<sup>176</sup>

#### *Diagnosis following publicity about Hepatitis C: GPs often dismissive*

Some people read about Hepatitis C, or saw something on TV and, having been unwell for a number of years, sought a test from their GP. Suzanne Brandt had received transfusions prior to gynaecology surgery and had felt unwell for several years:

*“I saw an article with the headline ‘Helping hand for victims of mysterious blood disease.’ The article was about a woman who had a blood transfusion after spinal surgery and had later been diagnosed with Hepatitis C. Her symptoms were the same as mine and so, at my next appointment ... I asked [my doctor] for a Hepatitis C test. He laughed at me for asking and asked if I had a history of drug taking. I told him that I had had a blood transfusion but I still had to stick to my guns to get the test.”*

She forgot to attend her next hospital appointment and was given her next appointment four months later. Consequently, she thought it could not be urgent. However, at that appointment she was told that she had tested positive for Hepatitis C.<sup>177</sup>

Jayne Kouadio had a transfusion after childbirth:

*“My mum phoned me one night and just said that she had seen a preview for a programme on Panorama for anyone who had a blood transfusion before 1990. I think that was about 1993 ... It sounded like they were talking about me. So I spoke to my GP ... who said he thought I was being silly but that he would give me a blood test anyway. He was then really apologetic a few days later when he had to tell me that I had tested positive for HCV.”<sup>178</sup>*

Michelle Tolley had blood transfusions in 1987 and 1991 following childbirth. In the early to mid 1990s she saw an item on TV discussing blood transfusions and Hepatitis C and, because she was feeling very fatigued, she rang the helpline who suggested she speak with her GP. She was “*made to feel completely stupid for having such concerns*” – “*like a silly little girl*” – and told that she had four young children, so what did she expect? She had further tests over the following years, and was diagnosed with chronic fatigue and type 2 diabetes, and by this point Michelle says: “*I felt awful as I was suffering with so many different symptoms.*” Only when she changed GP surgery was Hepatitis C diagnosed. That was in

176 Written Statement of ANON paras 9-11 WITN1400001

177 Written Statement of Suzanne Brandt paras 2.13-2.15 WITN0312001

178 Written Statement of Jayne Kouadio para 10 WITN0131001



November 2015. She felt “*let down*” and “*betrayed*” that for so many years the opportunity to give her “*a simple test*” was not taken.<sup>179</sup>

Another woman watched a programme that “*advised viewers to pursue a HCV test if they experienced symptoms like mine. Whilst never told by a doctor to get tested I intuitively decided to see my doctor and plucked up the courage to do so in 1994 or 1995*”. She tested positive for Hepatitis C having been infected through blood transfusions she had received after a car ran into her in 1984.<sup>180</sup>

When Anita Roddick<sup>181</sup> spoke on *This Morning* about how she had contracted Hepatitis C from a blood transfusion, a woman “*really identified with the symptoms [Anita] was describing – feeling ill, tired and depressed over the years*”. However, she says: “*I had assumed that I was feeling run down due to caring for three children under five years old.*” She went to the GP and requested a blood test “*just to rule out HCV*” – but she tested positive.<sup>182</sup>

### *Diagnosis discovered by chance*

Others only learned about their diagnosis with Hepatitis C by chance through unrelated health checks or medical procedures.

For some that was because they attended a general checkup and raised liver enzymes were identified. Jean Short was infected with Hepatitis C through a blood transfusion given during an emergency caesarean section in 1983. She was not diagnosed until 2008 when she attended a Well Woman clinic.<sup>183</sup> Since giving her statement Jean has died. Kenneth Nicholls was diagnosed with Hepatitis C, transmitted by blood transfusions after a road traffic accident, after attending a Well Man clinic in 2012. Hepatitis C was diagnosed and in 2013 a liver biopsy identified that he had hepatocellular carcinoma.<sup>184</sup>

For others, the general medical check was to obtain some form of insurance. Peter Frith had a medical check for life insurance which revealed an enlarged liver. On further testing, he was diagnosed as Hepatitis C positive. He says: “*For 30 odd years leading up to my diagnosis, I appear not to have been affected at all, or at least I did not attribute any issues to it ... Had the insurance company not asked me to have a medical examination, I would not have discovered that I had Hepatitis C and I could well be dead by now. A fact which does prey on my mind.*”<sup>185</sup> Linda Johnson had a series of gynaecological surgeries in 1974-1984 receiving a number of blood transfusions. In 1984, blood tests revealed abnormalities but no further diagnosis was made. In 2001 she went for a private medical assessment

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179 Michelle Tolley Transcript 7 May 2019 p66, pp73-74 INQY1000005, Written Statement of Michelle Tolley paras 13-19 WITN0276001

180 Written Statement of ANON paras 8-9 WITN0308001

181 The Body Shop founder, an early victim of the disease.

182 Written Statement of ANON paras 7-9 WITN1907001

183 Written Statement of Jean Short para 4 WITN0445001

184 Written Statement of Kenneth Nicholls pp1-2 WITN0027001

185 Written Statement of Peter Frith paras 20-27, para 46 WITN4118001

for a mortgage and Hepatitis C was diagnosed.<sup>186</sup> Wayne Stewart discovered he had Hepatitis C following a routine medical assessment for mortgage insurance in 1995. Despite having moderate to severe Haemophilia A, he was not told by his haemophilia centre about his infection.<sup>187</sup>

One man discovered he had been infected with Hepatitis C, through blood products to treat von Willebrand disorder, because of a series of pre-operative tests and believes that if not for that, he “*probably would not have known about the infection until it was too late.*”<sup>188</sup>

A number of witnesses discovered that they had contracted Hepatitis C as part of standard testing for fertility treatment. Daphne Whitehorn was infected with Hepatitis C from a blood transfusion during a kidney transplant, only learning that she had contracted it in 2001 during a routine check-up. She transmitted Hepatitis C to her daughter, Janice, during childbirth. Janice’s infection was not diagnosed for 37 years (despite her being unwell for a number of years with symptoms associated with Hepatitis C) when she had tests prior to fertility treatment; she was told the diagnosis by telephone “*Just like that.*”<sup>189</sup> Mark Harrison had some blood tests and received a letter stating that he was “*reactive to hepatitis C*” and requesting his permission to refer him to a hepatologist. He says that when he attended that appointment: “*I was unsure if I even had Hepatitis C; I had never heard of it before, so ‘being reactive to’ meant nothing really. When I saw Dr Gallagher [the hepatologist] ... I asked her whether I had hepatitis C and she replied by saying ‘yes of course you have’. I remember going numb.*” This was 24 years after he had received a transfusion after a road traffic accident.<sup>190</sup> David Pritchard was diagnosed in 2005 after receiving multiple doses of plasma and Factor 8 between 1985 and 1986. He says “*I kept thinking it was 2005 and the health professionals knew all about my Factor VIII and blood plasma treatments in the 1980s so I was puzzled as to why they had not found me to check whether I had been infected.*” Instead he was told during routine blood tests at a private fertility clinic at what “*was meant to be a really happy and positive time for us and a time for new beginnings.*”<sup>191</sup>

Others discovered their diagnosis when they went to give blood. Breda Pow gave blood, for the first time in decades after she had received blood after childbirth, and then received a letter from the blood transfusion service telling that she had Hepatitis C. She says: “*The letter said if I had any concerns to go to my GP. I felt as if the bottom had fallen out of my world. This was the first time I had given blood since childbirth ... The letter was stark, impersonal and devoid of any feeling of the effect that receiving this news could have on someone.*” She experienced panic attacks when she went to get the post for three months after getting the original letter.<sup>192</sup> Another woman, who discovered her diagnosis in the same

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186 Written Statement of Linda Johnson paras 4-7 WITN3421001

187 Written Statement of Wayne Stewart paras 17-20 WITN1546001

188 Written Statement of ANON paras 8-10, para 14 WITN1462001

189 Written Statement of Daphne Whitehorn paras 7-12 WITN0191001, Written Statement of Janice Whitehorn-Cox paras 12-14 WITN2000001

190 Written Statement of Mark Harrison paras 8-9 WITN1895001

191 Written Statement of David Pritchard para 8, para 11 WITN1479001

192 Written Statement of Breda Pow para 8, para 13 WITN0030001

way, describes the letter she received as “pretty ‘cold’ in its nature, blunt, uncaring and to the point.”<sup>193</sup> One man describes his wife receiving a letter from the Blood Transfusion Service after giving blood informing her that she had contracted Hepatitis C. He says: “She was simply told in a letter. Not advised to see her GP or a hospital doctor where she could have been given such potentially life-changing news in person. She made an appointment to see a [consultant] ... [who] was fairly matter of fact and, to be honest, played down the seriousness of the virus.”<sup>194</sup>

Hayley Simpson was infected with Hepatitis C when she was given a blood transfusion during orthopaedic surgery. She donated blood and was then informed by letter she had tested positive for Hepatitis C and advised to see her GP. She worries about what might have happened: “I did not receive any follow up to this letter from the blood service – I dwell on the fact that this letter could have been lost in the mail and I wouldn’t have known that I was infected.”<sup>195</sup>

The follow-up that people received after the letter from the Blood Transfusion Service was very variable. One woman received a letter telling her that she had been infected with Hepatitis C and describes: “I went to visit my GP. My GP sent me away, telling me ‘they’ were more concerned with Hepatitis A and B, and I shouldn’t worry. After an initial feeling of relief, I realised the National Blood Authority would not have written to me in the way they did if it was nothing to worry about.” She spoke to someone else in her surgery and was referred to a hepatologist.<sup>196</sup>

A number of other people were identified through the lookback exercise which is discussed elsewhere in this Report. Robert Bamforth received a letter from the Blood Transfusion Service two years after an accident and prolonged recovery period, says: “My wife, upon reading the letter, was extremely worried. She believed that I had been having an affair” and the relationship broke down shortly thereafter. “As a result, I lost my house, my wife and daily contact with my children and step-children. This was devastating, all the while I was back living at my mum’s house and not knowing whether I was going to die.”<sup>197</sup>

### Poor communication of diagnosis

A significant number of people have spoken of the poor manner in which the diagnosis was communicated. Gary Sheriff, who was infected by Factor 9, states:

*“I was surprised to be diagnosed with Hepatitis C in 1996, as I had not been experiencing any symptoms. I was given the diagnosis during a routine clinic appointment and I found it quite a difficult way to be told. It was almost*

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193 Written Statement of ANON paras 10-11 WITN0324001

194 Written Statement of ANON para 14 WITN0874001, Written Statement of ANON paras 7-9 WITN1974001

195 Written Statement of Hayley Simpson paras 7-8 WITN0082001

196 Written Statement of ANON paras 14-16 WITN0105001

197 Written Statement of Robert Bamforth paras 20-21, para 52 WITN4414001

*as I was leaving the appointment that Dr [Jonathan] Wilde mentioned that I had been exposed to Hepatitis C, and that I had tested positive for the virus. Once I realised what he had said, I sat down again and I asked him to explain it to me. Dr Wilde tried to make the conversation positive and explained that treatment was available. I have never been told which batch of Factor IX infected me. I was just told that I had contracted Hepatitis C from contaminated blood products ... I believe there has been a lasting impact on me because of the way the diagnosis was delivered. I do not think it should have been left until right at the end of the appointment and the news given to me as if it were an afterthought.”<sup>198</sup>*

A man who has von Willebrand disorder describes being told about his Hepatitis C infection *“in the hospital corridor/foyer”*. He says: *“I do not recall what we were talking about but I remember Dr [Helena] Daly saying to me as we parted ‘by the way, you should know that there is a slight trace of Hepatitis C in your blood.’”* It was only when he heard about Hepatitis C in the media that he realised that *“it was a lot more serious”* than he had initially thought.<sup>199</sup>

Sam McMahon, who has moderate Haemophilia A, describes being told *“very tactlessly”* of his infection at the age of 19: *“I remember leaving the room after the information was communicated to me expecting to die in the near future ... I have never been the same person since”*.<sup>200</sup> One woman recalls being told that her son had contracted Hepatitis C from Factor 8 treatments and says: *“I can’t remember exactly when it was, but I know it came as a huge shock ... I was on my own; my husband wasn’t with me, and I had no idea at the time what was going to come.”*<sup>201</sup>

By contrast, another woman describes how her GP gave her the information about her positive Hepatitis C result *“with great kindness and sensitivity.”* She goes on to say:

*“The GP and I explored the possible cause of this infection from my previous history and we could not identify any possible means of contracting this infection except through a blood transfusion ... My GP immediately referred me to the Hepatology Unit at Manchester Royal Infirmary and reassured me that I could be treated effectively ... The hepatologist tried to establish the means of infection; he was discreet and subtle in the way he approached it, he was also sensitive, thorough and informative about the condition and the implications for treatment.”<sup>202</sup>*

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198 Written Statement of Gary Sheriff paras 24-26 WITN1014001. Dr Jonathan Wilde has responded to the statement and said: *“While I may not have always presented the bad news in the manner an individual patient would, on reflection, have preferred, I always did my best to ensure the information was conveyed sensitively and in a way that it was understood. That said, I was deeply saddened to read that this patient had the experience he described in his witness statement. Naturally, I would like to apologise if the way I did deliver the news regarding his diagnosis of HCV did cause upset. The very last thing I would want is for the way in which this diagnosis was delivered to have had a lasting effect on top of the impact of the diagnosis itself.”* Written Statement of Dr Jonathan Wilde para 5 WITN3086006

199 Written Statement of ANON paras 7-8 WITN1499001

200 Written Statement of Sam McMahon paras 10-11 WITN1386001

201 Written Statement of ANON paras 20-21 WITN1435001

202 Written Statement of ANON para 9 WITN1892001

### *Assumptions about alcohol*

Assumptions about alcohol misuse were frequently made, resulting in delays in diagnosis and or treatment. One mother describes how her daughter became jaundiced and unwell aged 16. She had sickle cell disease and had received her first transfusion aged 5. One of the medical records from hospital included the comment: “*A complex appearance comprising mildly active cirrhosis (with features suggestive of an alcoholic type aetiology)*”. As her mother says, “*She was a 16 year old child and did not drink alcohol*”. Initially she was refused a liver transplant because her liver disease was so extensive but her mother sought a second opinion and two months later she had a transplant. However, she was “*too ill for her body to accept it.*” She died at the age of 17.<sup>203</sup>

One woman contracted Hepatitis C from transfusions that she received during operations for skin cancer in 1977. She was not diagnosed until 2006 following a hip operation. In the years in between she was tested for diabetes and thyroid, kidney and liver functions because she was unwell. She says: “*On every occasion this happened, I was quizzed about my drinking habits. When I told the GP that I drank very rarely ... I felt that I was not believed.*” When she was diagnosed with Hepatitis C “*it was actually somewhat of a relief because I finally knew I wasn’t just a hypochondriac.*”<sup>204</sup>

Anne Fitzgerald received blood transfusions after the birth of her fifth child and was infected with Hepatitis C. She says: “*The mental effect of being infected with Hepatitis C has been dealing with this everlasting frustration. I kept going back and forth to different doctors and hospitals to find out what was wrong with me: they all thought I was an alcoholic.*”<sup>205</sup>

Danielle Mullan’s late mother Marie Cromie was infected with Hepatitis C following a transfusion: when informed of the diagnosis she was asked about “*whether she had taken drugs, whether she had had any tattoos, had she ‘slept around’*”, which was “*terribly upsetting*” and made Marie “*feel quite embarrassed and ashamed in a way*”. Danielle said that later there were “*rumours*” that her mother “*was an alcoholic because of her liver problems*” – “*In Northern Ireland people associate liver problems with alcohol abuse, particularly given the case of George Best which was very prominent at that time.*”<sup>206</sup>

David Rankin was informed of his Hepatitis C infection “*verbally in one of the corridors, and the doctor suggested it was a result of my lifestyle.*” He was offered no support after being told of the diagnosis and on his journey home, he says: “*I became angrier about the way I was informed – it was in such a clumsy fashion. It probably was not the intention of the young doctor, but to this day it is one of the things I still resent*”. He was subsequently reassured that it was nothing to do with his lifestyle; he had been infected through blood products.<sup>207</sup>

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203 Written Statement of ANON paras 33-37 WITN1823001

204 Written Statement of ANON paras 2.5, 5 WITN0014001

205 Written Statement of Anne Fitzgerald para 5 WITN0050001

206 Written Statement of Danielle Mullan paras 2.6, 5.9 WITN2439001, Written Statement of Marie Cromie paras 5.3, 5.38 WITN2429001, Written Statement of Russell Cromie para 2.1 WITN2430001

207 Written Statement of David Rankin paras 27-29 WITN0357001

### *Information about Hepatitis C provided at diagnosis*

The level of information given about the seriousness of the infection also varied.

Terence O’Hora, after a delay of two years from testing positive for Hepatitis C, says: *“The doctor reassured me that although the overall prognosis was unclear, there was a good chance that I would not require therapy ... I asked if there were any symptoms of Hep C and the doctor said that I would have flu-like symptoms, but nothing serious and it would not affect me for another 20/30 years.”*<sup>208</sup>

Another man with mild Haemophilia A recalls that in around August 1987 he was informed by Mary Fletcher (a haemophilia centre nurse) that he had hepatitis. He says: *“The way in which I was informed was curious. Mary Fletcher was talking to me as if I knew that I had hepatitis and when I asked her what she was saying, she was surprised that I did not already know. Her reaction was to tell me that hepatitis was a common side-effect of factor VIII ... and that there was nothing to worry about though alcohol was not advisable. It was all dealt with in a rather casual manner as if it was not something of much significance.”*<sup>209</sup>

By contrast, Allan Pepper, who has mild Haemophilia A, was told in 2010 that he had contracted Hepatitis C and says: *“[Dr Lakhani] was very good, he sat me down and explained what the HCV was, and that he was 98% certain that I got it from infected blood products ... I asked Dr Lakhani about long term consequences and proposed treatment, and he gave me a great overview and told me to speak to the consultant at St Thomas’ Hospital as well.”*<sup>210</sup>

A man who was infected with Hepatitis C by Factor 9 describes being told of his diagnosis and says: *“The Haematology Department arranged for me to meet with the Hepatology Department. This was arranged as a joint visit, to help me to understand what this meant and whether there were any treatments and how it would affect my haemophilia. I had around 4 or 5 joint visits in total.”*<sup>211</sup>

Anna Maria Preston’s husband Alan was diagnosed with Hepatitis C in 1995, having been infected in 1983:

*“The GP said that my Alan got his infection from a blood transfusion and told him he had 2 years to live as it was an incurable disease. I was furious that the doctor imposed a time limit like this on him and I believe that the doctor should have given Alan hope by suggesting that just maybe there was a cure, as we are discovering cures every day. My Alan’s face looked totally destroyed; it told it all ... When we got home, my Alan just sat in his chair and had given up, as if he was now waiting to die ... all of a sudden he was sat at home waiting to die; he became depressed.”*<sup>212</sup>

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208 Written Statement of Terence O’Hora para 20 WITN1438001

209 Written Statement of ANON para 17 WITN0655002

210 Written Statement of Allan Pepper paras 13-14 WITN1463001

211 Written Statement of ANON para 7 WITN1071001

212 Written Statement of Anna Maria Preston paras 9-10 WITN1477001

Others felt that there was a lack of openness in how they came to contract the virus. Eileen Dyson contracted Hepatitis C from blood transfusions after childbirth. She had been unwell for a long time and was admitted into hospital for tests to explore why she remained so unwell. She was told: *“I am pleased to tell you lots of the things we were looking for you did not have but you do have Hepatitis C virus and this is why you are experiencing the symptoms of pain, sickness and fatigue.”* She had never heard of Hepatitis C and was told that it was contracted through shared needles or numerous sexual partners. She had to insist that she could not have contracted it in that way. Eileen says it was then *“hinted that some people get Hepatitis C through blood transfusions. I asked how I could find out if my blood transfusions were infected but they completely evaded the question and only stated that it was now about monitoring the virus so they could look for indicators of cirrhosis or cancer ... I was absolutely devastated ... I was so afraid I would not be able to care for my young family and I would die prematurely.”*<sup>213</sup>

### *Impact of the diagnosis*

The feeling of devastation in light of the diagnosis was widespread.

One man who was infected with Hepatitis C by a transfusion after a serious road traffic accident says that after he was told about his diagnosis: *“I went home with my mind in absolute turmoil and told my wife. I had difficulty coming to terms with the diagnosis. I was in tears and extremely emotional.”*<sup>214</sup>

Another man, who was told he had Hepatitis C when he was 12 at an appointment with his mother, says: *“I didn’t know how I was supposed to react. I didn’t cry. I was in shock ... I spent my teenage years knowing that I might die, get cancer or need a transplant but that I probably wouldn’t survive a major operation.”*<sup>215</sup>

A man, who had been treated with Factor 9, worried that he may have contracted Hepatitis C and says: *“Feeling a need for continued secrecy for the time being, I discovered I could be tested anonymously at a sexual health clinic without results being placed on medical records. I wept with relief when told the HIV result was negative but numbed as I learnt I was HCV positive. The following weeks became a psychological hell as I tried to decide what to do.”*<sup>216</sup>

Catherine Johnston recalls the meeting at which her late husband Paul was diagnosed with Hepatitis C: *“I remember asking the doctor; ‘If Paul has it can I have it? Could the kids have it?’ The doctor said that it can only be passed from the mother to the child. I then asked him; ‘Do I not then need to be tested because my kids are 3 and 5?’ I remember him replying that if I wanted to, I could ... He then took my blood and we went off down the road. We were in total shock, just numb.”*<sup>217</sup>

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213 Written Statement of Eileen Dyson paras 14-17 WITN2130001

214 Written Statement of ANON para 14 WITN0123001

215 Written Statement of ANON paras 12-17 WITN1436001

216 Written Statement of ANON para 18 WITN0053001

217 Written Statement of Catherine Johnston para 9 WITN0158001

Another woman recalled that her late husband was “*in a state of shock*” after his diagnosis. “*He was normally a decisive man but suddenly he did not know which way to turn ... [He] became a shadow of his former self with the weight of the world on his shoulders.*”<sup>218</sup>

For some, this came after already being diagnosed with HIV.

One man, who had already been told he was HIV positive having been infected through blood products as a child, recalls being tested for Hepatitis C and being asked “*By the way I have your results – do you want to know?*” He was told he was Hepatitis C positive and there was then “*a brief discussion about the connotations and we then had a conversation about prioritising my illnesses and haemophilia. Hepatitis C was effectively at the bottom of the list of things for me to worry about.*”<sup>219</sup>

Another man, co-infected with HIV, Hepatitis C and Hepatitis B, was informed of his Hepatitis C infection in 1992 and says: “*I was told this wouldn’t be a problem for me because I would die from an HIV related illness long before HCV would cause me any concern. There was no mention at the time of increased morbidity rates of the co-infected.*”<sup>220</sup>

Julia Mitchell recalls that she and her late husband, Pete, were told about his Hepatitis C infection and says “*[because we] knew that Pete had antibodies to Hepatitis A and Hepatitis B as a result of his treatment ... when we were told he had NANBH, we were not concerned. We thought ‘it’s just another Hepatitis’; we were focused on the diagnosis of HIV.*”<sup>221</sup>

Another man describes being told about his HIV diagnosis as “*more of the bombshell and finding out about the Hep C was like an aftershock.*”<sup>222</sup>

For a few, the diagnosis brought a sense of detachment. For example, one man with mild Haemophilia A describes that his diagnosis of hepatitis was “*very weird news*” because at that time, he “*felt fit and healthy.*”<sup>223</sup>

What is quite clear is that no psychological support or counselling in the sense of psychological therapy was provided to people when they were diagnosed, whether with Hepatitis C, HIV or Hepatitis B. Stephen Dorey, who was infected with Hepatitis C through blood products, refers to a note in his records from the year after his diagnosis that says he was “*counselled*” and says “*I can only assume that the note saying I had been counselled was in fact me being told that I had contracted the infection as I cannot recall any formal counselling whatsoever.*”<sup>224</sup>

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218 Written Statement of ANON para 17 WITN0637001

219 Written Statement of ANON para 24 WITN1387001

220 Written Statement of ANON para 17 WITN1003001

221 Written Statement of Julia Mitchell para 25 WITN1010001

222 Written Statement of ANON para 26 WITN1533001

223 Written Statement of ANON para 2.15 WITN0002001

224 Written Statement of Stephen Dorey para 7 WITN0063001



### *Sharing the diagnosis with family and friends*

Once they had been diagnosed with Hepatitis C, people faced the unenviable task of telling their spouses, partners and loved ones about the diagnosis. Paul O’Hora, who was infected with Hepatitis C through Factor 9, recalls being given his diagnosis and then “*going home in shock*” and having to tell his wife. He says: “*It was such a difficult conversation to have and to tell her that I had the virus and also that I could pass the infection on to her through intimate/sexual contact. It was a difficult and emotional conversation to subsequently have with our daughters. It was hard for them to comprehend that if, for example, I had an accident and was on the floor bleeding and possibly dying, they could not touch me. The thought of that was unimaginable to them.*”<sup>225</sup>

One woman describes feeling “*compelled*” to tell her family about her diagnosis once she knew the seriousness of her infection with Hepatitis C and says that “*was a very emotional conversation to have*” with her loved ones. She was in a new relationship at the time of her diagnosis and says “*once my diagnosis was confirmed and I told [him], he ended the relationship out of fear of catching hepatitis C and of the future prospects our relationship would have.*”<sup>226</sup> John Aubrey says: “*When I was first informed that I had Hepatitis C, I was told to contact past partners so that they could get checked out. This was a horrible and an extremely uncomfortable thing to have to do. I had recently become engaged ... and when I told her, she promptly ended the relationship.*”<sup>227</sup>

### **Hepatitis B**

Catherine Guthrie contracted Hepatitis B from blood transfusions she received during an operation in 1972. Her parents were told that she might only have three weeks to live. She was admitted to an infectious diseases ward and kept in isolation. She says: “*I recall when I was first admitted the doctor kept on insisting that I was an alcoholic. I was shocked by this as I had never even tried alcohol at that point, let alone developed a drinking problem. The doctor kept on demanding that I admit that I had a drinking problem. I was feeling so ill that being subjected to that was an awful experience.*” Eventually the link was made to the eight pints of blood she had received. She then says: “*I was not told if I was still infectious to others or not after I was sent home*” and passed the infection on to her husband before she knew “*there was even a risk of cross contamination.*” A month later he became very ill and she believes his early death was a direct result of complications that came from being infected with Hepatitis B.<sup>228</sup>

Some people infected with Hepatitis B experienced physical symptoms shortly after their infection. Anthony Sullivan, known as Sully, had surgery for a brain tumour and was infected with Hepatitis B through blood or blood products. After the surgery, the physical impact of

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225 Written Statement of Paul O’Hora para 9 WITN1440001

226 Written Statement of ANON para 2.3, para 5.8 WITN2580001

227 Written Statement of John Aubrey para 18 WITN0071001

228 Written Statement of Catherine Guthrie paras 5-8, para 10, para 23 WITN7499001

the hepatitis was significant and soon after diagnosis, *“his health began to deteriorate and he developed ascites causing his stomach to swell up ... Over the period of months that he had ascites, he regularly went back to drain the fluid to alleviate the pain. He felt ill and had a general malaise.”* The mental impact on Sully was *“devastating ... to find out, mid-recovery, that he had been infected with a life threatening virus was truly horrible and was totally unexpected.”* He died of an oesophageal haemorrhage.<sup>229</sup>

Philip Lovell, who had mild Haemophilia A, contracted Hepatitis B from blood products. Shortly afterwards he says: *“Physically, I started to feel unwell ... I became jaundiced and tired. I went from being a very active person to suddenly not wanting to get out of bed. It was difficult to sleep and I felt nauseous. All of a sudden I was in a condition completely opposite from my normal life.”* He had been tested for Hepatitis B during inpatient treatment but was not informed of the result for three months. He says: *“Since 1978 to the present day the psychological impact that the infection had in my life has been huge. It is very rare that I do not think about the damage to my liver or the possibility of liver cancer.”*<sup>230</sup>

However, early symptoms did not necessarily result in a person being informed at that time that they had been infected with Hepatitis B. A man with severe Haemophilia A was treated with cryoprecipitate at about nine and *“turned yellow ... and was taken to hospital as I was jaundiced. I managed to recover naturally but it took me about a year. I had about 4 months off school and I was permanently tired in this time; I just slept all day.”* He was told later that he had had Hepatitis B as a child.<sup>231</sup>

Some people faced a long period of ill health before being diagnosed. Michelle Leaman contracted Hepatitis B from two units of blood given to her after a postpartum haemorrhage in 1973: *“I was very tired and lethargic to the extent going to work became increasingly difficult. Around 1983, I started to notice the onset of flu-like symptoms without having the actual cold. I was suffering from aching joints and stiffness and was diagnosed with rheumatoid arthritis at the time (though it later transpired this was a misdiagnosis).”* Her health deteriorated and in 2005 she had her gallbladder removed and was then taken ill with *“a fever and chills and I was in a lot of pain”*. She was taken to hospital and was diagnosed with Hepatitis B. She says she was told: *“it was a chronic infection and that I had fibrosis of the liver.”* Michelle was informed while on a busy ward, alone and without support.<sup>232</sup>

Norman Graham contracted Hepatitis B from blood transfusions he received after a road traffic accident in 1982. He *“lived a normal life”* until he developed stomach pains in 2016. He was then diagnosed as having been infected with Hepatitis B that had cleared, but a fibroscan showed cirrhosis of the liver and he has been unwell since then.<sup>233</sup>

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229 Written Statement of Judith Sullivan paras 14-15 WITN1782001

230 Written Statement of Philip Lovell paras 9-11, paras 26-27 WITN0111001

231 Written Statement of ANON paras 5-6 WITN1225001

232 Written Statement of Michelle Leaman paras 5-7 WITN0951001

233 Written Statement of Norman Graham paras 4-6, para 8 WITN1749001

One woman was “advised that ‘It was unfortunate I had the HBV, but I should be grateful that the transfusion after the birth saved my life.’ I should just move forward, not worry, and live my life as normal!” She “felt really let down for any information at that point. I had no idea of how it affected my liver or other health implications of it ... I had to go online to source my information, which was frightening. I read that if the infection was more than six months on and hadn’t cleared, you were a chronic sufferer. I had had the virus for several years by this stage. This was how I learned that my Hepatitis B was chronic.”<sup>234</sup>

### *Impact of the diagnosis*

Raymond Keen was infected with Hepatitis B and says that when he was told of his infection, “I was stunned. I could not understand where I had got this infection from.”<sup>235</sup> Shirley Hunkins says she was not given much information about her Hepatitis B infection:

*“I feel that the way the diagnosis was communicated to me was handled very badly. I was a young single mother with two young children, and was given this diagnosis of something I had never heard of before and told that there was no cure for it and that it would eventually kill me. It left me feeling scared that I would die and leave my children on their own with no one to take care of them. I felt that the hospital didn’t explain anything to me about how to manage life with the infection, they just left me on my own to deal with it.”*<sup>236</sup>

One woman who had been unwell for some time before she was diagnosed says that a doctor “gave me the shocking news that I had cirrhosis of the liver, resulting in cancer which was caused by the HBV. It was unexpected and devastating news for me and my family. I was very shocked and upset. I came home thinking: ‘how did this happen? Why and when did this happen? Who did I get it from?’”<sup>237</sup>

## **Effects of the infections**

### **HIV: physical effects**

The physical effects of HIV were and are manifold because of its impact on the immune system. This was often profoundly worsened by the treatment that was given to treat HIV, particularly in the early days.

Gary Webster, infected with HIV through blood products, says: “My immune system is so low that I catch just about any infection I come into contact with. A simple cold invariably becomes flu and turns into a chest infection. I am constantly fatigued. I have had warts, countless chest infections and bouts of pneumonia and many sickness bugs.”<sup>238</sup>

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234 Written Statement of ANON paras 22-26 WITN3283001

235 Written Statement of Raymond Keen para 11 WITN2638001

236 Written Statement of Shirley Hunkins para 14 WITN1906001

237 Written Statement of ANON para 17 WITN0727001

238 Written Statement of Gary Webster para 20 WITN1723001

Carol Osborne describes that initially after his diagnosis, her husband Jeffrey's condition "*did not cause him any obvious symptoms; however, once his health deteriorated he suffered from night sweats, diarrhoea, shingles, pneumocystis, dermatitis, chronic fatigue, a cough, shortage of breath, depression and anxiety.*" Over time he gave up his hobbies and social events and missed out on time with their son due to chronic tiredness.<sup>239</sup>

One man, infected with Hepatitis A, Hepatitis B, Hepatitis C and HIV, listed some of the related conditions that he suffers from "*as a result of the viruses and medications*". These are "*Lipodystrophy, asthma and constant breathlessness/heart palpitations, chronic fatigue, peripheral neuropathy, polyneuropathy, kidney problems, opportunistic infections, regular vision problems, chronic stomach pain, diverticulitis, acid reflux, pruritus, myalgia/arthritis pain, fibromyalgia, vitamin D deficiency.*"<sup>240</sup>

Jo-Anne Cohrs recalls her late husband, Keith, "*picked up pretty much any infection due to his weakened immune system caused by the HIV ... Keith suffered from other conditions related to his HIV and Hep C, such as candidiasis, Kaposi's sarcoma, pneumocystis carinii/jirovecii, ataxia and continual diarrhoea.*"<sup>241</sup>

Many of the witnesses who were infected as children, have never known anything different. As Stephen Martin-Hanley explains, "*I don't really know what it is like to be 'normal' (not infected).*"<sup>242</sup>

For many people one infection led to another.

One man describes having a "*particularly bad year*" in 1996. He says:

*"in addition to the molluscum contagiosum on my face [that required surgery] and the usual nausea and night sweats, I contracted shingles, had pneumonia (PCP) and haemoptysis. I remember thinking that this was the beginning of the end and it was very scary. I knew my HIV had progressed to AIDS and that things did not look good for me. Fortunately treatment became available just in time for me and I slowly recovered physically from this intense episode but emotionally remained scarred."*<sup>243</sup>

Another woman describes an episode of ill-health that her husband, infected with HIV, Hepatitis C and Hepatitis B from blood products, sustained:

*"In 2006, [he] became very unwell and was in a lot of pain ... [Some weeks later] I took him back to the Hospital and he was admitted. Ultimately, he had to have an emergency operation to have his gallbladder removed as the bile ducts had been blocked with a fatty substance, it had turned gangrenous and he was going to die. [He] survived the operation but when I went to see him in the Intensive*

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239 Written Statement of Carol Osborne para 20 WITN1445001

240 Written Statement of ANON para 11 WITN1315001

241 Written Statement of Jo-Anne Cohrs para 21, para 24 WITN1162001

242 Written Statement of Stephen Martin-Hanley para 21 WITN1376001

243 Written Statement of ANON para 15 WITN1430001

*Care Unit, I could see he was not in a good way. He had gone into septic shock, one of his lungs had collapsed and he was very unwell. I was devastated ... The doctors cannot say with certainty that the complications with [his] gallbladder were a result of his infections or the associated medications but they cannot rule it out. I am absolutely convinced that it was because of the medication he was on at the time and is connected to his lipodystrophy ... [He] still struggles with his breathing and has a permanent hacking cough. He sounds like he has smoked 40 cigarettes a day when, in reality, he has never had a cigarette in his life.”<sup>244</sup>*

One mother’s young son contracted HIV from blood products. He suffered from pneumonia and pancreatitis then “*another bout of pneumonia between Christmas 1989 and the 1990 New Year. I knew that things were going to end badly but I couldn’t face the thought and I was in a state of denial ... He had sepsis and was in critical care and on a ventilator before he died*”. He died aged 15.<sup>245</sup>

### *Effects on the brain*

A number of witnesses have described the terrible impact of the virus on their loved one’s brain, affecting their sense of self.

One woman described her late husband, infected with HIV through blood products, as suffering with “*chronic herpes simplex, candida in his mouth and alimentary canal, poor sleep due to night sweats, abdominal pains, loss of appetite, weight loss and chest infections.*” Prior to his final admission into hospital “*the virus had started to affect his brain which led him to being disorientated, weak and unable to walk unaided.*”<sup>246</sup>

Another woman describes how the HIV virus affected her husband’s brain as well as his mental health, and he became violent towards her and suffered hallucinations.<sup>247</sup>

Barbara Scott’s husband, Ronald, was diagnosed with HIV in 1984. It was not until the summer of 1992 that he began to deteriorate and “*started to seem a lot more fragile*”. Barbara says that “*After Christmas 1992 I persuaded Ronald that he could just stay at home. It was very clear to me that his ability to find words had massively deteriorated and it was also confirmed that he had progressive multi-focal leukoencephalopathy. This is a demyelinating disease of the white matter of the brain and causes mental deterioration, ataxia, speech disturbance, paralysis, coma and eventually results in death ... Eventually, Ronald succumbed and tragically died from the effects of HIV infection, 10 days after his 50th birthday*”.<sup>248</sup>

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244 Written Statement of ANON paras 20-22, para 26 WITN0899001

245 Written Statement of ANON paras 21-22 WITN1325001

246 Written Statement of ANON para 19, para 23 WITN1337001

247 Written Statement of ANON para 24 WITN1284001

248 Written Statement of Barbara Scott para 22, para 28, paras 35-36 WITN1020001

Diana Blake says of her late son:

*“Stuart was six and a half when he was diagnosed with HIV. He had bouts of not being very well, he had swollen glands, he suffered from night sweats to the extent that I regularly had to change his bedding, he lost weight, which led to symptoms of anorexia, he had sore throats, a cough, he suffered from stomach problems, shingles and severe diarrhoea ... Unfortunately HIV affected Stuart’s brain and changed his personality. He was very bubbly and he had a great sense of humour however with time he became very aggressive and anxious, he didn’t know what he was doing, he couldn’t sleep, his sleep was poor, he was frightened of dying, frightened of what was going to happen to him, frightened of not getting married and not having children and was frightened of how people treated him when he had open wounds. The disease totally destroyed him.”<sup>249</sup>*

### *Painful decline*

Some of the most poignant evidence before the Inquiry has borne witness to a slow, painful death, wasting away from AIDS before the eyes of the witness. Their accounts have been particularly powerful where they have described children, who ought to be full of the vigour and vision of youth, failing in an unequal struggle against the fatigue of fighting infection after opportunistic infection until they can go on no longer. To hear of those barely old enough to know that death is imminent realising this, and that their dreams and hopes will never be achieved, and yet worrying about the gap they will leave in their parents’ lives and those of their siblings is to hear some of the most moving of the accounts given to the Inquiry.

One man says of his young son:

*“He was an active, healthy-looking boy, but in the end he ended up being wheelchair bound. In the last ... weeks of his life his appearance changed completely; he was very thin, had a protruding stomach, could not walk, was incontinent, his hair got very thin and he had a yellow appearance. He also had repeated pneumonia and he was also not able to eat much during his last year of life. Towards the end of his life [he] developed dementia-like symptoms. He constantly kept forgetting things that he just asked about. We had to watch as his memory got worse until near the end it was completely gone and he would repeatedly ask the same question over and over.”<sup>250</sup>*

Another anonymous witness says:

*“We lost Dad long before he passed away. He lost his speech, he had changed so much. Gradually he became a living skeleton. It was a slow, painful decline; we had to help Mum take him to the toilet and wash him. It felt disloyal to admit it, but eventually when he was so ill and every day seemed like it would be his last,*

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249 Written Statement of Diana Blake para 20, para 22 WITN1101001

250 Written Statement of ANON paras 18-19 WITN1042001

*it felt like we were waiting for him to die. When I went into the room to visit I used to hope that he would be asleep because he would try to talk to me and often I wouldn't be able to understand what he was saying".*<sup>251</sup>

Another woman describes how her son's condition "steadily deteriorated" with him catching various illnesses that could not be diagnosed and:

*"By 1988, [my son] was vomiting frequently and we had all become used to helping manage his symptoms. He suffered from bad (haemophilia) nosebleeds, diarrhoea, vomiting and I can remember him crying during these episodes ... He was also suffering from terrible thrush which formed in a rash about his throat and mouth. The thrush made eating and swallowing incredibly painful ... [In 1991] he contracted numerous infections. He also suffered with shingles, episodes of spitting blood, spasms of the oesophagus, a dystonic reaction to the drugs, ulcers and thrush ... By the time of his death in 1993 ... one of his legs had stopped working, followed by a hand ... He had a large spongy lump on the side of his head. [My son] had become less and less mobile as well as losing most of his sight and speech ... he was in such pain that he would scream when touched."*<sup>252</sup>

Meg Parsons' brother, Robert was diagnosed with HIV when he was about 14 or 15 years old. He was infected by Factor 8 treatment. Lymph cancer was identified when he was 17 and Robert required surgery and chemotherapy:

*"At the age of seventeen, Robert was in his prime; an intelligent, well built, handsome young man, but the chemotherapy hit him hard. He lost weight, lost his hair and struggled to continue with his A levels at school. He continued to lose weight, and had several stays in hospital ... He deteriorated very quickly in the months leading up to his death. He had a persistent cough and he was very weak. He spent the weeks leading up to his death in hospital, where his body could not cope with the AIDS associated infections".*

He died aged 21.<sup>253</sup>

Gary Morris describes his brother's decline with HIV, transmitted through Factor 8: *"Jeff went from about 11 stone to 6 stone because of the HIV and HCV. He got to the point where he looked like he had starved. His eyes were huge and his eye sockets were deep and sunken ... Jeff's dementia got worse and worse and he would have intense hallucinations. He began losing his sight and he was in and out of consciousness for months."*<sup>254</sup>

Colin and Denise Turton's son, Lee was infected with HIV. They describe that from the age of five in 1986, he *"started really going downhill ... He would get tired. He didn't want to eat, did he? He was just not himself. He was just really, really low. He just wanted to go*

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251 Written Statement of ANON para 23 WITN1607001

252 Written Statement of ANON paras 20-21, para 26, para 30, para 32 WITN3123001

253 Written Statement of Meg Parsons paras 35-36, para 41 WITN1460001

254 Written Statement of Gary Morris paras 25-26 WITN0035001

to bed". From April 1989, he was never well: *"He couldn't walk far, he couldn't breathe, he couldn't eat, he was fed eventually through a tube. He had intermittent ... where he couldn't hear and some days he couldn't see properly, bloated stomach. It was just infection after infection. We spent most of the time in hospital, in and out of hospital with him and they never – could never find out what was wrong with him, what infection it was ... He would say 'I'm frightened'"*.<sup>255</sup> Lee died in 1992 aged ten years old.

One woman describes her husband's ill health and decline having been infected with HIV and Hepatitis C from blood products:

*"In 1987, he developed a dry cough and had difficulty speaking on occasions especially on the telephone. He also suffered with shortness of breath which was diagnosed as a nervous disorder ... By August 1987 during our time on holiday in France his health started to deteriorate rapidly ... he was diagnosed with bacterial pneumonia which resulted in him losing 10 kilos in weight ... Then things got worse rapidly and he developed candida oesophagus with drastic weight loss and he had to be admitted into hospital again in February 1989. He came home in late March for about a fortnight but during that time he was totally bed ridden ... He then had to return to hospital for the final time and he was so very ill. He was also very confused and his memory really suffered ... He then went slowly into a coma and never recovered."*<sup>256</sup>

Richard Titheridge witnessed the slow decline of his wife, Patricia, infected through a transfusion:

*"Patricia first began to show symptoms in about 1999 ... When she was first diagnosed Patricia was in a very poor physical state. One day in January 2003 we went in to the hospital and the consultant told us she had multifocal leukoencephalopathy, inflammation in all different areas of the brain. It seemed that the HIV had bypassed everywhere else and gone straight to her brain ... The HIV affected her brain in all kinds of ways. It affected her hormones and mood; for the next 2-3 years after she was first diagnosed she cried constantly, she was on several drugs to try and help with the crying and mood, but they didn't work and she would get hysterical unless I was with her. She wouldn't want anyone else around her, only me, and I had to stop working to be with her all the time ... Another way in which the HIV affected her brain was that she would hear voices in her head. If I was talking to her, that would echo in her head over and over. So in order to get rid of that effect, we had music playing in the house 24/7 because if music was playing then she would concentrate on that ... It also seemed like the brain damage had affected her logic, you couldn't reason with her. You would explain something one day and the next day it would be gone ... You never knew*

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255 Denise and Colin Turton Transcript 8 October 2019 p20, p24, p26 INQY1000037

256 Written Statement of ANON paras 19-20, paras 22-24, para 27 WITN1227001



*what went on in her head because you couldn't rationalise it in any way. She wasn't the woman I married, she was a completely different person.*"<sup>257</sup>

### *Long-term impacts*

Alan Burgess says *"Over the years I have suffered from numerous serious health problems due to both my HIV and the medication that I have had to endure ... I feel that the HIV medication has played a massive role in how I have felt over the years (both physically and psychologically) and that it will continue to do so for the rest of my life"*. Over the years he has had mouth ulcers, skin infections, candida, chest infections, cardiovascular difficulties, bone thinning, pancreatitis, kidney disease and side effects of treatments included sickness, diarrhoea and night terrors.<sup>258</sup>

Mr AN says:

*"I was forever going to see the doctor ... why do I feel so lethargic and tired and can't concentrate? I was always told, 'Well, it could be the hep C, it could be the HIV, it could be the meds for the HIV. We don't know' ... being diagnosed with HIV today is not the same as being diagnosed back in the 1980s, when there was either no treatment or only experimental treatment available. Some of the medications given at the time did as much harm, if not more, than the virus itself."*<sup>259</sup>

### **HIV: mental health effects**

Andrew Hearne, who was infected with HIV and Hepatitis C from blood products, says: *"It does feel like I have had the longest terminal illness possible, over 30 years and the fear doesn't go away."*<sup>260</sup> That inevitably has had a profound impact on many people's mental health: when first diagnosed, there were no effective treatments and a diagnosis was understood to be a death sentence.

Some people boxed up their feelings about their infection. Raymond Briscoe was diagnosed with HIV at 17 years old. He was told that most people did not live more than two years: *"I found it very difficult to associate myself with the person who was infected. I had in my head that the person who was infected was different to the person who I really was; it was like I was two people ... This worked for the first 30 years but it became progressively more difficult."* He describes being unable to process the emotional impact of his diagnosis and that he *"just buried it and I still do today."*<sup>261</sup> One man explains how he copes: *"In order to survive and cope with having to live with the infections, I try not to look into them too much."*

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257 Written Statement of Richard Titheridge para 5.1, para 5.4, para 5.6, paras 5.9-5.11 WITN0252001

258 Written Statement of Alan Burgess para 39 WITN1122001, Alan Burgess Transcript 28 October 2019 pp33-34, pp48-49 INQY1000045

259 ANON Transcript 16 October 2019 pp27-28 INQY1000042, Written Statement of ANON para 91 WITN1387001

260 Written Statement of Andrew Hearne para 47 WITN1281001

261 Written Statement of Raymond Briscoe paras 17-18, para 22 WITN1107001

*I would not be able to function if I became consumed with the fact that I had been infected as a result of contaminated blood products, the same treatment that was supposed to save my life. I think if I was submerged into all of this I would have jumped off a bridge. I live each day as it comes and this is my way of coping.”<sup>262</sup>*

One man, infected with HIV and Hepatitis C as a child through blood products, says *“Living with HIV and HCV has resulted in my suffering from chronic anxiety, social anxiety and depression, as well as symptoms of depersonalisation, derealisation, PTSD, low self-esteem, low self-confidence and low self-worth ... I had no life outside of the illnesses I was developing as a result of HIV and probably HCV that I did not know about.”<sup>263</sup>*

Tracey Loder describes how her late husband Charlie reacted to his diagnosis with HIV: *“He became destructive, he lashed out, he was angry and frustrated. He had addictive (gambling) tendencies, which I believe was his way of coping with the diagnosis.”<sup>264</sup>*

Andrew Quinn was infected with HIV, Hepatitis B and Hepatitis C through blood products:

*“I was so ashamed at the fact that I was infected so I planned to take my own life. However, I only planned to go through with this if my health plummeted. I purchased a hose and kept this in the back of my car whilst at the same time stockpiling pain medication. This occurred in or around 1984-1985. I even scouted out places where I could take my own life; I was mad about motorbikes so would go out searching suitable locations where I could carry out my plan. I was just stuck in my thoughts and I could see the writing on the wall and knew that my future was not bright.”<sup>265</sup>*

Karen Millard describes that when her husband, Russell, was diagnosed with HIV, contracted through blood products, *“he disintegrated into a shell of his former self. He became angry and distressed. He almost gave up overnight because he correctly predicted that HIV was a death sentence. Russell struggled mentally ... Russell was upset and completely devastated that he would not see his daughter Samantha and his son Daniel grow up.”<sup>266</sup>*

One man who was infected by his mother, who had been infected with HIV from a blood transfusion, describes losing his mother *“which not only deprived me of a mother but additionally a normal childhood. The fact that I was also infected was too much to handle emotionally because it shattered all of my hopes and dreams for the future and put paid to me having children or any type of ‘normal’ family life ... I can’t even say the word ‘HIV’. I avoid it and everything to do with it. During the meeting to prepare this statement I was only able to refer to HIV as ‘the condition’.”<sup>267</sup>*

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262 Written Statement of ANON para 24 WITN1512001

263 Written Statement of ANON para 26, para 37 WITN1300001

264 Written Statement of Tracey Loder para 28 WITN1353001

265 Written Statement of Andrew Quinn para 18 WITN1482001

266 Written Statement of Karen Millard paras 34-35 WITN1396001

267 Written Statement of ANON paras 14-15 WITN4452001

Another man who was infected with HIV and Hepatitis C through blood products as a child says that *“as soon as my understanding of the infection became clearer, I began building mental walls. I thought I was dangerous. How do you behave if you know that you’re dangerous? How can I have any sort of partner? Ultimately you know this thing is a killing machine which makes you a danger to anyone”*. He went on to have a mental breakdown at age 17 *“because of the implications of meeting a girl. My brain couldn’t deal with it.”*<sup>268</sup>

A mother recalls her late son’s manifestation of his mental illness as the development of *“serious paranoia ... He walked around carrying a camera, taking pictures of people. He used to say that he had to take pictures of people because they were following us ... He also became obsessed with the news, especially when the Contaminated Blood Scandal was broadcast. He was terrified of it.”*<sup>269</sup>

### *Change of personality*

For some, the mental health problems of their loved ones manifested in a changed, and sometimes violent, personality.

Anne-Marie Powell recalls that her father, who had contracted HIV and Hepatitis C from blood products, *“was always in bed. He was always tired, asleep or had his feet up and he would be yellow. He had terrible mood swings and, in hindsight, he was obviously depressed, but that isn’t something you would be aware of as a child ... He started to become violent occasionally ... I don’t blame this on my Dad; I blame it on his illness.”*<sup>270</sup>

Simon Lindsay describes how his father changed after his diagnosis with HIV, contracted through blood products and he was *“always very angry ... He was very bitter.”* Simon says: *“he took it out on me. My father was very, very frustrated with everything. From the age of about 12 years old I started getting hit ... I didn’t understand at the time why my father was acting like this but now I don’t blame my dad for hitting me because I can’t even dream of how he felt.”* Simon was expelled from school and was then told to leave home at 16.<sup>271</sup> His brother Samuel describes their father as being *“very jealous of us being healthy and so he did not want to know about things we were doing.”*<sup>272</sup>

One woman describes her late husband as *“like Jekyll and Hyde. He would be the life and soul of the party when we socialised, but he was very different behind closed doors.”* She recalls that: *“As a family we suffered from the moment [he] was diagnosed with HIV until his death. He was permanently bad tempered, had no patience and would especially take out his frustrations on our son.”* He hit her at times, there never having been physical or verbal abuse prior to his infection.<sup>273</sup>

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268 Written Statement of ANON paras 52-53 WITN0008001

269 Written Statement of ANON para 29 WITN1428001

270 Written Statement of Anne-Marie Powell paras 18-19 WITN1473001

271 Written Statement of Simon Lindsay para 13 WITN1348001

272 Written Statement of Samuel Lindsay para 25 WITN1349001

273 Written Statement of ANON paras 55-57 WITN0906001

### *Suicide and suicide attempts*

Other people turned in on themselves and a number of witnesses describe suicide attempts.

Kim Newhouse recalls that her father attempted suicide shortly after being told of his infection with HIV from treatment with blood products. She says: his *“infections meant that my father had to live with terrible depression which affected his life greatly and it also affected my mother and me.”*<sup>274</sup>

Andrew March, infected with HIV, Hepatitis C and Hepatitis B from blood products, says: *“At the approximate age of 14, I was not coping well. There was no counselling available back then. My adolescence was a traumatic and delicate time. I had been told by my GP, rather insensitively, that I would not live to see my 18th birthday. I had been crying a lot and whilst outside, I looked straight up at the sky questioningly, asking ‘why is this happening to me?’”* In hospital after taking a whole bottle of aspirin because *“I didn’t want to live any longer as an outcast with HIV”*, he *“had a moment of calm acceptance as I realised that there would be no easy escape for me. I don’t think there was meant to be.”*<sup>275</sup>

One young man, infected with HIV, ended his life in his early 20s when he jumped off Beachy Head after a relationship breakdown caused a spiral into excessive alcohol usage.<sup>276</sup> Mathew Machen took his own life in 2003, just four days after he was told that he had AIDS with a limited life expectancy, leaving behind his wife and two year old daughter. His wife says that she does not *“believe that Mathew ever came to terms with the fact that he had been infected with HIV and Hepatitis C. He tried his absolute hardest to live a full and joyful life but he was prone to spells of melancholy, suffered with severe depression and self-medicated with alcohol.”*<sup>277</sup>

Wayne Ellis ended his life aged 42. After he was diagnosed with HIV, Wayne’s *“life almost fell apart at the seams.”* He suffered from very severe depression, making a number of suicide attempts. He was discharged from a psychiatric unit shortly before his death.<sup>278</sup>

Collette Convery’s brother was told he had HIV when he was just 18. Collette explains that *“As Colin’s health deteriorated, he began drinking heavily. He told me when we discussed it, that he intended to hasten his death as he had no wish to die in the lingering way the media had portrayed.”* He died at the age of 24.<sup>279</sup>

Catherine Phelps’ brother was diagnosed with HIV when he was 22. She says: *“David’s reckless misuse of opiates after his HIV diagnosis was his way of committing suicide. He knew the HIV was a death sentence so he used hard drugs, an easy pathway for him, as a*

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274 Written Statement of Kim Newhouse paras 11-12 WITN1429001

275 Written Statement of Andrew March para 62 WITN1369001

276 Written Statement of ANON para 32, paras 35-37 WITN0603001, Written Statement of ANON para 27, para 41 WITN0822002

277 Written Statement of Lorraine Howgate-Gray para 22 WITN4453001, Written Statement of Amelia Howgate-Gray para 8 WITN4454001

278 Written Statement of Irene Madden para 53, para 65, para 68, para 79 WITN4600001

279 Written Statement of Collette Convery para 39 WITN0503001

*means of escaping from the reality of what was happening to him.*” David died aged 22, just short of his 23rd birthday.<sup>280</sup>

### *The effects of stigma on mental health*

The stigma attached to HIV (linked to the public rhetoric and campaigns) compounded the mental health difficulties of those infected.

One man was told of his HIV diagnosis alone at about age 19 and says: *“The only memory I have after I left the hospital that day was fear ... I was terrified about the stigma. The media at the time ran a horrible campaign with images of gravestones and messages like, you only have to sit on a toilet seat to spread the infection. I stopped reading newspapers, I stopped watching TV, I walked away from most of my life.”*<sup>281</sup> Another man describes being told by his parents that he was HIV positive, contracted through blood products, as a fourteen year old. He says: *“My world caved in when they did because as a young lad I had seen this on the news, all the hysteria, the ‘plague’; AIDS was going to wipe people out”*.<sup>282</sup>

Sarah Neasham has described how her father was infected with HIV, Hepatitis C and Hepatitis B through treatment with blood products for his severe Haemophilia A: *“When Freddie Mercury died in November 1991 it became clear to my father, that’s what was going to happen to him. My dad never recovered after that. I think he didn’t tell anyone outside the family he was dealing with a death sentence as he didn’t want his family to suffer any social stigma.”*<sup>283</sup>

After Sharon Pace’s father was diagnosed with HIV: *“He became introverted and hugely depressed, there were even suicide attempts as he tried to cope with the stigma attached to not only him but his children as well. He felt in his own words ‘dirty’ and knew that being open about it was not an option.”* He moved with Sharon and her brother away from Essex to the Midlands to be away from those who knew about his diagnosis: *“He became almost reclusive. He stayed in bed for most of the day and would only really go out for hospital visits etc. He always said that he felt he had a big red arrow over his head pointing him out and felt that everybody knew about the infection.”*<sup>284</sup>

### *Trauma of deaths*

Families anticipating possible multiple deaths knew that they would face more grief and heartache over the years. John Cornes said: *“Four of my brothers have died as a result of being infected, leaving my brother ... and I wondering who might be next ... I remember*

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280 Written Statement of Catherine Phelps para 38 WITN7404001

281 Written Statement of ANON para 19 WITN2232001

282 Written Statement of ANON para 6 WITN2149001

283 Written Statement of Sarah Neasham para 12 WITN1423001

284 Written Statement of Sharon Pace para 20 WITN1448001

when Gary was dying; Roy and Gordon looked at each other, and I remember they both had a look on their face, contemplating who would be next.”<sup>285</sup> John died in May 2023.

Derek Martindale’s brother, Richard, died of AIDS in November 1990. On the eve of their sister’s wedding, Richard wanted to talk. *“He knew he was dying. He knew that he had AIDS and that he didn’t have long to live and he just wanted to talk ... talk about his fears, how scared he was but I couldn’t. It was too close to home for me ... It was like looking into my future.”*<sup>286</sup> The depth of his feeling as he gave evidence of this was palpable.

One woman, whose two sons contracted HIV from blood products, says:

*“It was very hard for my late son and it was terribly upsetting as a parent to witness your child’s demise in this way; particularly when the infections took hold. I have memories of constantly rubbing his back because he was always in so much pain ... It was also a very difficult time for my other son ... as he had also been infected with the same three viruses. At the time when [my late son’s] health was failing, [my other son] thought he was not going to be here much longer than [my late son] and it was hard for me as I was really scared for both my boys. When [my late son] passed away, the whole family were petrified that [my other son] was going to be next.”*<sup>287</sup>

Clair Walton describes caring for her husband Bryan as he died of AIDS and knowing that she was also infected:

*“his brother and I and his parents ... held his hand while he took his last breath. It was 10.00 Saturday night ... somebody took me back [home] in the car and I afterwards thought ‘Oh my God’. Afterwards I was feeling who’s going to be there for me? And that was the trauma, the beginning of trauma ... On top of watching my husband die I felt like I’d lost everything ... I was a normal healthy young woman with all my life ahead of me when I met Bryan. It prevented me from having a normal healthy life and denied me the opportunity to have children and a loving family life.”*<sup>288</sup>

With the death toll, came the funerals. Stephen Nicholls says: *“the emotional toll of attending the funerals of my school friends up to 10 times a year is indescribable. They were all in their 20s, young men with their whole lives ahead of them.”*<sup>289</sup> Toni Poole describes a similar effect on her father, who was infected with HIV through blood products, as he *“frequently received phone calls to let him know that one of his friends had passed away. It must have been very frightening for him having to go to his friend’s funerals and wonder when it would*

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285 Written Statement of John Cornes para 3, para 61 WITN1170001

286 Derek Martindale Transcript 30 April 2019 pp28-29 INQY1000001, Written Statement of Derek Martindale para 35 WITN1688001

287 Written Statement of ANON para 25, para 33 WITN1301001

288 Clair Walton Transcript 2 May 2019 p32 INQY1000003, Written Statement of Clair Walton paras 40-41 WITN1589001

289 Written Statement of Stephen Nicholls para 43 WITN1432001

be him. He was depressed, he had panic attacks and extremely low self esteem and he also became addicted to tranquilizers.”<sup>290</sup> Alan Burgess describes visiting a close friend who died of AIDS a week later and he says: “I felt awful then because I could see myself laying there, when I was visiting him. You know, I thought, right, that’s going to be me, I suppose, you know, and it was not nice. It was a horrible time.”<sup>291</sup>

Roger Kirman became chairman of his local Haemophilia Society group when the previous chairman and secretary became ill.

*“I watched in disbelief as young colleagues and friends infected by these viruses became ill and died. I have a memory of being on a hospital ward, speaking to a friend who was thin, frail and very unwell. I can see him as he stood next to his drip stand receiving antibiotics and staring out of the window before we said goodbye. It was the last time I saw him ... Although I contracted Hepatitis C and carried it for more than thirty years I have survived the tragedy that befell so many friends and someone with whom I share so many things.”<sup>292</sup>*

Neil Armstrong was infected with Hepatitis B and C from factor products that he received when he attended Treloar’s School. He says: “It was extremely difficult growing up in a school where all my friends were becoming ill and dying. I lost my two best friends to HIV, one aged 17 and the other aged 19, and I think, to this day, I suffer from survivor’s guilt that I am living with my wife and children whilst they were never given that opportunity.”<sup>293</sup>

## **HIV: impact of treatment**

Many different treatments have been used for HIV over the years, with a variety of side effects and consequences. The early treatments were particularly detrimental and remain a significant cause of ill health for the people infected with HIV, even where their viral load is now low.

One man says: “I have also suffered physically as a result of the treatments. I have just been diagnosed with diabetes, and my previously well-functioning kidneys may be damaged. My anxiety is due to the weight of this diagnosis while already coping with a severely damaged liver (due to the effects of Hep C). I was also diagnosed with osteoporosis and hypertension due to the toxic medication given to me to control the HIV/AIDS virus.”<sup>294</sup>

Andrew Evans, infected with HIV and Hepatitis C by blood products, describes his late teens:

*“I signed up to stay on at school to go to sixth form but I then became very ill. At 16 years old, I had a fungal infection at the back of my throat and my CD4 count was under 200, which technically meant that I had full blown AIDS. I was regularly*

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290 Written Statement of Toni Poole para 27 WITN1471001

291 Alan Burgess Transcript 28 October 2019 p25 INQY1000045

292 Written Statement of Roger Kirman para 19 WITN1334001

293 Written Statement of Neil Armstrong para 15 WITN1078001

294 Written Statement of ANON para 24 WITN1513001

*physically sick and I would wake up in the middle of the night sweating. I was taken to hospital in an ambulance many times where in each instance I stayed for a couple of weeks on intravenous antibiotics, and they sometimes gave me medication that I was allergic to which made everything worse. I gradually had to drop my subjects as I felt so far behind in college. I was always either in hospital or recovering from a stay in hospital ... I had chronic chest infections, sinusitis and several ENT-type conditions ... When I took Pentamidine I had to be on my own in a sealed room with a hosepipe going out of the window. Nurses weren't allowed in because the stuff was so toxic, but we would be breathing it in for up to half an hour at a time ... Dr Wilde moved me onto 3TC and I gradually started to see some improvements in my CD4 count.”<sup>295</sup>*

In the early days, the medication was often experimental. Robert Hodgkins was diagnosed with HIV at around the age of 15 and says:

*“In the early 1990s, the doctors had realised that my immune system had become very weak ... Since there was no one specific treatment for HIV, agreeing to the experimental treatments seemed like my only chance. I did not necessarily believe that those drugs would save me, but I hoped that they would save someone else in the future ... As a result of the various experimental HIV treatments, I have developed serious long-term side-effects. These include: problems with my kidneys and my blood lipids (which affects my metabolism) and damage to my central nervous system ... The medications have been also a massive strain on my liver (together with the Hepatitis B and D) and I had to have my gallbladder removed in 2016 ... I have also struggled with severe fatigue and depression.”<sup>296</sup>*

AZT treatment was particularly punishing. One woman describes her husband, who had contracted HIV from blood products, becoming “*very breathless shortly after starting his AZT treatment, which was still in its early stages ... He was admitted and remained in the hospital until his death two weeks later ... I now believe that the dose of AZT [he] was given was too high and may have contributed to his sudden deterioration.*”<sup>297</sup> Another woman recalls her son receiving AZT treatment in his mid teens and how he “*started getting ill from the drugs ... There was a period ... in his late teens when he was very very ill. His weight was down to five stone because he had a long while where he couldn't eat, due to sores and thrush all in his mouth and throat, a condition caused by the HIV. I don't think he'd have cared if he didn't eat ... [He] lost loads of weight and became so thin, like what we came to recognise as someone with AIDS*”.<sup>298</sup> One man says of AZT: “*I was affected really badly; I was unable to sleep, I had continuous sweating, I had to go to the toilet a lot and I constantly had bad dreams every night – this was really significant to me. The major*

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295 Written Statement of Andrew Evans paras 25-26, para 31 WITN1213001, Andrew Evans Transcript 10 May 2019 pp27-32 INQY1000008

296 Written Statement of Robert Hodgkins paras 47-50 WITN0009001

297 Written Statement of ANON para 18, paras 20-21 WITN1415001

298 Written Statement of ANON paras 33-35 WITN0353001



*thing was the tiredness and my weight, it would fluctuate whilst I was on the medication.*<sup>299</sup>  
Jill Cunnington described the effect of AZT on her husband Robert:

*“About 6 months after the diagnosis, Robert started treatment with AZT. This treatment would knock him about. He would have to wake several times a night to take the drugs, but the drugs just made him more ill. He had to stop treatment, though had other trial cocktails of drugs until his death. Robert would suffer from diarrhoea, nausea, balance issues and weakness ... Robert was 11 stone when he was infected but only 5 stone when he died. He was like a skeleton; he could not move or walk so I would have to carry him everywhere and he was forced to use a wheelchair”.*

He died four years after he was diagnosed, after a chest infection developed into pneumonia.<sup>300</sup>

The impact of AZT was also described by one man in the light of how he felt when he stopped taking it: *“my appetite came back. I also had a better outlook on life and was feeling more positive”* on newer medications for his HIV. His T-cell count also improved.<sup>301</sup> Another man describes his medication being changed from AZT when he was nineteen: *“I went into remission a bit. When I was around twenty two I started eating more and I was able to start college again.”* He continues to suffer from a distended stomach, trouble sleeping and neuropathy which he understands to be due to the medication.<sup>302</sup>

Pentamidine nebulizer treatment was particularly unpleasant as Andrew Evans described above.<sup>303</sup> Another man describes his PCP prophylaxis as getting his *“lungs ‘steam cleaned’*. *No else could be in the room as it was so unpleasant to breathe in.”*<sup>304</sup>

Other medication caused different side effects. Lesley Poole’s son, Simon, *“was given every medication they could think of ... He was given cocktail after cocktail of medication. He had sickness, his skin fell off, and some medication made him feel lethargic, or gave him bad headaches. The side effects were dreadful. He was anorexic and he struggled to walk. He was tube fed.”*<sup>305</sup> One woman records that her late husband started combination treatment for AIDS: *“During this time he was very sick, he had no quality of life or social life, he lost a lot of weight, was in and out of hospital and he almost died on several occasions. He also reacted badly to the medications, which caused him severe nerve pain in his feet and hands and pancreatitis.”*<sup>306</sup>

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299 Written Statement of ANON para 30 WITN1345001

300 Written Statement of Jill Cunnington para 13 WITN0154001

301 Written Statement of ANON para 24 WITN0054001

302 Written Statement of ANON para 30 WITN0354001

303 Written Statement of Andrew Evans para 26 WITN1213001

304 Written Statement of ANON para 69 WITN6478001

305 Written Statement of Lesley Poole para 37 WITN2974001

306 Written Statement of ANON para 36 WITN1427001

One man describes the impact of lipodystrophy and explains: *“I continue to hide my facial features behind a beard. I still appear thin all over except for my stomach which is rounded and feels like there is a ‘ball in it’.”*<sup>307</sup>

Another woman describes that for her husband:

*“A side effect of one of [his] earlier HIV medications was terrible diarrhoea. He was prescribed Loperamide which eased the symptoms but a consequence of persistent and long term diarrhoea is malabsorption of calcium and [he] now has issues with low bone density. He has to be monitored and take calcium supplements. This is another concern for us because of the effects of osteoporosis and fragile bones in conjunction with the bone damage that he has already suffered as a result of his haemophilia.”*<sup>308</sup>

The impact of co-infection with Hepatitis C has been particularly challenging. One man describes the first time he was given treatment for Hepatitis C: *“An error was made with the treatment as the Pegylated Interferon contraindicated one of the HIV drugs I was on and they should have changed it beforehand. They therefore had to change my medication half way through the treatment and I only lasted 4-6 weeks, during which time I felt generally unwell, tired and physically sick.”*<sup>309</sup> Another man describes the impact of infection with HIV and Hepatitis C:

*“I have been on various antiretrovirals for HIV since 2003. The various treatments had to be changed over the years because of side effects, including diarrhoea, extreme fatigue, incontinence, hallucinations, swollen joints, depression, headaches, and so on ... HIV is suppressed in my body now but I have also suffered osteoporosis and body/face fat distribution which is horrible. I have regular “newfill” treatment which consists of injections into my face. I am limited to how many I can have and on occasion have paid privately at the cost of £700 ... The effects of co infection with HIV/HCV are worse than the effects of just one virus and of course I still have HIV and HCV, just that HIV is currently suppressed.”*<sup>310</sup>

For Peter Mitchell, the Hepatitis C became the major difficulty. His wife, Julia, says *“Pete’s HIV was very well-controlled. The drugs generally seemed to work well and his symptoms were kept in check. We did not believe that HIV was his greatest health risk, certainly he did not think that that would kill him. By 1992, we knew about the Hepatitis C ... Pete believed it was his liver that would kill him eventually.”*<sup>311</sup> Peter died in 2003 of metastatic disease with an unknown location of the primary tumour.

The fact of taking the treatment was difficult for children. One man describes that he *“unknowingly started treatment”* for HIV when he was eight years old:

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307 Written Statement of ANON para 17 WITN0254001

308 Written Statement of ANON para 27 WITN0899001

309 Written Statement of ANON para 19 WITN1557001

310 Written Statement of ANON paras 33-35 WITN1005001

311 Written Statement of Julia Mitchell para 43 WITN1010001

*“The treatment was contained in a syringe and I had to drink it. I vividly remember standing by the sink and telling my mum I didn’t want to take it because it tasted bad. My mum said I had to drink it and could have a glass of coke if I did. After that, I had it in my lunch box at school as I had to take it twice a day. Most people had a sandwich and a packet of crisps; I had a sandwich, a packet of crisps and a syringe. I later found out that this was my HIV medication, AZT.”<sup>312</sup>*

## Hepatitis C: physical effects

The myriad of non-specific symptoms resulting from Hepatitis C were described in numerous written statements. The intermediaries reported: *“People also described the impact of hepatitis C in vivid detail. Chronic, debilitating fatigue was an early symptom, with this often lasting for years without diagnosis. Other symptoms were severe aches, gastro-intestinal problems, skin changes and sweating. Cognitive impairment was frequently described as ‘brain-fog’, a debilitating level of confusion and inability to focus, often combined with anxiety and depression.”<sup>313</sup>*

These symptoms, especially the life-changing impact of debilitating fatigue, have had significant effects on people’s lives. One woman, who has since died, said *“I never thought that I would be sat here unable to do things for myself because I was so fiercely independent ... I need help with my shopping, and can just about manage in my house by holding on to things and using my stair lift. I can’t really do much outside.”<sup>314</sup>* Michael Payne talks about his mother Margaret who was infected with Hepatitis C: *“She loved planning family days, spending time with her grandchildren, being involved in the community and once she became ill she was not able to do any of that. I remember she came over for one of my children’s birthdays and had to go upstairs to sleep as she was so tired.”<sup>315</sup>* Joanna Smith describes how her father *“became less able to do the normal things in life such as going to the shop for a newspaper and routine things like that. As he became less active my mother needed to spend a lot more time taking care of him.”<sup>316</sup>* Delia Wetherall describes Hepatitis C and the treatments having a *“significant effect”* on her family life, and that she *“couldn’t really go out and do activities”* with her children when they were young. She had to retire early on health grounds.<sup>317</sup> William Leggatt said *“I have developed many further medical complications and conditions ... the doctors don’t say, ‘this is definitely down to the Hepatitis C’. But the conditions are common amongst people with Hepatitis C.”<sup>318</sup>* Since giving his statement William has died.

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312 Written Statement of ANON para 32 WITN0125001

313 Intermediaries Report 2019 15 January 2020 p8 WITN4000001

314 Written Statement of ANON para 20 WITN0328001

315 Written Statement of Michael Payne para 18 WITN7357001

316 Written Statement of Joanna Smith para 18 WITN1980001

317 Written Statement of Delia Wetherall para 44 WITN1998001

318 Written Statement of William Leggatt para 8.2 WITN0016001

There are a minority of people who have not experienced significant symptoms from Hepatitis C. Alastair Macrae participated in an early trial of interferon that was successful and says *“I would regard myself as being at the minor end of the scale of how Hepatitis C has affected me ... I look well and I am well.”*<sup>319</sup> A man who had transfusions after a childhood accident and was diagnosed 38 years later says: *“Throughout the majority of my adult life, I had no inclination that I was HCV positive. I did not experience any obvious health problems until my diagnosis in 2015. I was always fit, active and seemingly healthy. The HCV did not affect my everyday life, and on reflection it did not make me feel any different to normal.”* However, he says: *“My infection with HCV has caused irreparable damage to my liver ... in keeping with long-term HCV infection.”*<sup>320</sup>

### *Chronic fatigue and brain fog*

Hepatitis C has had a substantial impact on people’s energy levels, with many people experiencing severe fatigue and feeling extremely unwell. One woman who had a transfusion after a difficult caesarean section says: *“Before the HCV, I had good energy levels, but leading up to my diagnosis I had felt increasingly tired. I also had digestion issues and generally felt like something wasn’t right.”*<sup>321</sup> One man explained:

*“The biggest impact that stands out for me was the tiredness. It was a constant drained energy feeling that I had as a child and this in turn affected me mentally and it grinds you down. At the time I did not realise what I was going through as I was not aware that I had Hepatitis C. It was only when I came out the other side that I realised that it was caused by the Hepatitis C ... I often did not want to do things because I was so tired and then I began to think that perhaps I am lazy, which made me feel worthless. I remember my teachers saying I needed a stick of dynamite up my butt and that I had no motivation for anything.”*<sup>322</sup>

One woman was diagnosed four years after a transfusion when she had twins: *“I struggled to come to term with the previous four years. I then realised that the chronic fatigue I had suffered with when the twins were still babies was disproportionate and not down to them. I had had a terrible four years. I had pretty much isolated myself from my friends because I was too tired to accept visitors. I remember not answering the door to my friends in the hope that they would think that I was out.”*<sup>323</sup>

Caz Challis describes brain fog as *“similar to severe jetlag; it is a deep fatigue where both coordination and cognition are heavily impaired.”*<sup>324</sup>

Jayne Young thought that her physical symptoms were:

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319 Written Statement of Alastair Macrae para 49, para 30 WITN0132001

320 Written Statement of John Devine para 28, para 30 WITN4871001

321 Written Statement of ANON para 50 WITN4338001

322 Written Statement of ANON para 22, para 24 WITN0844001

323 Written Statement of ANON para 10 WITN7545001

324 Written statement of Caz Challis para 20 WITN0622001

*“down to going through menopause ... My sleeping has always been the same, horrendous. I go to sleep at half-past nine and wake up at two in the morning. I stay awake and watch the telly, then fall back asleep on the sofa. I always suffered from fatigue, sometimes to the point of exhaustion and I simply put all that down to having kids and being a mum, but this all started to happen after I contracted Hepatitis C and thinking back I had some of these problems before the kids came along.”*<sup>325</sup>

Joan Thompson, who was infected from a postnatal blood transfusion, describes the health conditions she suffered after her infection until she was diagnosed 31 years later: *“fatigue, sleeping problems, night sweats, digestive problems, headaches, itching, bloating, floaters and blurred vision and oesophageal varices ... I tried not to let my health problems interfere with work which I did find hard at times, especially not knowing why I felt like I did.”*<sup>326</sup>

Jacqueline Stephens graphically describes Hepatitis C as being *“like when you have the worst case of flu and a hangover, all at the same time, that is what it is like.”*<sup>327</sup> Joan Edgington describes it as like having a *“flat battery”*: *“The car was running but if you put your foot on the accelerator there was no extra go.”*<sup>328</sup>

*“Brain fog”* has been a common experience; a feeling of being *“sluggish”*,<sup>329</sup> unable to concentrate, and having difficulty remembering things.<sup>330</sup> One man says: *“The impaired brain function means most days you are unable to concentrate or make decisions. My short and long term memory is poor”*.<sup>331</sup> Tess Townsend describes the effect of Hepatitis C on her late ex-husband: *“Alan began to suffer with brain fog, which became worse over time and he started to forget things, which was very uncharacteristic. He certainly lost the ability to recall information as he did before and I believe he attempted to hide the fact that he had lost this ability.”* As the Hepatitis C progressed: *“The brain fog would come in and out depending on the toxicity in his body, and he was unable to keep a diary, make phone calls or manage appointments reliably.”*<sup>332</sup>

### *Advanced liver disease*

Many people have developed internal bleeding and oesophageal varices which are both terrifying and potentially catastrophic. One man says: *“I began fainting out of the blue. I was told that I had internal bleeding and after some banding and a transfusion I was okay. However, a few months later the same thing happened again. The doctors discovered that there was something wrong with my liver, and I had to have a stent put in my liver to*

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325 Written Statement of Jayne Young paras 17-19 WITN0948001

326 Written Statement of Joan Thompson para 19 WITN0171001

327 Written Statement of Jacqueline Stephens para 62 WITN0566001

328 Written Statement of Joan Edgington para 22 WITN0065001

329 Written Statement of ANON para 16 WITN4358001

330 Written Statement of Marcus Nightingale para 17 WITN1434001

331 Written Statement of ANON para 30 WITN0356001

332 Written Statement of Tess Townsend para 14, para 33 WITN7381001

*keep the aorta open and stop the veins popping in my oesophagus.*<sup>333</sup> A woman describes when she developed oesophageal varices: *“Vomiting blood into a bowl whilst waiting for an ambulance was not how I wanted to spend my Saturday morning. I would have rather been taking my daughter to her ‘Under 8’ football session”*.<sup>334</sup> Rhiannon Hatton, whose husband was infected with HIV and Hepatitis C, says that *“banding”*, the treatment for oesophageal varices, *“completely traumatised”* her husband who *“until then had been so brave.”*<sup>335</sup>

Oesophageal varices are one indicator of liver failure which also manifested itself in other ways. Christopher Cross describes his father Raymond’s deterioration: *“He struggled with fluid retention in his legs and feet in particular. His ankles and feet would swell up to the extent that my Mum would cut the elastics on his socks because they were painfully tight for him. At his most ill, he could not put shoes on. Eventually, he could not even put slippers on. For a man who would never go out unless he was in a suit and tie, this was a real blow.”*<sup>336</sup> Deepak Datta describes the impact of Hepatitis C on her mother: *“The Portal Hypertension had caused varices to develop. Her stomach was also consistently swollen from the excess fluid. She developed breathlessness and was given ace inhibitors for her heart although she was never diagnosed with a heart condition. This breathlessness tended to coincide with the excess fluid in her stomach area.”* Her type 2 diabetes also became *“very erratic”*.<sup>337</sup>

Ronan Fitzgerald describes how his mother, Jane, developed ascites: *“The cirrhosis caused fluid to build up in her abdomen, legs and feet. As this ascites worsened, her liver was fitted with a stent which helped for a very short time before the ascites built up in volume and my mum had to have her abdomen drained roughly every 10 days. This experience was hell on earth for my mother.”* He described how she was often left to wait for up to seven hours *“surrounded by drug addicts and alcoholics”*, not knowing if a bed or the equipment would be available, and then the procedure itself took between six and twelve hours.<sup>338</sup> Barry, Jane’s husband, describes how, after a short period when Jane seemed to have improved, her liver stopped functioning, *“everything was breaking down completely”* and *“the ascites came back with a vengeance.”*<sup>339</sup> Margaret Howells describes her father having *“26 pints of fluid”* drained from his abdomen,<sup>340</sup> and another person describes their father being unable to breathe properly because of the fluid that had gathered.<sup>341</sup>

Liver failure, for those who could not have a liver transplant, meant a long and painful decline. Susan Delglyn’s husband, Michael, was not told of the Hepatitis C infection until six to eight months before his death in June 1993. Susan says:

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333 Written Statement of ANON paras 46-47 WITN1225001

334 Written Statement of ANON para 17 WITN0316001

335 Written Statement of Rhiannon Hatton para 10 WITN1279001

336 Written Statement of Christopher Cross para 33 WITN0940001

337 Written Statement of Deepak Datta para 14, para 11 WITN0935001

338 Written Statement of Ronan Fitzgerald paras 12-13 WITN1874001

339 Barry Fitzgerald Transcript 8 October 2019 pp129-132 INQY1000037

340 Written Statement of Margaret Howells para 20 WITN1296001

341 Written Statement of ANON para 19 WITN2011001

*“Michael suffered a slow, tortuous death. He often broke down. He knew he was dying. There was nothing we could do but watch him slowly die. He would have had a quicker, more dignified death without pain if he had died when he had the brain haemorrhage. It was however clear from the speed in which Michael deteriorated and died that his liver disease was well advanced. In failing to tell Michael sooner about the HCV, he was deprived of the opportunity for treatment.”<sup>342</sup>*

Another aspect of liver failure is the development of hepatic encephalopathy. Hedwig Morrow described how her husband, Norman, suffered from *“total madness and paranoia in the last 9 months of his life”* as a result of the progression of Hepatitis C contracted from Factor 9 treatment: *“He would telephone our children at all hours, displaying both emotional and clingy traits, which was very out of character for him. He also told our children that it was me who was losing my mind.”* Norman died in April 1994.<sup>343</sup> Pete Burney described how encephalopathy affected him and his wife:

*“From what I can gather, at night time I would go to sleep for 5-10 minutes. I would wake up thinking I had been asleep for hours. Then I would start my morning routine ... This would happen four to five times a night. I remember her telling me one time, ‘Peter you’re putting toothpaste on your razor blade to clean your teeth.’ I realised then that I had a problem. I could not turn the TV over, could not make a telephone call; I could not do anything. I always thought I had a really strong mind; that whatever happened, I would get over it with my mind. I still think I have a strong mind but I continue to get bouts of encephalopathy ... Frightening is the word I would use to describe this condition. I can go into a room in my home and not know where I am or why I am there.”<sup>344</sup>*

Pete died in December 2019.

### *Liver transplants*

A number of witnesses required liver transplants due to Hepatitis C infection. One woman’s treatment had been unsuccessful and she was admitted into Edinburgh Royal Infirmary for further tests in 2009: *“At the end of the week, Professor Hayes came to my bedside and told me that I was a candidate for a liver transplant. I remember the following month I was very unwell physically. I was constantly in and out of Crosshouse Hospital to get my stomach drained as I was filling up with fluid. Mentally I was very depressed and anxious about whether a donor would be found. In October 2009, I was advised that I was in the final stages of liver failure. It was a very stressful time.”* She received a call that a liver had been found: *“I was absolutely terrified and delighted at the same time. I remember being quite emotional. Everything happened quite quickly after that. I had the transplant that day. The liver transplant was a success and I had a good recovery. I was very lucky.”<sup>345</sup>* Doreen

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342 Written Statement of Susan Delglyn paras 23-25 WITN1183001

343 Written Statement of Hedwig Morrow para 22 WITN1412001

344 Written Statement of Pete Burney para 28 WITN0061001

345 Written Statement of ANON paras 21-22 WITN0091001

McCleave's husband became more unwell as the years progressed: *"His energy levels dropped and he was always tired. The chronic fatigue meant he would often be asleep on the sofa wrapped in blankets and with a hot water bottle, despite the heating being on. His health rapidly deteriorated and he suffered with swollen legs, joint pain and itchy skin as a result of the infection"*. He subsequently had a liver transplant, being flown from Belfast to King's College, London. She said that the new liver *"gave him a new lease of life and another 13 years"* but the Hepatitis C infected the new liver.<sup>346</sup>

Anne Riley describes waiting for a liver transplant:

*"Life on the transplant list was a whole new ball game. Life comes to a standstill and you are unable to make plans to do anything. Permanently waiting, hoping and not knowing if the day will come, whether you will live or die before a donor can be found. It messes with your mind and emotions, along with the hopes of your family too. I waited ages for a liver transplant and on three occasions I was 'blue lighted' to Kings College Hospital, only to find out that the liver was not suitable. The feeling of devastation was unbearable"*.

On the fourth occasion, Anne had a liver transplant which was successful though she continues to suffer a number of physical symptoms and requires a large amount of medication.<sup>347</sup> Ann Dorricott, speaking about her husband Mike, describes *"Just the waiting was bad enough but having three false alarms, you know, you'd get to the hospital and then they'd decide they wouldn't use the liver because it wasn't healthy enough and then the call that he did get was okay and they went ahead with the transplant."*<sup>348</sup>

For people living in Northern Ireland, there was the added stress of having to travel to King's College Hospital, London, for treatment. Sharon Lowry's husband Richard was assessed for a liver transplant in London and then returned to Belfast to wait to see if an organ became available and as they waited, some of those on the ward died and: *"other people were being flown off to London for transplant. He got so low after nearly three months, it was getting to both of us ... eventually, it was the end of November, when a donor organ became available ... we were flown over [to King's] in the middle of the night ... Then, about 8.30 on the morning of the Tuesday, they decided to go ahead with the transplant, and they took him to theatre. I was left sitting in a corridor ... eight hours later I was still sitting with our suitcases"*. Richard spent four months in King's following that transplant, in and out of intensive care, and many more months in hospital in Northern Ireland. He died in November 2011. In his last days he begged Sharon to kill him: *"He just wanted to die. He had had enough. He was so distressed."*<sup>349</sup>

Marie Cromie had *"an agonising wait"* for a transplant at King's College Hospital. Her first transplant, in 2007, initially appeared to be a success but within a few months she was told

346 Written Statement of Doreen McCleave paras 19-20, para 32 WITN0348001

347 Written Statement of Anne Riley paras 37-38 WITN0202001

348 Ann Dorricott Transcript 21 June 2019 p57 INQY1000024

349 Sharon Lowry Transcript 24 May 2019 pp23-24, pp42-44 INQY1000012



that Hepatitis C had started to attack the new liver. Her health deteriorated. She was back and forth between Belfast and London before a second transplant in 2015. In her statement in 2019 Marie said that she got *“very down and depressed because I thought that I would be able to get out and about and live a normal life ... There are some days when I feel reasonably okay but there are a lot of days when I wake up and feel terrible ... I cannot though really go out anywhere on my own ... I struggle to climb the stairs at home and have had several falls both in and outside the home.”*<sup>350</sup> Marie died in 2023.

David Rankin came close to death after a first liver transplant failed, and describes his second experience:

*“On the 6 December 2005 I had the second transplant and it was a far more traumatic experience ... The recovery was extremely slow and I plateaued ... Finally in late February I was transferred home – I was not getting any better or worse in hospital, so I could return home to convalesce. I remember it well, it was the first time I had smelt fresh air and seen outside since October the previous year. I had become a difficult and uncooperative patient as I resigned myself to the fact that I would not be able to walk again. I ended up having counselling in regard to this, as I struggled to forgive myself with how I have behaved ... I went into Addenbrookes for the first liver transplant weighing 24 stone and by January 2006 I weighed a little over 11 stone. I had no strength that I could not even pick up a beaker full of water. The initial delight of being discharged soon faded ... It took 3 months before I could walk again and in August 2006 I managed to find my car keys to drive to my house. Overall it took a year from liver decompensation to being able to function independently.”*<sup>351</sup>

One woman describes the transplant process as: *“a roller coaster ride that lasted for nine weeks. A liver transplant is a new lease of life, but it comes with risks and it comes at a cost. For me to have a chance someone else has to die. I will simply say that it was a hard road physically as well as mentally but that I thank my donor’s family every single day for the gift I have been given.”*<sup>352</sup>

Even where the transplant is successful a person may remain unwell. Michael Kennelly says: *“I constantly worry that sooner or later my body may reject the transplanted liver. I suffer from depression and I am on anti-depressants. I still get the scary dreams”*.<sup>353</sup> Christopher Munn says: *“Following the successful liver transplant I had to learn to walk again and had extensive treatment from a physiotherapist. Since the transplant I now have to take the anti-rejection drug (Tacrolimus) daily, which suppresses my immune system and subsequently I*

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350 Written Statement of Marie Cromie pp8-9 WITN2429001, Danielle Mullan Transcript 22 May 2019 pp54-61 INQY1000010

351 Written Statement of David Rankin paras 58-71 WITN0357001

352 Written Statement of ANON paras 25-26 WITN0316001

353 Written Statement of Michael Kennelly p5 WITN0028001

*seem to catch every cold and flu. I now try to avoid large crowds and public places.” He can no longer attend football matches and says his social life has been “decimated.”<sup>354</sup>*

Dawn Mobey’s husband underwent a transplant process that was ultimately unsuccessful. After suffering varices in August 1999, he had a liver transplant on 29 March 2000. Initially the transplant was thought to have been successful. However, Christopher’s kidneys failed. In about October 2000, his liver started to fail and he had more internal bleeds. He had a second transplant in May 2001 but died in hospital on 24 August 2001. He left behind Dawn and their three young children.<sup>355</sup>

### *Liver cancer*

Hepatitis C can cause people to develop hepatocellular carcinoma, that is, liver cancer. Living with the fear that this might become a reality is a heavy psychological burden. Christine Kelly was infected with Hepatitis C during a blood transfusion after childbirth. She has cleared the virus but continues to have liver scans twice a year. She says: *“I am waiting for them to tell me any day now, ‘Mrs Kelly, you have cancer’. I absolutely hate going for my medical appointments, and I feel sick when the time arrives for them ... Nine times out of ten I am physically sick when I arrive home from my medical appointments.”<sup>356</sup>*

People who developed liver cancer have faced chemotherapy, treatment such as transarterial chemoembolization (“TACE”) and transplants.

Steve Hill was diagnosed with Hepatitis C in 1995 and had interferon treatment shortly afterwards. In June 2011 a tumour was detected. He was placed on the liver transplant list in August 2011, alongside treatment to prevent the growth and spread of the cancer. Unfortunately, the cancer spread to outside the liver and *“After fully complying with all the restrictions of being on a transplant list for just over a year”* including not attending his mother-in-law’s funeral because it was two hours away from the hospital, Steve was removed from the transplant list in July 2012. He died in September 2014.<sup>357</sup> Therese Young cleared Hepatitis C, transmitted by transfusion during surgery, on the second attempt in 2015. She said: *“Although this is good news, it’s too late as I have already developed liver cancer and am living with the severe side-effects of Interferon and Ribavirin”*. She had seven cycles of TACE treatment before it stopped working and then she had chemotherapy. At the time of writing her statement she had been told that she was terminally ill and she died in December 2019.<sup>358</sup> Rodney Prosser developed hepatocellular cancer, requiring TACE treatment. He was able to have five treatments but could not have the sixth. In his statement he wrote: *“things have progressed on from there so that will not be possible ... I asked the specialist if there were other treatments in the pipeline and he said there are, but the problem is that we*

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354 Written Statement of Christopher Munn para 18 WITN0691001

355 Written Statement of Dawn Mobey para 7, paras 14-17 WITN1402001

356 Written Statement of Christine Kelly paras 53-54 WITN0409001

357 Written Statement of Ira Hill paras 9-10 WITN7431001

358 Written Statement of Therese Young paras 5j-5k WITN0044001

*have to get rid of the HCV before these become a viable option. The TACE has given me an extra year and a half.*<sup>359</sup> Rodney died in February 2019.

In some cases, the development of the cancer was so swift no treatment was possible. One woman describes how her late husband did not have interferon treatment until 2002. She does not know why he was not treated earlier. In January 2003 he suffered with extreme bloating in his stomach and went for a scan. Before the results came back, he “*suffered again with severe stomach cramps and ... [he] went into hospital by ambulance.*” She says: “*I was told that [he] had liver cancer and was unlikely to survive the day. This was a complete shock ... We had no idea that he had cancer and that was the first time that cancer had ever been mentioned.*” He died shortly afterwards, leaving a two-year-old daughter.<sup>360</sup>

### *Other cancers*

Other cancers may also develop. Nicola Jones was diagnosed with breast cancer in 2010. She had treatment by way of lumpectomy and gland removal, as well as post – operative radiotherapy and hormone therapy, Tamoxifen.<sup>361</sup> Another woman infected with Hepatitis C through a transfusion was diagnosed with breast cancer in 2009: “*I don’t think I would have got that if I didn’t have hepatitis. It raised questions in my mind. I was really concerned ... No one else in my family has ever had breast cancer so I think there could be a connection.*”<sup>362</sup> Sarah Taylor’s father was infected with Hepatitis C and she describes his last few years as “*very tough*”. He had diverticula and colon bleeds. In July 2011 “*he was told that he had bowel cancer and liver cancer and the doctors told us that it was probably caused by the Hep C. He was told that the doctors were going to remove the infected bowel/intestine and then he could start chemotherapy but unfortunately he had a bleed and died. It was the worst 2 weeks of my life to watch him go through that.*”<sup>363</sup> Carole Anne Hill was diagnosed with ovarian cancer and told the Inquiry that her husband, a retired doctor, “*does a lot of reading of research papers, American research papers largely, and he told me that there had been intimations that there may be some links*” between Hepatitis C and ovarian cancer.<sup>364</sup>

### *Impact despite self-clearing*

The fact that a person has self-cleared the Hepatitis C infection does not mean that they have not experienced adverse consequences.

David Green has Haemophilia B and was infected with Hepatitis C. He self-cleared the virus but recalls that from about age 11 to age 15, he was “*always ill with major fatigue, malaise and depression*”. He was regularly off school and unable to play sport. He had two other periods of similar ill-health and was diagnosed at the age of 26 with Hepatitis C which he

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359 Written Statement Rodney Prosser para 31, paras 36-37 WITN0142001

360 Written Statement of ANON paras 15-16, para 24 WITN1314001

361 Written Statement of Nicola Jones para 56 WITN1756001

362 Written Statement of ANON para 15 WITN0248001

363 Written Statement of Sarah Taylor para 28 WITN3033001

364 Carole Anne Hill Transcript 30 April 2019 p51 INQY1000001

had cleared naturally. His diagnosis “sent [him] into a ‘tail-spin’” and he remains extremely anxious about the potential issues that Hepatitis C may have left him with and that people are dying from it.<sup>365</sup>

One man describes symptoms of depression and anxiety, exacerbated by the fact that his brother died of Hepatitis C: “My symptoms of fatigue and mental health problems are attributable to the Hep C”. He describes “being very tired and lacking energy”, and the Hepatitis C being “a living mental hell of painful memories and constant anxiety that my future with my family is uncertain.”<sup>366</sup> Another man describes living with “chronic bowel irritation, cramps and back pain” as well as being “extremely lethargic and exhausted” and having brain fog.<sup>367</sup>

### Hepatitis C: mental health effects

The impact of Hepatitis C on people’s mental health has been profound, particularly in combination with the physical effects of the infection, and the impact of treatment. One man says that “Being informed that I was infected with HCV had a huge impact on my mental wellbeing. Knowing that I had been suffering with it all this time, with it damaging my liver without me knowing, definitely added to the stress of it all.”<sup>368</sup> Laureen Fargie describes how her late husband reacted to his diagnosis: “George certainly changed after being diagnosed with HCV. He was a very proud man but felt degraded and dirty because of the infection. He became a shadow of the man he was before – he had always been a jolly man and enjoyed a laugh.”<sup>369</sup> Claire Loynd describes her mum going from someone “who was always happy and laughing to just being completely in herself and she barely smiled, she was just terrified of what might happen.”<sup>370</sup>

One woman describes the Hepatitis C diagnosis as “like a death sentence; you don’t know when it will kill you but you know it will.”<sup>371</sup> Patricia Hopton says that “Mentally, I have struggled with my diagnosis and more so once I carried out my own research and realised the severity of Hepatitis C. I had not appreciated that people could die from it until I started reading into it ... I started to go downhill and became depressed.”<sup>372</sup>

#### Social isolation

Many people describe disengaging from the world because of the mental health impacts of the diagnosis. Kate Ashton says: “Engaging with people has become difficult due to worsening depression over the years. As a result, in recent years I have taken jobs

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365 Written Statement of David Green para 9, paras 12-13, para 15, para 17 WITN7599001

366 Written Statement of ANON paras 20-23 WITN1556001

367 Written Statement of ANON para 17, para 19 WITN7466001

368 Written Statement of ANON para 46 WITN4212001

369 Written Statement of Laureen Fargie para 26 WITN4670001

370 Written Statement of Claire Loynd para 26 WITN0048001

371 Written Statement of ANON para 41 WITN1400001

372 Written Statement of Patricia Hopton para 22 WITN3955001

which have required me only to type or proofread and do not involve too much personal interaction.”<sup>373</sup> Linda McKinney describes that she “was very outgoing and had a very active social life but then I lost all of my confidence because of the infection.” She now cannot cope with crowds and does not like meeting new people.<sup>374</sup> One man says he has:

*“an overriding sense of detachment and no longer feel part of society. It is a bit like I am watching everyone else but I am not included. It’s a strange feeling that is difficult to put into words, dystopian, slightly paranoid, distrust and a feeling of anticipation that something bad is going to happen quite frequently. I can rationalise it, but it’s always back soon without any obvious linkable triggers ... These days it’s very difficult to establish a sense of purpose. I don’t do anything anymore I just procrastinate with myself that when I am better I’ll be able to do this or I’ll be able to do that. The lack of self-esteem provides a wealth of insecurities across every aspect of my life and relationships.”*<sup>375</sup>

One woman felt “a lot of anger and frustration” following her diagnosis with Hepatitis C: “I felt frustrated there appeared to be no way to right the wrong I knew had been done to me. I often felt consumed by this anger and alone with the burden and stigma of the disease, which I kept a secret from most people.”<sup>376</sup>

Concerns about infecting others have led to isolation. One man says:

*“For 24 years I suffered from chronic fatigue, ‘brain fog’, chronic migraines, recurrent ‘flu like’ symptoms, irregular heart rhythm and a general malaise. In 1994 I had to leave my job owing to the increasing stress of trying to cope with the illness ... My social life, too, came to a halt and I became isolated and almost hermitical. I felt like a social pariah and at times wondered if I could be a public danger: I was constantly anxious about the possibility of transmitting the infection to others ... In short, the impact of being infected with HCV has been to blight over one third of my life and to leave all my hopes and aspirations in ruins.”*<sup>377</sup>

### *Suicide and suicide attempts*

For some, their mental health difficulties developed into suicidal thoughts, and attempts. Angela Powell’s husband had mild haemophilia. He contracted Hepatitis B and Hepatitis C:

*“I believe that John’s depression had progressed slowly through from the time of his potential diagnosis with HIV, and how it could have affected me, the diagnosis of HBV, then HCV and all its complications and finally the vCJD ... In 2007, John was sectioned and there were concerns over my mental health. I was on the*

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373 Written Statement of Kate Ashton para 5 WITN1416001, Kate Ashton Transcript 1 May 2019 pp82-86 INQY1000002

374 Written Statement of Linda McKinney paras 16-18 WITN0247001

375 Written Statement of ANON para 26, para 29 WITN1266001

376 Written Statement of ANON para 13 WITN2853001

377 Written Statement of ANON para 5 WITN0015001

*verge of a breakdown trying to cope with John's behaviour and keep the family together and functioning as normal. John had tried to hang himself, threatened to jump in front of a train and on one occasion attempted to jump into a local river. He just did not want to be here anymore. How could he be left to deteriorate so far without it being recognised within the medical profession? John became an alcoholic due to his depression; he would take loads of tablets and drink vodka."*

John passed away in 2016.<sup>378</sup>

One mother describes what happened to her son during his second attempt at treatment:

*"Every few weeks to a month [my son] would be self-harming by cutting his arms and letting himself bleed uncontrollably ... On another occasion ... [my son] had disappeared, and when I went and found him in the back garden he was pouring petrol over his head ... On at least three occasions [my son] swallowed handfuls of various pills of the numerous tablets that he took as part of his medication. He always did this along with drinking a lot of alcohol ... It was a truly awful time. I would often stay with [my son] for days, monitoring him, and he would sit in the corner of his room with his head in his hands and not say a word for hours. It was heartbreaking what had happened to him and how it was continuing to take him in a downward spiral."*<sup>379</sup>

Another woman describes how her late husband told her that *"he had to move out from a tower block as his depression was so deep that he often had the urge to throw himself from his balcony. He was so scared of the temptation that he eventually decided to move out."*<sup>380</sup>

Stephanie Clifford's husband Adrian was infected with HIV, Hepatitis C and Hepatitis B. He required Factor 8 concentrates for mild haemophilia and had a blood transfusion in 1984 after a car accident. He was able to continue working until 1992 when he had a bout of shingles and lost a lot of weight. There were problems with their neighbours who spray painted *"you have HIV"* and *"you are gay"* on their garage and stopped their children playing with other children. From 2013, Stephanie saw a decline in Adrian's mental state, he was unable to sleep well and *"said he was generally fed up."* In 2015, he ended his life. Stephanie considers that *"a major contributory factor to his suicide ... [was] the impact of his HCV on his health which led to his depression and ultimately his suicide."*<sup>381</sup>

Keith Francis took his own life after interferon and ribavirin treatment, which had caused a significant deterioration of his mental health, had failed. Karen Francis, his ex-wife, describes that he was *"deeply depressed. When he wasn't overcome with fatigue he would have wild bouts of energy. His ability to make decisions and his behaviour was erratic. He made some*

378 Written Statement of Angela Powell para 32, paras 36-37, para 40 WITN0729001

379 Written Statement of ANON paras 54-56, para 58 WITN0477001

380 Written Statement of ANON para 33 WITN1581001

381 Written Statement of Stephanie Clifford paras 5-6, para 18, para 20, para 22, paras 41-43, para 50 WITN7511001

*extreme life changing decisions, to leave our marriage, to make himself homeless/become a missing person and (ultimately) to take his own life.*<sup>382</sup>

### *The effects of stigma on mental health*

The reactions of others, and the stigma of the disease, has added to the psychological burden. When Huw Thomas went to his local rugby club: *“A member of my rugby club who was an undertaker found out I had HCV and said to me ‘Ah, 5ft 7 and 13 stone – call me when you need me’ and handed me his business card. This made me feel really upset and I struggled to be in his company at future events. I eventually stopped going to the club.”*<sup>383</sup>

One woman describes the effect on her partner: *“The stigma of the [Hepatitis C] infection was something that weighed on [his] mind a lot. He didn’t want people to think that he was a dirty person, or a person that used drugs, or someone that was having unprotected sex with multiple people. So, he hid his infection from most people, even the majority of his family, for a very long time ... I think the stress of keeping the infection a secret was something that affected us both quite a lot.”*<sup>384</sup> Jane Ebrillwen Jones recalls that she *“was congratulated by one of [her husband] John’s friends for being pregnant when I had the severe ascites, and after I corrected him and said that I was there for a liver scan, he said ‘Gosh, who would have thought, you an alcoholic’.”*<sup>385</sup> One man describes how other family members reacted to his mother’s infection with Hepatitis C following transfusion: *“There has been a taboo in some parts of the family and it hasn’t been spoken about ... They went from being so welcoming, to not allowing her near their kids.”*<sup>386</sup>

The daughter of a woman who was infected with Hepatitis C following a transfusion in 1986 and who died in 1998 around a year after being diagnosed, reports that the stigma weighed heavily on her mother: *“In those days hepatitis C was known as a dirty infection related to drug abuse and prostitution. My mother was a devout Catholic and being associated with a dirty disease was something she found difficult to live with ... she had to keep the news of her diagnosis to herself and this caused her to become even more withdrawn. My mother regularly attended Church, however, after her diagnosis my mother never attended Church again.”*<sup>387</sup>

### *Other psychological effects*

Cressida Haughton describes how her father *“tried as best he could to take control over the life he had left, not dwell on what may have been taken from him”* and that the irritation he showed the couple of times she tried to talk to him about the infections was *“indicative of*

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382 Written Statement of Karen Francis para 17 WITN4455001, Written Statement of Carly Bayford paras 10-11 WITN4178001, Written Statement of Jennifer McCabe para 20 WITN4179001

383 Written Statement of Huw Thomas para 25 WITN0023001

384 Written Statement of ANON para 30 WITN6871001

385 Written Statement of Jane Ebrillwen Jones p6 WITN2360001

386 Written Statement of ANON para 22, para 24 WITN6905001

387 Written Statement of ANON pp3-4 WITN2460001

*deeper feelings on the matter rising to the surface but he did not feel comfortable addressing them or discussing them”.*<sup>388</sup>

Gerald Stone says that being diagnosed with Hepatitis C worried him “*exactly the same as between ‘83 and ‘85 where I was worried about having AIDS, which I didn’t have fortunately. But I had the same effects then in 1993 because I was extremely worried then.*” He describes “*a lot of sleepless nights worrying*”, his mood being affected and perspiration: “*it was just sheer fear.*”<sup>389</sup>

Cuth Wood describes how his mental health difficulties fuelled his alcohol consumption:

*“This led to a continuous, vicious cycle of at first just social drinking, then it hit hard due to Hep C and alcohol mix (unknown to me having the infection), then increased weakness and illness – which meant I turned to alcohol to reduce symptoms of now increased weakness. In turn that alcohol and Hep C was the cause of the increased weakness and illness ... Although I was dependent on alcohol, I was not a full blown alcoholic. Using it only as a means to an end, to get me out of the house. I felt I could stop whenever I wanted to, which I did in 2012.”*<sup>390</sup>

When his father was diagnosed, Adrian Pagan says: “*his mental health instantly deteriorated. He became paranoid, aggressive and over-emotional. He was not able to work or sleep. It was completely out of character for him.*” He started drinking a lot of beer because “*at that point he felt like he had nothing to lose.*” His marriage with Adrian’s mother broke down as did other family relationships.<sup>391</sup>

In addition to depression, one witness developed “*severe OCD and anxiety as a result of the infection with HCV. I became very conscious about cleanliness and would use Dettol on everything I touched. Whilst infected I would shower up to 4 times a day on average. I became completely obsessed with cleanliness.*”<sup>392</sup>

Many people have had to deal with the Hepatitis C diagnosis against a backdrop of already managing a chronic health condition. One man says: “*For me I had been dealing with Thalassaemia which was not easy back then and then I had this on my plate. It led me to become depressed about it all. I do not remember a great deal but my partner said that I told her that I couldn’t carry on taking my iron chelation therapy for the Thalassaemia because what is the point; even if I am treating the Thalassaemia, the Hepatitis C is going to kill me. My whole outlook on life changed and I thought what is the point?*”<sup>393</sup>

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388 Written Statement of Cressida Haughton para 66 WITN3125001

389 Gerald Stone Transcript 23 July 2019 p52 INQY1000033

390 Written Statement of Cuth Wood paras 27-29 WITN1729001

391 Written Statement of Adrian Pagan para 16, para 21, para 23, para 28 WITN1451001

392 Written Statement of ANON para 29 WITN0007001

393 Written Statement of ANON para 15 WITN1943001



The inability to give blood reminds people of their infection and for some, it has had a significant impact. Suzanne Jones explains that despite being clear of Hepatitis C, she is still unable to give blood. She says: *“This made me feel resentful, I thought I had been cured but I hadn’t ... People often tell me I should become a donor but I can’t, I have to tell them the reason and it brings back all of my emotions. I feel labelled; I feel I have always been labelled. It is not easy to discuss with people, it is easier to not say anything.”*<sup>394</sup>

The paradox of needing a blood transfusion which resulted in Hepatitis C infection has proved difficult to reconcile. One man, infected with Hepatitis C through a blood transfusion has *“an on-going emotional quandary because the blood that saved my life was also the blood that was killing me. I just haven’t squared it in my head. It’s such a weird feeling.”*<sup>395</sup> Marlene Bonser explains: *“I was really angry at first but I talked myself out of it because there’s no point in being angry as I’ve had all these years which I wouldn’t have had, had I not had the blood. It’s like a catch-twenty-two in that way. If I hadn’t had the blood, I would be dead but the blood I was given was going to eventually kill me.”*<sup>396</sup> Marlene was infected with Hepatitis C through transfusions she received for acute myeloid leukaemia.

### Trauma of deaths

Losing loved ones to Hepatitis C or HIV resulted in fear of facing the same fate for people living with Hepatitis C infection.

Christina McLaughlin recalls visiting her brother, Shea, in hospital after their cousin died: *“Shea was panicked and kept saying ‘I think I have two months left’ ... Shea was fully aware how Michael died and it worried him.”* Like his cousin, Michael, Shea died from liver cancer.<sup>397</sup>

Brian Ahearn’s brother and cousin both died of HIV. In his statement, he said: *“I was there when Kevin and Andrew died and, since then, I have been terrified that the same thing will eventually happen to me. I often felt as though time was just ticking down until the day when they say there is nothing more they can do for me. Unfortunately, that day has now come.”* Brian’s ultrasound scan when he was preparing his statement in 2019 showed a mass in the right side of his liver. He was told he had liver cancer and was given a terminal prognosis in April 2019. In his statement, Brian said *“I am a practical person and so, in the past week [since the diagnosis] I have been putting all my finances in order. My main worry is how my family will be financially supported once I die. I know that it might be old-fashioned of me but I can’t help feeling like I have failed Jackie and the kids.”*<sup>398</sup> Brian died in July 2019.

A number of people describe experiencing survivor’s guilt. Sean Nevin says *“When I meet or hear about haemophiliacs who are HIV positive I immediately think ‘thank God I dodged*

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394 Written Statement of Suzanne Jones para 19 WITN0017001

395 Written Statement of ANON para 61 WITN0148001

396 Written Statement of Marlene Bonser para 3.9 WITN0029001

397 Written Statement of Christina McLaughlin paras 28-29 WITN2778001, Written Statement of Laura Birtles para 2 WITN2880001

398 Written Statement of Brian Ahearn para 3, paras 62-63, para 71, para 89 WITN0165001

*that bullet'. This is not the normal, rational thought of an unaffected person.*"<sup>399</sup> Another man explains that after the death of a friend and his nephew: *"I struggled to come to terms with why I had survived and they had both passed away"*.<sup>400</sup>

### **Hepatitis C: impact of treatment**

A liver biopsy to assess the state of a person's liver uses a long needle to remove a small sample. Louise Cannon describes it as *"the worst hospital procedure"* she has ever had and describes the needle they used as *"like the ones we used to use on the cows to administer magnesium."*<sup>401</sup> Jon Tribbeck describes it as *"to say the least very traumatising and painful."*<sup>402</sup> Robert Bamforth says: *"During the liver biopsy I was in absolute agony. I have never felt pain like it in my life."*<sup>403</sup> Latterly, fibroscans have been available. These painlessly measure the elasticity of the liver and represent a substantial improvement, although access to them has been patchy depending on geography.

Early treatment for Hepatitis C came in the form of injections of interferon. They were then paired with ribavirin tablets. The vast majority of people suffered severe side effects both physically and psychologically. One of the worst aspects was that despite taking treatment often lasting 48 weeks, more often than not the early treatments failed. Many went through multiple attempts at treatment to try and clear Hepatitis C.

Lisa Wilkinson recalls her late mother being very unwell during treatment: *"She was so sick and tired all the time. Mum had little energy to do anything. She vomited a lot and turned a dreadful colour; I remember her eyes turned yellow and can recall thinking how unusual this was. The treatment severely drained her and was completely debilitating."* That treatment was unsuccessful.<sup>404</sup>

Paul Sartain says:

*"I suffered significant physical and psychological effects and the treatment regime was progressively reduced to the minimum possible treatment effectiveness level because of the impact on my immune system. In particular, neutropenia and subsequent infections were an ongoing problem ... I had severe depression for 12 months post-treatment, which included intense suicidal thoughts for at least the first six months. The physical effects returned to normal over a period of time, however the erratic sleeping patterns and occasional instances of a dermatological issue continue to present day."*<sup>405</sup>

Philip Hatton says:

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399 Written Statement of Sean Nevin para 55 WITN1425001  
 400 Written Statement of ANON paras 34-35 WITN1339001  
 401 Written Statement of Louise Cannon para 31 WITN0726001  
 402 Written Statement of Jon Tribbeck para 9 WITN1573001  
 403 Written Statement of Robert Bamforth para 34 WITN4414001  
 404 Written Statement of Lisa Wilkinson paras 16-17 WITN0341001  
 405 Written Statement of Paul Sartain paras 58-59 WITN1013001

*“From August 2011 until November 2014, while I was on treatment, and for many months after, I became a virtual recluse. The side effects of my treatment were truly awful, everything was such hard work, I had no energy, shortness of breath, my muscles wasted away, I had absolutely no appetite, I had to start taking antidepressants, I could not sleep, I became very antisocial, very irritable, very weak, I struggled to stay warm even in the summer, I lost weight, I suffered from frequent severe nosebleeds, nausea, headaches, dizziness, haemorrhoids, very poor concentration (during & after treatment), skin rashes & itchiness, I also suffered from neutropenia during my second course of treatment ... [so] we had to be extremely careful that I wasn’t exposed to any viral infections (colds/flu etc), this made it extremely difficult for my wife to socialise our baby son at playgroups etc ... During treatment, we were unable to do normal family activities such as holidays, day trips, meals out, swimming lessons, parties, family gatherings; we were more or less housebound for the entire duration of the treatment ... Again these lost years can never be returned to any of us.”<sup>406</sup>*

One woman says: *“Those 6 months were hell. I was so sick. I could hardly get out of bed, I felt like I was 100 years old. All my bones hurt, I ached all over, it was a weird feeling. I felt sick all the time. I was exhausted.”*<sup>407</sup> One woman explains that her *“48-week course of treatment took a big toll on my health and I never felt as well as I did when I was younger.”*<sup>408</sup> James Penberthy describes his treatment with interferon as *“absolutely devastating”* and that *“it completely knocked me sideways and I felt like I was dying. I experienced severe fatigue, forgetfulness, weight loss and suicidal thoughts.”* Despite clearing the virus, James suffered post-viral fatigue syndrome and had to leave his role as the chairman of the board of a charity.<sup>409</sup> Another man says he *“lost a whole year during that treatment.”*<sup>410</sup> Bill Wright described in his evidence that the treatment was *“grim, it’s just vile ... like a constant, permanent, huge, massive hangover, throbbing headache, nausea ... constant for 12 months.”*<sup>411</sup>

One woman had to stop interferon and ribavirin treatment because it caused concerns about her heart. Although her cardiac condition has improved, her heart will never make a full recovery from the damage caused by the treatment.<sup>412</sup> Another woman whose daughter was also infected says *“it was really important for me that she received the treatment before I did ... It terrified me, the thought of her seeing my side effects and then being too scared to have the treatment herself. In fact, she did say to me afterwards that she never would have taken Interferon if she’d seen how bad I was on it.”*<sup>413</sup>

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406 Written Statement of Philip Hatton para 20, paras 24-25 WITN0699001

407 Written Statement of ANON para 58 WITN4338001

408 Written Statement of ANON para 43 WITN4311001

409 Written Statement of James Penberthy paras 15-17 WITN0095001

410 Written Statement of ANON para 32 WITN0364001

411 Bill Wright Transcript 5 July 2019 pp47-48 INQY1000028

412 Written Statement of ANON para 25, para 28 WITN0522001

413 Written Statement of ANON para 59 WITN0419001

The need to time interferon treatment in order to manage the severe side effects was a widespread experience. Martin Theaker says: *“I took the treatment on a Thursday so that I could work Monday to Thursday. I would stay out of the way of the family in my bedroom mainly between Friday and Sunday so that my mood and behaviour had the minimal impact on them.”*<sup>414</sup> Catherine Fyfe was infected with Hepatitis C through blood products to treat Haemophilia A. She describes her routine when on interferon treatment: *“I used to finish work at 3.30pm on a Friday, drive across to Huddersfield, get the interferon injection, make it back home about 30-40 minutes before the start of the headaches, sickness and dreadful unwellness feeling, then get into bed until 4 o’clock on the Sunday. I was totally incapacitated during this time.”*<sup>415</sup> Another man recalls: *“I would inject myself on a Sunday night and within an hour I would be drained of energy, have a terrible flu and would be sweating and shivering. By Thursday and Friday I would just about start to feel a little better and then Sunday would come back around. I would look at the interferon pen and think to myself ‘do I really want to do this?’”*<sup>416</sup>

There were also significant psychological side effects. One woman describes how when her husband had treatment for a second time, the side effects were worse than the first time. She describes *“walking on eggshells”* around him:

*“I had to make sure the kids were quiet and didn’t upset him or start screaming etc. [he] went off the rails, he got into credit card debt, we had a limited company and he didn’t pay all the business bills; he was struggling keeping a business afloat whilst taking the medication ... I remember another time ... I thought that he was in Brighton until I got a phone call from my bank to say that my card was being used abroad. [He] had gotten on a plane and gone to Spain; he just said that he needed a holiday to clear his head and that I didn’t understand how he was feeling. Again, this was so out of character for [him]. Our business ended up going under because [he] couldn’t cope with running it whilst on the medication; this left us with debts because we had personally guaranteed a loan. On top of this, we also had [his] credit card debts which I did not know about and I still had three children and [his] erratic behaviour to deal with; I was struggling to cope.”*

They subsequently discovered that he did not in fact have haemophilia and never needed the blood products that he had been given.<sup>417</sup> Lynn Johnson describes suffering from *“the rage associated with ribavirin.”* She says: *“The Manchester Royal had warned me about this before I started the treatment ... I did not take it too seriously at first as I thought it would not happen to me. But it did. It happened when I was socialising at a pub (I ordered a coke and orange juice), and a man commented on the fact that I was not drinking alcohol. I lost my temper, to the extent that my partner had to pull me out of the pub.”*<sup>418</sup>

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414 Written Statement of Martin Theaker para 27 WITN1560001

415 Written Statement of Catherine Fyfe para 21, para 50 WITN1879001

416 Written Statement of ANON para 26 WITN1230001

417 Written Statement of ANON para 32, paras 35-36, paras 42-44 WITN1803001

418 Written Statement of Lynn Johnson paras 22-23 WITN0026001

Although Stephen Dorey recalls that his treatment for Hepatitis C had a limited impact on him,<sup>419</sup> his wife Carolyn says that during treatment *“it was like being married to a different person. Previously he was always such a consistent, logical and well-tempered individual but he changed into a Jekyll and Hyde character. Stephen was depressed and his ability to make decisions changed dramatically. At times, Stephen could not make decisions at all but when he did, he was impulsive and abrupt including with the children, who were very young at the time.”*<sup>420</sup>

Another man who was infected with Hepatitis C says: *“Whilst I was on the medication, I experienced profound shifts in my mood. Whilst ordinarily I am very even tempered (I am often described as being so laid back that I am horizontal), under this course of treatment my moods became extremely changeable, and spectacularly quick to anger.”*<sup>421</sup>

Trevor Marsden describes the treatment he had for Hepatitis C as *“extremely difficult for me. It made me severely depressed and I had suicidal thoughts whilst I was on the treatment. We live close to a railway line and on one occasion I stood on it waiting to die. Before anything happened, Louise found me and pulled me away. That was a very difficult episode for me and is still hard to admit out loud. I feel ashamed about it, but I felt so low and could not take any more.”*<sup>422</sup> Louise told the Inquiry how she *“came home. I knew something was wrong and I knew I had to find Trevor, and that’s where I found Treveor, on the railway line.”*<sup>423</sup>

This was not a unique experience. Another man says:

*“About 8 years ago I was given treatment for my Hepatitis C. I cannot remember the name of this treatment but it made me very depressed which culminated in me making an attempt on my life. My poor wife had only popped out to the hairdressers and upon her return she discovered me in an unresponsive state, having consumed numerous tablets. She was unable to rouse me so telephoned our GP ... who attended immediately. He arranged for an ambulance to take me to the Hospital. As a result of this incident, my Hepatitis C treatment was stopped and I failed to clear the virus. I am of the view that I should have been given far more information and advice on the possible side effects of this treatment.”*<sup>424</sup>

Mr AC described how the treatment made him want to *“end it all”*. *“It was just horrific. I couldnae sit down. I was wandering about the house. I was smashing things up”*. There was no support to help him through the treatment and it was his father who talked him down from throwing himself out of a window. Although a third and final course of treatment was successful in clearing the virus, he has been left with significant bladder problems and with

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419 Written Statement of Stephen Dorey para 15 WITN0063001

420 Written Statement of Carolyn Dorey para 7 WITN0064001

421 Written Statement of ANON para 79 WITN1708001

422 Written Statement of Trevor Marsden para 38 WITN1372001

423 Louise Marden and Trevor Marden Transcript 9 October 2019 pp39-41 INQY1000038

424 Written Statement of ANON para 20 WITN1808001

ongoing psychological problems: *“I still have flashbacks. I can wake up screaming”*.<sup>425</sup> Mr X said that treatment with interferon and ribavirin was *“like being napalmed from the inside out.”* He was aggressive, angry, experienced suicidal thoughts and his body came out *“in suppurating pustules and blisters which got infected.”*<sup>426</sup>

Some people ended their own lives while taking this treatment. One woman describes how her husband was infected with Hepatitis C by numerous blood transfusions during orthopaedic surgery in 1983. He developed depression. He was diagnosed with Hepatitis C in 1997 and started interferon and ribavirin treatment in 2000. The specialist registrar raised concerns about the risks to his mental health from the treatment and said in a letter to his GP that *“we would need to watch him closely”* because of the effects of interferon. Her husband took his life during treatment, taking an overdose of his prescription medication.<sup>427</sup>

Over time, other treatments became available and those who had not been treated with interferon and ribavirin or who had not cleared the virus with that treatment were treated with a variety of drugs.

Daphne Whitehorn was treated with sofosbuvir and ribavirin. The treatment affected her personality and made her aggressive. Her haemoglobin dropped and she had trouble breathing as well as having a complete lack of energy. Her dosage was halved and she *“was worried that it would not work”* because she was on such a low dosage. She continues to suffer from breathlessness.<sup>428</sup> By contrast, Michael Miles describes the side effects of sofosbuvir (without ribavirin) as *“like having a mild flu and I recall feeling groggy, but I was still able to work during the treatment.”*<sup>429</sup>

Another woman had treatment with Viekirax, Exveira and ribavirin and cleared the virus. However, she says *“I could not get very excited about this news because I was in an appalling state ... I went from managing my life and getting used to living with HCV to now being an unwell person ... It was so debilitating.”*<sup>430</sup>

Lesley Alexander describes being treated with telepravir: *“I cannot put into words the hell I went through. I lost a couple of stone and would have to stop half a dozen times to walk into the local town.”* She describes being nauseous, losing her hair and being *“extremely low and depressed throughout the treatment, but refused to be brought down by the virus. My sleep was affected due to anxiety.”*<sup>431</sup> Terrence Lewis had found his treatment with ribavirin and interferon *“extremely difficult”* and says: *“I struggled terribly with fatigue to the extent I found walking uphill or upstairs very hard.”* His second treatment with telepravir was *“worse ... and I also suffered badly from haemorrhoids and became very cold, especially at night.”*<sup>432</sup> Fiona

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425 ANON Transcript 11 July 2019 pp 67-73 INQY1000032

426 ANON Transcript 10 July 2019 pp12-14 INQY1000031

427 Written Statement of ANON paras 12-15 WITN1968001

428 Written Statement of Daphne Whitehorn para 17, para 22, para 24 WITN0191001

429 Written Statement of Michael Miles para 18 WITN0753001

430 Written Statement of ANON para 114, para 118 WITN5822001

431 Written Statement of Lesley Alexander paras 27-29 WITN0075001

432 Written Statement of Terrence Lewis para 8.1, para 8.13 WITN0019001

Rennie describes the effects of the treatment as “draining” and says: “*The hardest part was trying to swallow fat to line my digestive system before taking Telepravir. I would be heaving constantly and my family would try to distract me whilst I tried to down the fat. I would often panic, but I knew that if my stomach was not lined, the tablet would cause me considerable pain.*”<sup>433</sup> Jackie Britton described having telepravir and ribavirin: “*you had a timer on the bottle of pills, you had to have them on the timer and you had to have them with 30 grams of fat. So again it was like 5 in the morning you had to have a pint of full fat milk and spoonfuls of peanut butter so that it would work, so it wasn’t nice*”.<sup>434</sup> Jackie was hospitalised during the treatment. She had colorectal issues, itching all over, bleeding and abdominal pain.

A step change in treatment occurred when direct-acting antivirals became available. These have a much greater success rate and are generally perceived as resulting in far fewer side effects. One man describes Harvoni treatment as painless and complication free, as well as clearing the virus.<sup>435</sup> John Batchelor does “*not recall having any side effects to the Harvoni treatment aside from a sensitivity to light in the first three weeks.*”<sup>436</sup> Another man describes not suffering “*many side effects other than a little tiredness and a dry mouth. However, towards the end of the treatment, I became more tired and much more emotional. My emotional state was heightened and my sleep was disturbed.*”<sup>437</sup> For another man, the treatment made him anaemic and very depressed. He says: “*it became quite difficult to manage the stresses of my job. Things that didn’t used to bother me at all became very stressful and the little everyday pressures often became too much. I remember sitting in a meeting and feeling an overwhelming urge to just burst into tears.*”<sup>438</sup>

People with other health conditions had different experiences of Hepatitis C treatment. One woman describes that an effect of the interferon and ribavirin treatment was that she required blood transfusions more regularly than usual for beta thalassemia because the Hepatitis C treatment was depleting her haemoglobin levels more quickly. She says: “*Psychologically it was like ‘crikey this is just too much.’ Having to go to the hospital so regularly was taking its toll ... A knock on effect of the Hepatitis C treatment and the increased number of blood transfusions I was receiving was that my iron levels went up. I had to use the Desferal pump more often to avoid an iron overload ... I was always tired, but I couldn’t sleep because of the discomfort.*” Her veins struggled with the additional transfusions and pump and so a port-a-cath was fitted which resulted in her getting thrombosis.<sup>439</sup> Louisa Martinez, who also has beta thalassemia, explains that having cleared Hepatitis C, she has an ongoing issue of having an increased blood consumption than others of her age and proportions which

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433 Written Statement of Fiona Rennie para 24 WITN2933001

434 Jackie Britton Transcript 3 May 2019 pp48-49 INQY1000004

435 Written Statement of ANON para 24 WITN1422001

436 Written Statement of John Batchelor para 70 WITN0406001

437 Written Statement of ANON para 5.17 WITN0877001

438 Written Statement of ANON paras 27-29 WITN4211001

439 Written Statement of ANON paras 25-27 WITN0861001

she believes is in response to the interferon treatment causing her haemoglobin levels to drop rapidly.<sup>440</sup>

The role specialist nurses played is a theme in the evidence. A number of people were very positive about the difference they made during treatment. Christine Simpson describes that she was referred to Addenbrookes Hospital where she was assigned to a specialist nurse called Tracy: *“The nurse was very good. She was very nice and very helpful. HCV was her specialism and she really knew her stuff. She gave me a lot of information regarding HCV.”*<sup>441</sup> Imelda Stephenson says that her specialist nurse, Katherine Barry, *“was absolutely amazing. She always kept me informed and was able to tell if I was having a good or bad day. She would calm me down if I came to them in tears.”*<sup>442</sup> Rosemary Mills says: *“Sandra was incredibly supportive. She gave me her personal mobile phone number so that my husband and I could ring her if she was at home. She was, in my husband’s words, an ‘angel from heaven’ ... I was fully aware of the side effects of the treatment and the support given to me was exceptional. Without the HCV nurse, Sandra, it would have been a very different experience.”*<sup>443</sup>

Very many people continue to suffer from physical and psychological symptoms post-treatment. One man says: *“I believe that my personality has changed. I have been dealing with anxiety and depression which are the cause of a constant state of irritability; I suffer from abrupt mood changes accompanied with feelings of being unable to cope. I also have functional sexual problems as a result of the treatment as well as problems sleeping.”*<sup>444</sup> Thomas Farrell described being *“effectively bedridden for a year”* while on interferon treatment. He says that since then: *“I am permanently fatigued because of the liver damage, requiring me to take a nap around midday for an hour. Also, I have learned since taking it, that interferon destroys your immune system.”* He frequently contracts colds and infections.<sup>445</sup> Another man says: *“My skin is still quite uncomfortable and I have a lot of issues with itching. I frequently suffer an upset stomach.”*<sup>446</sup> One man said that he was *“always tired and fatigued”* as a result of Hepatitis C and had to sleep a lot but since treatment *“I can’t sleep. I have severe insomnia, so I have gone the other way around.”*<sup>447</sup>

Another man describes: *“I have been left with erratic moods and fatigue as well as brain fog. Over and above this, I have a lowered immune system, frequent headaches, anxiety, poor memory, inability to sleep, shooting pains and then more chronic pains in the soles of my feet as well as a bloated stomach and insomnia. My teeth are crumbling and this was never*

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440 Written Statement of Louisa Martinez para 3, para 13, para 38 WITN0860001

441 Written Statement of Christine Simpson para 39, para 41 WITN5898001

442 Written Statement of Imelda Stephenson para 21 WITN4135001

443 Written Statement of Rosemary Mills para 18, para 24 WITN0773001

444 Written Statement of ANON para 33 WITN1374001

445 Written Statement of Thomas Farrell para 30, para 32 WITN0087001

446 Written Statement of ANON para 38 WITN0315001

447 Written Statement of ANON paras 64-70 WITN4995001



*the case before taking interferon.*” He had been misdiagnosed and never needed the factor products that he received.<sup>448</sup>

Since having treatment, Andrew Bragg says his *“immune system has been much less effective ... I have been susceptible to both viral and bacterial infections. As a result I am frequently in poor health as I cope with successive infections. More seriously, I have had Biliary Sepsis three times ... as well as Pneumonia ... These infections have significantly impacted on my health and ability to work. I have had four life threatening infections and it is always a concern that the next one may not be survivable.”*<sup>449</sup>

Gill Fyffe’s symptoms during and after her treatment were severe and were subsequently identified as systemic lupus erythematosus, an autoimmune condition causing extreme light sensitivity which causes the skin to swell and thicken when exposed to light and which can also affect the function of the heart, kidneys and the range of motion in the limbs. Gill explains:

*“My skin adversely responds to foreign substances including SPF cream and even my own sweat. I regularly apply an emollient to prevent suppurating, which can occur even when indoors and under limited light. I am no longer able to watch television or use a computer. I am unable to shower due to the pressure of the water on my skin. Instead I bathe, which must be done in the dark, as the white bath and tiles reflect the bathroom light, which then causes swelling and suppurating.”*

Gill is obliged to wear a hat with a wide brim all year round, indoors and out, including in situations where this strikes people as odd – leading to comments. The emollient necessary for her skin has to be reapplied constantly including *“if I look out a south-facing window for more than a few seconds; if I cook at a hob or open an oven; if I walk for a short time outside; if I clean my teeth; if I hug a friend who does not know to take care; if my hat has pressed on my skin; when any light breeze blows my hair onto my face”*.<sup>450</sup>

Another woman describes blisters on her *“arms, neck, legs, back and stomach.”* Post-treatment she continues to develop blisters which become worse in the sun and which scar, affecting her willingness to go away on holiday with her family.<sup>451</sup>

Suzanne Jones has suffered from ongoing thyroid problems as a result of interferon injections and feels *“constantly fatigued”*. She also suffers *“bouts of physical pain such as severe headaches and joint pains”*. She is unable to work full time because of the fatigue.<sup>452</sup> Paul O’Hora’s depression meant that on the advice of his GP he *“reluctantly took early retirement at the age of 58.”*<sup>453</sup>

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448 Written Statement of ANON para 52, para 54, para 58 WITN1241001

449 Written Statement of Andrew Bragg para 18 WITN0195001

450 Written Statement of Gillian Fyffe paras 5.10-5.11, paras 5.13-5.18 WITN0363001

451 Written Statement of ANON para 34, para 62 WITN0308001

452 Written Statement of Suzanne Jones para 29, para 39 WITN0017001

453 Written Statement of Paul O’Hora para 16 WITN1440001

Linda Johnson says:

*“Even today I wish I had never had the treatment. I had to be talked into it at the time. If I had realised how bad it was going to be, how much it would change my life, I would not have done it. Suicidal depression was not something I wanted. My hair never grew back properly, it is weak and brittle and still falls out. I have psoriasis. I have memory problems which I did not have before treatment. My energy levels never completely returned to normal. I get frustrated when there are things I cannot do.”*<sup>454</sup>

### *Access to hepatologists*

One concern is whether people infected received the best care available as they were treated by haematologists, or other clinicians, rather than hepatologists. This had an impact on both the information people received about Hepatitis C and their treatment. One man says that he was told of his infection “casually” by a nurse at the Haemophilia Centre and that “I only started to understand the magnitude of this hepatitis infection years later when I was referred to a liver specialist”.<sup>455</sup> Another man requested to be tested for Hepatitis C after watching a Panorama programme. He was tested by a microbiologist in the pathology lab who then informed him of his diagnosis and treatment was started. He says: “Knowing what I know now, I would have thought that at least there should have been a referral to a hepatologist. There was no counselling offered, nor information on transmission”.<sup>456</sup>

A number of people have experienced a long delay in receiving treatment, and some were never treated. One woman, who was diagnosed with Hepatitis C in 1996, says: “For many years, my condition was only monitored and I was not offered any treatment ... For a long time, it felt as though I was just constantly going to Manchester Royal Infirmary for endless tests and monitoring”. She undertook treatment with interferon in 2005 which was unsuccessful as were sofosbuvir and Vosevi treatments.<sup>457</sup>

Judith Clarke’s mother was infected with Hepatitis C in 1984 and diagnosed in 2001. Judith says her mother “was advised that, as she had a mild form, there were no impacts or concerns. She was not offered any treatment or medication. She was essentially told not to worry about it and, as far as I am aware, they did not monitor the condition”. Towards the end of 2010, she was diagnosed with liver cancer and her consultant confirmed that this was as a result of the long-standing Hepatitis C. Judith explains: “Mum was shocked to learn this given no attempts had been made to inform her that this treatment had become available. Dr Gleeson told us that the treatment would have caused horrible side effects but I remember Mum saying that it could not have been worse than liver cancer and that she should have been given the option to decide for herself.”<sup>458</sup> Gordon Lusk was contacted in

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454 Written Statement of Linda Johnson para 21 WITN3421001

455 Written Statement of ANON para 6, para 11 WITN2118001

456 Written Statement of ANON para 22 WITN3564001

457 Written Statement of ANON para 6, paras 20-23, paras 25-29 WITN0358001

458 Written Statement of Judith Clarke para 1, para 14, paras 22-23 WITN0709001

1992 by the SNBTS after he gave blood and was told he had contracted Hepatitis C after receiving a blood transfusion in 1974. He explains that: *“It was not until June 2004 after noticing an article in the press about HCV that I contacted my local doctor who referred me to the Edinburgh Royal Infirmary, who tested me again and treated me for HCV. It is inexplicable that the medical authorities, knowing that I was HCV positive in 1992 took no action until I initiated treatment 12 years later in 2004.”*<sup>459</sup> Since giving his statement Gordon has died. Peter Brierly had treatment in 2010 but became so unwell that he was hospitalised and the treatment was stopped. He was then *“left without follow up checks”* until 2019 when he returned to the hospital with pain in the liver area. He was *“informed ... that my platelets were horrendously low and that my liver was functioning very badly. My GP said that he found a letter in my notes advising that I get a check-up every three months. They were meant to test my liver every three months and I wasn’t tested once. He said I should have received the letter, but I never did.”*<sup>460</sup>

### Cost of treatment

The cost of treatment was a key issue for many of those needing it. One man says he was *“very frustrated that my wife was repeatedly told how costly the treatment was. Although I can understand clinicians’ concerns about costly treatments, this should have no impact or bearing on my wife’s care and it was inappropriate to tell her about it. She should certainly not be made to feel guilty about it, particularly at a time when she was coming to terms with the diagnosis.”*<sup>461</sup> Another woman recalls that *“When I first went to Reading Hospital for treatment for HCV, I was told that I was ‘lucky’ as Royal Berkshire were paying for my treatment. I certainly did not feel very lucky at the time.”*<sup>462</sup>

The combination of cost and the required approval processes could delay treatment. One man says: *“I was told by a doctor at the [Oxford Haemophilia Centre] OHC that there were problems nationally for funding [of Hepatitis C treatments] and that they were waiting for the conclusions from [the National Institute for Health and Care Excellence] NICE which was due to produce guidelines on Hepatitis C treatment ... These two issues contributed to the delay in my treatment for nearly 4 years.”*<sup>463</sup> Another man, after a 40-year delay between infection and diagnosis, waited a further two years before receiving treatment. He was told that the delays occurred after his gastroenterology consultant recommended the treatment and sought approval because the *“treatment was on trial and very expensive”*. He commented that *“The treatment started much too late and meant that my condition was allowed to deteriorate even further. I am a very sick man as a result and have just been informed that I now have liver cancer ... Two years in someone’s life can make a lot of difference.”*<sup>464</sup> He has since died. Anthony Hughes was not allowed to have Harvoni until his

459 Written Statement of Gordon Lusk para 3, para 5, para 16 WITN0543001

460 Written Statement of Peter Brierly paras 24-26, paras 34-35 WITN1105001

461 Written Statement of ANON para 22 WITN3324001

462 Written Statement of ANON para 57 WITN0253001

463 Written Statement of ANON para 18 WITN1366001

464 Written Statement of ANON paras 19-20 WITN1967001

fibrosan results showed early signs of cirrhosis: *“It was shocking that I had to wait until my liver started getting worse before they could provide me with the Harvoni treatment to cure the hepatitis C that they originally caused!”*<sup>465</sup>

### Ongoing monitoring

Even where treatment is successful, the liver may already be damaged. While treatment may halt the decline, this is not always the case. There remains a significant risk of either liver failure or liver cancer. Some people continue to be monitored, which while helpful brings with it anxiety about their health. Kenneth Smith says that *“Every time I have a liver function test there is a nagging worry in my mind about the result.”*<sup>466</sup> One woman says that her *“main worry”* now is that her (cleared) Hepatitis C might re-appear. She says: *“In between tests, I tend to forget about Hepatitis C, though it is always somewhere in the back of my mind. However, as the tests draw nearer, I become increasingly nervous ... Even though I have cleared Hepatitis C, I cannot say that it no longer affects me because it is always a worry that it could come back.”*<sup>467</sup>

While fibrosans mean the condition of the liver can be assessed painlessly, access to them is not always straightforward. Jackie Britton ended up paying privately for a fibrosan: *“I was still feeling so poorly. My hospital at the time, it was new technology, they didn’t have a fibrosan, so I paid to go to London”*.<sup>468</sup> The scan showed that she had cirrhosis of the liver.

Many people have expressed concern about the lack of formal follow up care. Sharon Blee explains that *“I would like to have follow up care, as ever since my negative HCV result and I was discharged I have not had any appointments or scans or even information about how to keep my liver healthy. I don’t blame the people involved, I understand that it is down to the processes in place but I feel very out on a limb and very concerned that I may be doing something that may hurt my body or my liver. I would like some guidance about how to maintain myself, as I do not feel out of the woods.”*<sup>469</sup> Audrey Sheehy describes completing her treatment for Hepatitis C and then being discharged: *“I was not told what to do, or to come back to [the hospital]. I have not heard from them since that day. I do not recall whether my HCV numbers were down or actually cleared ... They left me with a few weeks supply of Prozac and told me if I wanted more I would need to see a doctor.”*<sup>470</sup> Dena Peacock says *“In terms of follow-up I had a test after a year, which showed I was clear. I have no other follow-up tests which I think is totally wrong. I am told I am cured, but I don’t know how my liver is. I don’t know the risks to me going forward.”*<sup>471</sup> Another witness who has cleared Hepatitis C says: *“I am now untrusting of medical professionals. I have not been offered 6 monthly or yearly ultrasounds to check the damage to my liver. This is contributing*

465 Written Statement of Anthony Hughes paras 59-62 WITN0262001

466 Written Statement of Kenneth Smith para 16 WITN7158001

467 Written Statement of ANON para 36 WITN0139001

468 Jackie Britton Transcript 3 May 2019 pp46-47 INQY1000004

469 Written Statement of Sharon Blee para 71 WITN0546001

470 Written Statement of Audrey Sheehy paras 34-36 WITN7298001

471 Written Statement of Dena Peacock para 38 WITN1954001

to my anxiety as there seems to be no follow up plan.”<sup>472</sup> Antoni Olszewski is frustrated that “there is no aftercare or monitoring of any sort after clearing hepatitis C. It’s like a ticking time bomb. You never know when it’s going to go off.”<sup>473</sup> Graeme Malloch fears he will “forever live with a sense of trauma about what has happened to me and fear and trepidation about what lies ahead. I may have cleared the virus six years ago, but having ultimately lived with hepatitis C for 30 years with slightly elevated liver function tests, I am not reassured that some damage has not been done. I am also not reassured that three courses of interferon treatment in different guises have not damaged me or added to the burden.”<sup>474</sup>

Another woman who self-cleared Hepatitis C remains very worried about her condition. She says that she reminds her GP practice every year to carry out a liver function test: “This is not booked in as regular after care for my condition from any NHS follow up procedure and after care.”<sup>475</sup> Having completed treatment for Hepatitis C, Jim Sweet says “Following discharge from the HCV clinic I have been pretty much persona non grata as far as the NHS is concerned. It concerns me that I have no ongoing after care and I have no idea what condition my liver is in.”<sup>476</sup>

### Hepatitis B: physical effects

Shirley Hunkins was infected with Hepatitis B after a hysterectomy around 1985. She describes her symptoms after surgery: “Shortly after my operation I began to feel sick as if I had the flu. I felt very lethargic and had no energy. I was also jaundiced, and I had a pain in the back and side of my abdomen that was so bad that it was hard for me to function.” These symptoms continued until she cleared the virus in around 2016.<sup>477</sup> Hepatitis B had a “major impact” on Francesco Casella’s father. He describes how “he basically became an invalid in his early fifties, going from a strong, fit, hard-working man, to someone who became very frail and vulnerable over a very short period of time.” He became “inactive very swiftly.”<sup>478</sup>

Dorothy Wright was infected with Hepatitis B through blood transfusions sometime between 1976 and 1978 in various medical procedures. She had a liver transplant in March 2000 and after that transplant she realised “how unwell I had been as a result of the liver damage ... I lived with so much pain, it wasn’t only the pain, it was the weakness, the exhaustion, the weariness, which I had lived with for so long that I did not appreciate how unwell I actually was.”<sup>479</sup> Since giving her statement Dorothy has died.

The impact of Hepatitis B, at times, could be rapid. Gail McKinney’s father was infected with Hepatitis B during heart surgery in February 1976. He became unwell over Easter

472 Written Statement of ANON para 45 WITN1921001

473 Written Statement of Antoni Olszewski para 12 WITN2522002

474 Graeme Malloch Transcript 9 July 2019 p93 INQY1000030

475 Written Statement of ANON p6 WITN7265001

476 Written Statement of Jim Sweet para 61 WITN7215001

477 Written Statement of Shirley Hunkins paras 4-6, para 28 WITN1906001

478 Written Statement of Francesco Casella paras 32-33 WITN7394001

479 Written Statement of Dorothy Wright paras 2-4, para 28 WITN0789001

in 1976 and was admitted to hospital. He died shortly after. Gail describes that her father was a “*different person*” after his heart surgery and “*For the Hepatitis B to just hit him out of nowhere and escalate so quickly, our worlds fell apart.*”<sup>480</sup> Richard Buss’ mother had a blood transfusion during his birth in 1971. A few days after she was discharged from hospital she went to the pharmacy because she was unwell. The pharmacist sent her to hospital because she was jaundiced. She died soon after Richard’s birth.<sup>481</sup>

For some people who were infected with both Hepatitis B and C it is impossible to disentangle the physical effects from each other. Susan Chadwick was treated with Factor 8 during a bowel biopsy in May 1980. She describes never feeling well since then. After she was discharged from hospital, she collapsed at work and was jaundiced. She was unwell and was monitored over several months. Susan was diagnosed with Hepatitis B and subsequently also with Hepatitis C. About three years prior to writing her statement, Susan was told that she had cleared the Hepatitis C naturally. However, she continues to have a number of long term conditions and says that “*I no longer sleep properly, my body aches and I am exhausted.*”<sup>482</sup>

### **Hepatitis B: mental health effects**

One man who required multiple transfusions after a very serious accident contracted Hepatitis B. He had some episodes of significant ill health a few years after the accident and continues to suffer from fatigue and anxiety: “*The infection scared me no end, and I always thought that I would die young as a result of the HBV virus.*” He has not told many people about his infection because of the “*dreadful stigma*” of being a chronic hepatitis sufferer.<sup>483</sup>

Catherine Guthrie was infected with Hepatitis B and had physical symptoms of sickness, jaundice and chronic fatigue. But she says that “*most of the impacts of having Hepatitis B have been mental*” arising particularly from her financial struggles from not being well enough to work and the stigma of having hepatitis.<sup>484</sup>

Another woman describes the mental impact on her mother after her diagnosis with Hepatitis B as “*significant*” because she developed what would now be understood to be obsessive compulsive disorder. She says:

*“I remember that my brother and I always had to thoroughly and regularly wash our hands. If we stood in dog excrement in the street, it was a big deal. This would stress my mum out and she would shout. Everything was sanitised within an inch of its life ... My family were the cleanest people I knew. I was not allowed to have friends to stay overnight at our house unless they brought their own bed*

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480 Written Statement of Gail McKinney para 2, paras 5-6, para 13 WITN3681001, Written Statement of Ann Phillips para 8, para 12 WITN3682001

481 Written Statement of Richard Buss para 2 WITN1846001

482 Written Statement of Susan Chadwick paras 7-11, paras 20-21, para 27 WITN1148001

483 Written Statement of ANON para 4, para 19, para 35, para 48 WITN7619001

484 Written Statement of Catherine Guthrie para 6, para 16, para 20 WITN7499001

*with them ... As a child, I also had to follow my mum around the house, checking that every switch and outlet was turned off. I would then be quizzed about it later. As children, we thought that this was normal behaviour.”<sup>485</sup>*

For Peter Sully, his Hepatitis B infection became too much to cope with and he ended his life in 1984. He had been infected by a blood transfusion during surgery to remove part of his lung.<sup>486</sup>

### **vCJD notifications**

When people received a letter warning them that they were at risk of vCJD, their reactions varied. One man describes the vCJD notification as *“an additional worry which like HCV had again come completely out of the blue.”<sup>487</sup>* The realisation of the risk of vCJD was described by Marcus Nightingale, who has moderate Haemophilia B and was infected with Hepatitis C from Factor 9, as *“just another ticking time bomb that could go off at any point.”<sup>488</sup>* Shaun Ames says that knowing that he is at risk of vCJD puts him *“in limbo. It is a possibility, it is like a lottery ... I have the ticket for something but I do not know if I will get it.”<sup>489</sup>*

Some people have been phlegmatic. Sheila Henderson’s late husband, David, was told about vCJD by his haemophilia nurse and she says: David *“came home and said ‘I might have mad cow disease as well’. We came to the decision that there was no point in worrying about it, because there was no way of finding out for certain.”<sup>490</sup>*

However, for the vast majority of people, the psychological impact of the letters was significant. Jack Leahy, who was infected with Hepatitis C from Factor 9, describes the notification that he was at risk of vCJD in the following terms: *“Psychologically, it drives a person mad thinking about what might be in your body. Each time you use a product you wonder just what it is that you are injecting into your own body. It is like a game of Russian Roulette.”<sup>491</sup>* Frederick Elliott, infected with Hepatitis C from blood products, states that

*“The thing that I am most worried about is the possibility of getting vCJD. I was given information and literature surrounding the illness, but this information has caused me great anxiety. Every time I lose balance – one of the symptoms – I start to think that it could be the vCJD. However it is hard to tell, as I am getting old and stability suffers as you get older. Living with the possibility of getting vCJD has been and still is a big worry for me; it is like living with a ticking time bomb. It is always in the back of my mind.”<sup>492</sup>*

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485 Written Statement of ANON paras 14-16 WITN7471001

486 Written Statement of Michelle Sully para 2, para 40 WITN3704001, Written Statement of Daniel Sully para 2, para 18, para 22 WITN3307001

487 Written Statement of ANON paras 91-92 WITN0325001

488 Written Statement of Marcus Nightingale para 13 WITN1434001

489 Written Statement of Shaun Ames para 39 WITN0361001

490 Written Statement of Sheila Henderson para 35 WITN0045001

491 Written Statement of Jack Leahy para 11 WITN1342001

492 Written Statement of Frederick Elliott para 20 WITN0183001

Matthew Johnson describes being informed of the risk of vCJD and that *“The idea of developing symptoms of nvCJD terrifies me and I find it difficult to speak about; the psychological impact of knowing of my exposure is overwhelming.”*<sup>493</sup>

Paul Thompson was infected with Hepatitis C through blood products and was also notified that he was at risk of vCJD:

*“It completely knocked me back down. I was devastated. It couldn’t have come at a worse time, it arrived without any warning and it was right at the end of my treatment [for Hepatitis C]. This made me really angry and sent me into a deep depression. I went and complained to the Haemophilia Centre. I said, ‘Why didn’t you tell me that the letter was going to come? You knew I was going to receive it and that I had just cleared the treatment. You knew I was suffering with depression. Why couldn’t you bring me in for a chat and explain it to me and tell me there wasn’t anything to worry about? ... Soon after learning about being exposed to vCJD, I began having suicidal thoughts again. I was feeling very low. I thought what is the point of living ... I would be sitting with my legs crossed, they would shake and I would think this is the start of vCJD. I began thinking that if I was going to spend my final few months dying of vCJD, what is the point in living? These thoughts continued to build up and I began planning to commit suicide ... I got in my car and headed towards Wales, to the location where I intended to commit suicide. When I set off on that journey I knew exactly what I was going to do. I got onto the motorway and I got stuck in traffic. I think there was an accident or something had happened on the motorway because I was stationary for ages. I am not sure what happened next but something happened to me ... When I had the opportunity I turned back, making a conscious decision not to carry it through.”*<sup>494</sup>

## Other infections

A number of witnesses describe being infected with other infections, whether separately or in addition to HIV, Hepatitis B and Hepatitis C.

William Stafford became anaemic during treatment for polyarteritis nodosa and required transfusions. He contracted cytomegalovirus from the transfusions resulting in retinitis and blindness.<sup>495</sup> Louise Walmsley notes that episodes of cytomegalovirus are recorded in her husband’s medical notes.<sup>496</sup>

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493 Written Statement of Matthew Johnson para 24 WITN1057001, Matthew Johnson Transcript 3 May 2019 pp13-19 INQY1000004

494 Written Statement of Paul Thompson paras 46-51 WITN0954001

495 Written Statement of William Stafford paras 6-19 WITN5274001

496 Written Statement of Louise Walmsley para 23 WITN2811001



One woman notes that in addition to Hepatitis B and Hepatitis C, her father was infected with parvovirus from his treatment for haemophilia A.<sup>497</sup> Another woman records that her father’s medical records show that he was infected with parvovirus in addition to Hepatitis C.<sup>498</sup>

One man infected with Hepatitis C and informed that he may have been exposed to vCJD from Factor 8 developed an HPV-related cancer. He said “*I knew how rare my condition was when I went for treatment because the other patients were women and at least thirty years older than me*” and after completing chemotherapy and radiotherapy looked into whether his diagnosis could have resulted from infected blood.<sup>499</sup>

One man was infected with Hepatitis E from a platelet transfusion during cancer treatment. Towards the end of his second cycle of chemotherapy, he developed flu-like symptoms, an incredibly itchy rash and he had raised alanine transaminase levels indicating liver damage. He was treated with ribavirin and the Hepatitis E is now undetectable.<sup>500</sup>

## Impact of lack of accountability

People’s mental health was affected by the failure of those in power to take responsibility for the infections. This was an aspect highlighted by the Psychosocial Expert Panel when its members gave evidence.<sup>501</sup> It has been emphasised in the Inquiry’s two interim reports and is discussed in the chapters about *Response of Government*. Delay in accepting accountability – and with it a lack of recognition, of vindication that concerns were justified – inevitably brings with it consequences for the individual.

One man self-harmed for the first time when told about his HIV infection aged 15, contracted from Factor 8, and describes his ongoing depression:

*“the cause of my symptoms still remains which is: the infections, the symptoms caused by the infections, the fact that I know that the NHS has been lying to me, the fact that I have to live on benefits due to my health conditions, the awful way I have been treated by the benefits agencies throughout my adult life, the fact that those responsible for the infections show no remorse or guilt for what they did to me and have been allowed to walk away unpunished.”*<sup>502</sup>

One woman recalls that “*the hospital first of all denied that I had contracted Hepatitis C from the treatment they had given to me following my accident. Then, when they finally accepted that they were responsible for infecting me I was told that I wasn’t entitled to compensation because in the early 1990s there was no screening for Hepatitis and it therefore was not*

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497 Written Statement of ANON para 5 WITN4009001

498 Written Statement of ANON para 10 WITN2087001

499 Written Statement of ANON para 5, para 7, paras 9-10 WITN1922015

500 Written Statement of ANON para 10, para 12, para 17, paras 20 – 23 WITN4695001

501 Expert Report to the Infected Blood Inquiry: Psychosocial Issues January 2020 EXPG0000003, Psychosocial Expert Panel Transcript 24 February 2020 INQY1000050, Psychosocial Expert Panel Transcript 25 February 2020 INQY1000051

502 Written Statement of ANON para 7, paras 18-19 WITN1442001

*their fault that I had been infected.*<sup>503</sup> Clive Forbes says that his mother recalls that when his father was informed of the Hepatitis C infection, it “*was very cold and calculated, quite clearly designed to avoid any admissions of guilt on their part. They kept saying it was accidental. There was a distinct lack of empathy or understanding and she remembers it was very much like, ‘This is how it is Mr Forbes, thank you and goodbye.’*”<sup>504</sup>

Another woman says “*All I want is a piece of paper to say sorry for what happened to [my brother] and to admit what they did. I can then attach this to [his] birth and death certificates to say to [him] that it wasn’t his fault.*”<sup>505</sup>

Stuart Carbery’s father, Russell, was infected with HIV. He says: “*The stress and anguish my parents had gone through was horrendous ... My mother had attended at least 50 funerals as the majority of my father’s friends were also affected by this scandal. Yet, no acknowledgement was provided, no apology, no explanation. The fact that my mother seemed to get nowhere after years of campaigning has taken a toll on her.*”<sup>506</sup> Ann Carbery, his mother, says: “*I am tired of living and I am tired of fighting.*” She is awaiting counselling for the “*never ending cycle*” of mental health difficulties she faces.<sup>507</sup>

Graham Simpson’s father was infected with Hepatitis C from blood products and “*developed severe liver problems which ended up killing him. I know my father wanted answers but my mother did not. He started writing letters over a number of years to people at the Health Service to get an explanation from the NHS as to what had gone wrong and to MPs, but he never received any apology or explanation. He was ignored and unfortunately he died before he could take things further.*”<sup>508</sup>

Gaynor Lewis says of her husband, Haydn, “*Eventually he channelled his frustrations into his research into the contaminated blood scandal. This gave him a focus ... Haydn fought to try to find the truth to his dying day. He did not die in ignorance.*”<sup>509</sup> Hadyn campaigned with his brother Gareth and their sister Beverley said they “*started a search for the truth.*”<sup>510</sup>

Sharon Tonkin’s husband David has been heavily involved in the Manor House group:

*“Within 5 months of attending his first meeting, David had become Chairperson of the Manor House Group and things spiralled out of control. He spent all of his time with the group, and I felt like a single parent during this time. He lived, breathed and slept the Manor House Group. He did a lot of good and raised a lot of awareness but I lost him during that period. I would have to care for the kids and get them ready for school and then make a breakfast buffet for the entire group.*”

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503 Written Statement of ANON para 25 WITN2745001

504 Written Statement of Clive Forbes para 9 WITN2749001

505 Written Statement of ANON p6 WITN3715001

506 Written Statement of Stuart Carbery paras 36-37 WITN3229001

507 Written Statement of Ann Carbery paras 46-47 WITN3250001

508 Written Statement of Graham Simpson para 18 WITN1518001

509 Written Statement of Gaynor Lewis p8, p13 WITN2368001

510 Beverly Tumelty Transcript 26 July 2019 p59 INQY1000036

*David had a desk under the stairs and he would sit there all night ... David didn't even see the effect it was having on our family because he was so focused.”<sup>511</sup>*

Carol Grayson explained that the toll of caring for her late husband and the campaigning work she has done over very many years has had a significant impact on her physical and mental health: *“I was born with asthma; it's made it a lot worse, the stress of it. I can't remember the last time I was able to sleep. I'm lucky ... if I get a couple of hours, because I'm sending emails at all times of the day and night, trying to get information out. I was diagnosed with PTSD.”<sup>512</sup>*

Maureen Murphy's children describe how she has *“spent the last 50 years consumed by the effects of William's infections following receipt of contaminated blood ... from initially retiring early to care for her gravely ill husband, to her inexorable pursuit to seek justice on his behalf. This has incrementally eroded her psychological wellbeing on an unfathomable level, such that she is no longer the person that she used to be.”<sup>513</sup>*

Christine Norval described the impact of her husband Bruce's campaign work: *“it's the first thing that he will speak about in the morning and it's the last thing he will speak about before he goes to bed, and within the day, no matter what the conversation is, we don't go half an hour without him discussing it, without somebody phoning up, without him looking on the internet and no matter where we go, what we do, he's constantly speaking to people, looking at things, putting two and two together, and he's done this from his bed a lot of the time.”<sup>514</sup>*

Many people expressed the feeling of being “bought off” by the provision of financial assistance without any acceptance of wrongdoing. Andrew Paddock feels that in accepting a Skipton Fund payment *“the Government were attempting to relinquish responsibility for what had happened and that it was a token to try and make the problem and the people disappear.”<sup>515</sup>* Paul Dornan describes how the Skipton Fund payment he received *“feels now like it was hush money.”<sup>516</sup>*

The wife of one man who was infected says that she *“would like the people or departments in Government to be found responsible for what they did to [my husband] as a child, just 8 years old ... We have lost so much. Sorry is a word that is just not enough anymore.”<sup>517</sup>*

## Bereavement

The deaths of children, spouses, partners, parents, siblings, other family and friends have been devastating. Many people have experienced the death of more than one person in

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511 Written Statement of Sharon Tonkin para 26 WITN1716001, Written Statement of David Tonkin WITN1567008

512 Carol Grayson Transcript 8 July 2022 p44 INQY1000223

513 Written Statement of Anne Anakin and Gregory Murphy para 3 WITN1944003

514 Christine Norval Transcript 9 July 2019 p47 INQY1000030

515 Written Statement of Andrew Paddock para 25 WITN3145001

516 Written Statement of Paul Dornan para 18 WITN4709001

517 Written Statement of ANON para 32 WITN3234001

their family or friendship group, and have watched one person die, knowing that person will not be the last.

### Deaths of partners

One woman describes how after her husband died from liver failure she tried to end her own life. At the last moment, she stopped:

*“Even so, nothing really eased the pain and loss I felt. Sometimes, when I heard a car passing my house or pulling up in the drive, I would think that it was [him] coming home ... [He] was cremated and I keep his ashes on my bedside table ... Even though it has been more than 12 years since he died, I can’t bring myself to scatter his ashes as I would feel like I’ve thrown him away with them. Having his ashes on my bedside table makes me feel like [he] is still here in a way.”<sup>518</sup>*

Maria Blacklock describing the death of her husband, says: *“I am left with no one now, I have no brothers or sisters to look after me, and I no longer recognise myself. I am not working now because I am mentally and physically unable to.”<sup>519</sup>*

Suzanne Archer says *“the day my father died, my mother lost her soul mate and we lost a much loved father ... We had so much we were going to do and celebrate together”* including her own wedding which was due to take place a few months after her father died.<sup>520</sup> Jean Hill states: *“Ron’s death broke me. He told me so many times ‘I don’t want to die’. He wanted to walk the girls down the aisle on their wedding day and see his grandchildren. After his death I was gripped by anxiety and depression (and I continue to suffer with anxiety). I could not function and did not want to leave the house, for something like four years ... The constant state of worry and distress I lived with whilst Ron was ill has never left me.”<sup>521</sup>*

Ian Craig’s wife Liz was infected with HIV following a blood transfusion during a hysterectomy in 1985 and died in 1993. He has *“never got over”* the loss of his wife and has difficulty coming to terms with the circumstances in which she died. *“There is nothing worse than seeing someone you love fade away in front of your eyes. She didn’t have the strength to fight the deterioration in her condition, it was terrible ... When eventually she couldn’t talk, she looked at me and said ‘you’ll be ok’, she was so brave.”* He would wake up at night and think *“where is Liz?”*, even after so many years.<sup>522</sup>

Joan Pugsley’s husband Philip was infected with HIV following treatment with Factor 8; so too was her grandson Daniel. She recalled watching the *AIDS: Don’t Die of Ignorance* television adverts:

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518 Written Statement of ANON para 53 WITN1437001

519 Written Statement of Maria Blacklock para 46 WITN4520001

520 Written Statement of Suzanne Archer para 20 WITN1417001

521 Written Statement of Jean Hill para 37 WITN1285001

522 Written Statement of Ian Craig paras 13-23 WITN0932001

*“I understand that this campaign was being used as an education tool to inform persons on HIV but it was too close to home for us. It was real life for us as a family. I believe that the advert had only highlighted that AIDS was a death sentence and that you were not to go anywhere near anyone with AIDS. I can recall the large tombstone on the advert clearly, as I used to wonder whether that would be my Philip or my Daniel.” When Philip died in 1991, Joan “did not know how to cope and it was a particularly difficult period for me. To this day, Philip is always on my mind ... Philip was strong; full of life and his life was cut short due to his Factor VIII treatment, which was meant to save his life. He was my husband, and I wished we could have spent a longer life together. He was such a kind and gentle man and he simply trusted the NHS with the treatment they were providing him with. He was my husband, my lover and my best friend.”<sup>523</sup>*

Mary Grindley’s husband John died in 1994, having been infected with HIV. She says:

*“I have lost the love of my life and been left to bring up my son alone. I lost my career as a teacher and have not been able to work since because of bad depression. I am still devastated by not having a second child ... It is very lonely with only the four walls to talk to. There is nobody to confide in, to make me a cup of tea or care for me when I’m ill, although my family help as much as they can and have been a great comfort, which is much appreciated. I think people must think that maybe after all these years have gone by I would somehow forget what had happened. In fact, John’s death has permeated every area of my life and affected every area of my life. I lost the love of my life and he is not here anymore.”*

She adds that *“The widows, some of whom I know, have been – and some of whom have been tragically infected themselves, have been made to feel like second class citizens, scroungers, and treated worse than dogs and left to survive themselves.”<sup>524</sup>*

## Deaths of parents

The impact is profound for children who lose a parent. They struggled to understand what was happening. There was the added difficulty of limited memories of their parent and discovering at a later stage what they died of. Graham Binks describes the impact of his wife’s death from Hepatitis C on his children:

*“My children knew that she was unwell but they had no inkling that she was dying ... One of my abiding memories is them waving her off in an ambulance on her final journey – oblivious to the seriousness of the situation. She died in the early hours of Friday 25 January 1980. I broke the news to them on the same day after school. The 7 year old could grasp the finality of death but the 5 year old couldn’t*

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523 Written Statement of Joan Pugsley para 93, paras 133-134 WITN4603001

524 Mary Grindley Transcript 1 November 2019 pp149-150, p168 INQY1000049

*and kept expecting her to turn up ... I explained that your body was like a pair of pyjamas and when you died you simply took them off.”*<sup>525</sup>

Daniel Millard’s father Russell died when Daniel was ten months old, as a result of HIV:

*“I do not have any memories of my father. To some extent, I feel glad because of course I heard some horrific stories of when my father was ill and I don’t have these awful memories. However, at the same time I miss him dearly but he is someone whom I was never fortunate enough to get the chance to get to know. I will never be able to have a relationship with him and I was therefore different from all the other boys who grew up with a father figure ... I behaved fairly horrifically throughout my secondary school years. I had no father or male role model figure in my life and I developed a number of anger management issues. I was so angry and I did not know then how to channel or direct this anger without ending up in yet another fight.”*<sup>526</sup>

Michelle Fuller was just seven when her father died of HIV, from blood products, and says that consequently *“a lot of my memories are based on what my family has told me about him. And also the family videos and photographs.”* She reflects that *“Growing up without a father had a negative impact on me and I think that this has been borne out in my first intimate relationship”*, which was abusive.<sup>527</sup>

Samantha Millard describes losing her father to HIV when she was three and says: *“People ask how I could possibly miss someone who I never really had in my life and my response is that I remember him so well and on top of that I miss everything that we should have done together including all of those memories that we would have made and I feel completely robbed of a father.”* She discovered that her father had died of HIV, and not a brain haemorrhage, when she saw something on television and questioned her grandmother about it. She then *“started suffering very badly with both anxiety and depression ... I started missing a lot of school and I cut myself off from my friends. I would sign in at school and then go and sit at the cemetery where my father was buried. This continued for a long time and I then started drinking alcohol. Sometimes I would drink until I became unconscious ... It was all too much for me and I wasn’t coping.”* She did badly in her exams, and then struggled to hold down a job for a number of years.<sup>528</sup>

For Sophie Smith, whose father died of HIV and Hepatitis C from blood products, *“the irrevocable impact”* of her father’s death affects her everyday life and *“the emotional debt can never be repaid”*: *“I lost my dad when I was 16; he was only 48 years old. He never got to see me pass my exams, go to university, become a grown-up. He never met my husband or my children. They never met their grandfather and will never know how wonderful he*

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525 Written Statement of Graham Binks paras 35-36 WITN0288001

526 Written Statement of Daniel Millard paras 35-39 WITN1393001

527 Written Statement of Michelle Fuller para 13, para 28 WITN1224001

528 Written Statement of Samantha Millard paras 23-25, para 29 WITN1395001

was.”<sup>529</sup> Sharon Davies-John, whose father died from Hepatitis C, said *“For weeks after my father passed away I locked myself in my bedroom and I just wanted to be alone ... I couldn’t come to terms with my father not being there for me anymore. Only six months into my studies my interest for studying went ... Unless you have experienced losing a parent so early in your life you will never fully understand the loss, I still feel this loss everyday.”*<sup>530</sup>

Some children developed significant mental health difficulties as a result of their parent’s death. One daughter *“had a massive breakdown after her father’s death. We were faced with multiple hospital admissions and worry as she kept trying to kill herself”*. Her father had died of HIV from blood products. It took eight years *“for her to emerge from that dark place.”*<sup>531</sup> Elizabeth MacRae describes the loss of her father at the age of 12 from HIV and Hepatitis C which he contracted through blood products. After he died, *“From the age of 12 until around 18 I ate as little as I could get away with, which caused me to be very thin, I had control issues and I self-harmed, cutting my arms ... This was my way of dealing with the pain and the emotions”*. She says that *“Losing a parent at such a young age affected my outlook on life. It made me realise that nothing is permanent, which in turn affected my relationships and life choices. I have moved around regularly for work, as a research scientist, and have had a lot of relationships but I could never really see anything as secure and permanent.”*<sup>532</sup>

A group of siblings who lost their mother when they were aged between three and seventeen told the intermediaries: *“We have all suffered from depression and have withdrawn from life at times. We were separated from each other and from our extended family, with no effort to maintain links to our family and culture ... We have often been told that we should ‘get on’ with our lives, that this was all a long time ago and that we should be over it by now. We are not ‘over it’. We have watched others being encouraged by their mothers throughout their lives ... None of this happened for us, we are just stuck.”*<sup>533</sup>

Mike Dorricott died in 2015: as a person with mild haemophilia, he had been treated with Factor 8 concentrates in 1982 for a dental extraction (without his parents’ consent – their understanding was that he would receive cryoprecipitate) and infected with Hepatitis C as a result. His daughter Eleanor states: *“He died when I was only 18 years old. Sarah and I should not have had to lose our father at such a young age. We should not have to explain to our children why they have not got a grandfather. We should not have to walk down the aisle without him. My mother should not have to be a widow at 48 years old. This could have been avoided. This should not have happened. We have to live our lives with no father to support us.”* Watching her father slowly deteriorate and watching him die whilst holding his hand has severely affected Eleanor’s mental health: *“severe anxiety, stress, depression and suicidal thoughts.”* Her sister Sarah explains that *“when you live with death on your*

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529 Written Statement of Sophie Smith para 37 WITN1527001

530 Written Statement of Sharon Davies-John pp6-7 WITN2458001

531 Written Statement of ANON para 38 WITN1776001

532 Written Statement of Elizabeth MacRae para 47, para 52 WITN1361001

533 Intermediaries’ Report: Supplementary 2 June 2023 pp4-5 WITN4000002

*doorstep constantly throughout your childhood and your teenage years it leaves a mark. I have quite bad anxiety now and I get very stressed quite easily and I have control issues”.*<sup>534</sup>

Witnessing the physical decline of a parent was acutely painful. One man, whose mother was infected with HIV following a blood transfusion, reflects *“You see your parents as invulnerable growing up, and to witness her decline was at times almost unbearable. Near the end of her life, my mother was wheelchair bound. She was completely incapable of taking care of herself – couldn’t use a bathroom on her own, couldn’t feed herself properly, eventually struggled to speak complete sentences.”* Despite being *“unbelievably sick”*, she *“still wanted to look after me, to be a mother to me.”* He was 12 years old when she died.<sup>535</sup>

Speaking of the loss of his mother Jane, Ronan Fitzgerald says: *“At 11.33pm on 13 November 2015, your pain and suffering came to an end. But losing you has left an irreversible and immeasurable ache in our hearts. We think about you every single day, every family meal, every birthday, every time the sun shines down on us, every time a robin lands close by, every day. My father has lost his wife. My brother and I have lost our Mum. My 9 year old son will grow up without his nanny.”*<sup>536</sup>

The secrecy surrounding infection exacerbated the loss. One woman, whose father died of HIV and Hepatitis C from blood products, can *“hardly ever talk about my father with my mother; it’s too painful and I still feel some slight resentment for having been kept in the dark which meant that I didn’t have enough time to say goodbye to my father.”* She was only told about her father’s infection a week before he died, although two years earlier she had found some of his medication and a newspaper cutting about HIV and was unconvinced by her mother’s explanation that her father was receiving preventative treatment. She kept her father’s infection a secret for 20 years and said he had died of cancer as she *“couldn’t deal with explaining what had really happened and justifying the fact that he had AIDS.”*<sup>537</sup>

## Deaths of children

A mother, whose son died of Hepatitis C contracted through blood products, describes how *“our family will never be the same again. This has totally devastated us as a family and we cannot believe he has been taken from us prematurely like this. Words cannot describe the hurt, loss, despair and total devastation we all feel in this family”.*<sup>538</sup> Susan Gray describes the loss of her son, age 28: *“I think about Steven every day and feel very alone with my grief. Although my relationship with my husband is good, I am unable to talk to him as he does not share the same grief. I have lost my only child and I have to live with this for the rest of my life. I cannot explain in any words how heart breaking this is for a mother.”*<sup>539</sup>

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534 Eleanor and Sarah Dorricott Transcript 21 June 2019 pp71-74 INQY1000024

535 Witness Statement of ANON paras 23-25 WITN3024001

536 Barry and Ronan Fitzgerald Transcript 8 October 2019 p148 INQY1000037

537 Written Statement of ANON paras 39-41 WITN1228001

538 Written Statement of ANON para 21 WITN1458001

539 Written Statement of Susan Gray para 26 WITN1248001



Brenda Dibnah's only child, David died at the age of 27: *"We were hurting beyond words and no one could make my hurt less, nor my heart break any further. David was my only child; not only did HIV and Hepatitis take our son's life, it took mine as well. My life and future all ended when David died. I would have no daughter in law, no grandchildren, no birthdays, no happy Christmasses and no memories to grow old with."*<sup>540</sup> Anna Curtis's son Matthew was coinfecting with HIV and Hepatitis C and died aged 39: *"I was absolutely devastated and for years felt like I was watching the world from deep inside myself, lost as to who I was or what I was aiming for."*<sup>541</sup> Shelagh Garrigan describes the loss of her brother to HIV and hepatitis: *"Losing David was devastating for our mother. It completely finished her off. She lost both of her sons and had been particularly close to David. She was never the same person and she never got over the loss. It broke her heart and she passed away five years ago. My siblings felt that not only had we lost our brothers but we also lost our mother."*<sup>542</sup> One woman describes the effect on her parents of the deaths of her two brothers, who were infected with HIV: *"Both of my parents died with broken hearts. It was awful watching my brothers dying from AIDS, as it was a horrible and traumatic death. My parents lost two sons as a result of the infections. My mother felt so guilty because she believed that she had given them the infected blood products which resulted in their deaths. She became very angry, bitter and guilt-ridden."*<sup>543</sup> One man describes the death of his brother from HIV when he was 28. He says: *"As a devout catholic, my mum leant heavily on her faith. She died of cancer in her 60s and during her demise, she told me that at least she would be close to [him] again. Mum managed her grief through her faith but this never replaced the hole that [his] death left. No parent ever expects to outlive their child."*<sup>544</sup>

Another mother says simply of her son: *"It was devastating for us as a family to lose [him]. A parent should never have to bury their child."*<sup>545</sup>

Lynda Walker says that *"Russell spent the last five months of his life in hospital and when I think about Russell, I always think of the last five months because they were so difficult. When I have dreams of Russell, it is always about him dying. These last five months have clouded my memory of his life and time we spent together."*<sup>546</sup>

Two of Susan Hallwood's sons died:

*"[Stephen] died at home in 1989 following the pneumocystis infection. When he died I kept him in my arms and wouldn't let him go. I couldn't come to terms with the fact he had passed away. I just couldn't understand it. I was told by one of the nurses that came round afterwards that we would have to take him to the funeral directors. I screamed at them and said 'you had better bring him back*

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540 Written Statement of Brenda Dibnah para 34 WITN1188001

541 Written Statement of Anna Curtis para 26 WITN1177001

542 Written Statement of Shelagh Garrigan para 32 WITN1229001

543 Written Statement of Cherry Nurse para 32 WITN1695001

544 Written Statement of ANON para 45 WITN7645001

545 Written Statement of ANON para 38 WITN1288001

546 Written Statement of Lynda Walker para 25 WITN3216001

*here, otherwise I will break in and get him myself.' They knew I was in a bad state of mind, and I would have done it. When they brought [Stephen] back the coffin lid was nailed shut. The last time I got to see my son was when they took him from my house to the funeral directors."*<sup>547</sup>

Her other son, Brian died five years later. She had brought him home from hospital and he went into a coma:

*"it was a few days I think ... it might have been a week, the days were just – I just – I just couldn't make heads or tails of all this. And I remember our haemophilia nurse standing there ... up to even then I thought [Brian] was going to wake up and he was going to be all right. So she said 'Sue let him go, it is time for him to go now'. But I can't. She said 'Yeah'. So then he just – he was still in his coma and he just went then ... Thomas [her other son] thought he was sleeping, Brian ... Because he got up, come down the stairs, gets on the bed with him, he thought he was still alive, puts his arms around him and he was going – so we had – I had to take him off because – I had to say – that's it."*<sup>548</sup>

## Death of siblings

Richard Kellett-Clarke describes the death of his twin brother from liver cancer in this way: *"To lose your twin, the only true friend in your life and the person who is so close to you they can finish your sentences and know what you are thinking before you say it, is an indescribable loss."*<sup>549</sup>

One woman says: *"Excluding my brother ... I am the only one left in the family. They have all died of AIDS-related illnesses. I have had to grieve the loss of my mum, dad and two sisters and witness their grief too."* Her mother contracted HIV through a blood transfusion after the birth of her brother in 1981. Her mother then had three daughters. All were infected with HIV: so too was the father. In 1989, her older sister died aged five, and her younger sister died aged three. Then in 1993 the father died. She had to cope with those losses within a distressingly short period of time. Her mother died in 2013, of HIV-related causes.<sup>550</sup>

Roger Kirman's brother George, who he had shared so much with *"even ... the same contaminated Factor VIII batches"* contracted HIV and Hepatitis C and died when he was 45, leaving behind a wife and young family. *"It is hard not to feel that some part of me died with him."*<sup>551</sup>

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547 Written Statement of Susan Hallwood para 41 WITN1267001

548 Susan Hallwood Transcript 29 September 2022 p45 INQY1000249

549 Written Statement of Richard Kellett-Clarke para 21 WITN1323001

550 Written Statement of ANON paras 16-17 WITN3771001. Dr Rak Nandwani, her mother's doctor at the time of her death, says: *"I chose to contact the inquiry because [she] is no longer in a position to do so herself ... What strikes me is [her] immense courage and her perseverance to raise a family and deal with the adversity that had been dealt to her."* Written Statement of Dr Rak Nandwani para 29 WITN3596001

551 Written Statement of Roger Kirman para 20 WITN1334001

Beverley Tumelty says of her brothers Gareth and Haydn Lewis, who were infected with HIV and Hepatitis C, that they were “*my constant guardians, my heroes, my moral compass. They were dealt a huge blow to their health in the prime of their lives and it changed them completely.*” Both of them “*should be alive. It’s just wrong from start to finish.*”<sup>552</sup>

## Burial arrangements

Many people’s grief was compounded by the manner in which their loved ones were treated after death. Margaret Madden says:

*“Daniel’s wish was to be buried at home in Manchester. The undertaker wanted to put him in a wooden box and cover it in sawdust. His brothers would not allow it and instead they took the front seat out of my car and propped his coffin up in the front and drove him back home in the middle of the night. The undertaker in Manchester could not believe what we had done and thankfully managed to smooth things over with the authorities because apparently it was illegal for us to do this. As a final insult to Daniel he had to be buried in a lead lined coffin so that he could not contaminate the dead.”*<sup>553</sup>

One man describes the difficulties they faced in finding an undertaker to bury his brother, who had contracted HIV and Hepatitis C through blood products. Even when an undertaker was found they would not dress the body so his brother was “*buried in a body bag with his favourite suit resting on top of it.*”<sup>554</sup> One woman’s husband died of AIDS and: “*When he died, I was with him and I was only allowed to see him for 20 minutes and no more than that. I never got to see his body again. The coffin was closed and did not even have his name on it. I therefore have doubts in my mind about why I was not allowed to see him after he died. I do wonder whether it was because they used his body for research purposes after his death.*”<sup>555</sup>

Susan Woollard’s father died of HIV having been infected through blood products. He had not told her about his infection before his death. Her mother called her to tell her of her father’s death and she and her husband arrived at the family home and:

*“couldn’t comprehend why my father had died until my mother – already in a state of shock – explained to us there and then his HIV diagnosis and that she also was HIV positive. It was all beyond belief and no words can express how life-changing this moment would be for the whole family ... While my mother and I were consoling each other, my husband recalls that when the undertakers arrived, they were wearing protective clothing and masks like Hazmat suits and*

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552 Beverley Tumelty Transcript 26 July 2019 pp57-59 INQY1000036

553 Written Statement of Margaret Madden para 80 WITN1364001

554 Written Statement of ANON para 31 WITN0010001

555 Written Statement of ANON para 19 WITN1474001

*proceeded to put his body in a sealed body bag. With neighbours looking on, this further intensified the trauma of the situation.”*<sup>556</sup>

When Mark Donnelly’s father died in 1989, having been infected with HIV from Factor 8, his body remained in the chapel rather than being in the house for the traditional wake: *“It was still effectively a wake house, but there was no body. There was no remains ... my mother knew that that was going to be a closed coffin funeral, and this was her way of avoiding the questions at a wake, and her way of not having to try to tell people or justify why it was closed .. back to secrecy again. Back to the stigma of what my father died of.”*<sup>557</sup>

Kathleen Watt says that because of her mum’s infection with Hepatitis C *“there were some problems with the funeral arrangements. We are catholic and expected the coffin to come home and have an open coffin with rosaries for the funeral. But we were informed ... that we couldn’t have her home, the coffin would be sealed and we couldn’t even provide an outfit for her to be buried in ... That was devastating to us all, not being able to give the funeral she would have wanted.”*<sup>558</sup>

## Impact of stigma

Grief was made even more painful by stigma and an inability to talk freely about the death. One woman says: *“When you talk to people on the ‘outside world’ you cannot tell them that one of your sons died from HIV and that your other son has HIV. You could not be honest with people about your life.”*<sup>559</sup> Another woman, speaking about her brother’s death from AIDS explains *“You need to be able to talk about your grief and rage and pain. All of this was denied to our family. The only people I could speak to honestly were my brother and sister and there comes a point when you don’t want to do this anymore because they too are suffering so much. So you are truly alone – isolated, stuck in some hideous cage of pain with no key to get out. You cannot live a healthy, integrated life, when you are living a lie and can’t talk about your grief.”*<sup>560</sup>

Elaine Taylor describes how after the death of her husband Jack, from HIV: *“I had no one to talk to about why Jack had died because we had kept everything quiet due to the massive stigma which surrounded HIV. When Jack was alive we did not really talk about it so I kept everything bottled up inside me which has definitely had a negative impact on my mental health. It was a long time before I told my mother and when I did finally tell her she was shocked that I had kept it from her for so long.”*<sup>561</sup>

Colin Turton says that since the death of his ten-year-old son Lee: *“We have become very wary of people, and we find it hard to make friends as we feel that we cannot really*

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556 Written Statement of Susan Woollard para 13 WITN1007001

557 Mark Donnelly Transcript 24 May 2019 pp64-66 INQY1000012

558 Written Statement of Kathleen Watt para 24 WITN2278001

559 Written Statement of ANON para 36 WITN1301001

560 Written Statement of ANON para 31 WITN0128001

561 Written Statement of Elaine Taylor para 40 WITN1558001

*trust anybody. Our life remains very private, we do not have many friends. After Lee died I have told people if prompted that we have three children not four as I cannot bear going through everything.”<sup>562</sup>*

### **Lack of support**

There was limited psychological support after a death and where it was provided, it was often inappropriate and unhelpful. Louise Edwards’ father died when she was 12. He had been infected with Hepatitis C and HIV from blood products. She explains: *“My brother and I were never provided with any support. There was no such thing as grief counselling for children. We were told our father died and we got on with our life because we had to.”<sup>563</sup>*

Brenda Millard lost her father and two sons to infections from blood products. After her son Russell died, *“a counsellor came to our house to see me. She asked if I was feeling angry. I replied that I felt sad because my son has just died. Unbelievably, she then said ‘When Robert [her other son] is gone, you will be able to grieve properly’. I told her to get out of my house because her remark was extremely insensitive and wholly inappropriate”. She said “I believe that this situation deterred me from seeking counselling later on in my life.”<sup>564</sup>*

Jason Evans lost his father when he was a child and describes the ongoing impact on his mental health:

*“I was never offered counselling when I was a child or teenager. Looking back now it seems strange that this was not made available to me as a young boy who had just lost his father. When I was older and going through a difficult time (between 2015 and 2017) I called the MacFarlane Trust to enquire about counselling. They told me to contact the Hepatitis C Trust who informed me they had run out of money years ago for counselling. I then wrote to the MacFarlane Trust and told them it might save my life if they provided counselling. I was feeling overwhelmed and consumed by it all at the time. It was only then that funding was made available to me. I was given a set grant for funding and had to make the arrangements with the counsellor myself. I managed to find a counsellor in Coventry with experience in childhood bereavement that I saw for about 8 sessions.”<sup>565</sup>*

### **Permanent loss**

The ripple effects of bereavement are felt throughout the years and throughout the generations. One man, speaking about the death of his son from HIV, says:

*“My wife and I have been trying to put this behind us, but we will never get over what happened to [our son]. If we hear a sound in the house at night, we think we*

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562 Written Statement of Colin Turton para 56 WITN1574001, Written Statement of Denise Turton paras 24-27 WITN1575001

563 Written Statement of Louise Edwards para 24 WITN0509001

564 Written Statement of Brenda Millard para 62 WITN1394001

565 Written Statement of Jason Evans paras 42-44 WITN1210001

*are listening out for [him] and sometimes catch ourselves thinking that he is there. It is especially upsetting when people talk about their children or grandchildren, because we have nothing at all.”<sup>566</sup> His wife says that he “loved Christmas but since he passed away [over 26 years ago] we have not been brave enough to celebrate it so we do not put up any decorations or celebrate the day at all.”<sup>567</sup>*

Gideon Bullock says of his father Kenneth, who died when Gideon was 26:

*“his suffering, how he died and its injustice have come to define my memory of him. The events that led to his death and the subsequent campaign have dominated my childhood’s positive, happy memories ... To compensate, I tried to distance myself from it. Ultimately, this was a fruitless effort. I was reminded of my father’s absence at every stage of life with a wave of anger at how unjust it was that he couldn’t be there, whether it was moving to a new home, starting a new job, needing a bit of advice on a DIY chore, or getting married and being blessed with children. Worse still, knowing those grandchildren would never get to meet their grandfather. And one day, they might learn why and how he had died, how our health service had failed him, and how politicians and medical professionals had closed ranks to protect themselves and their interests.”<sup>568</sup>*

Another man speaks of his sister’s death, after she was infected with HIV through her partner, who had haemophilia: *“We had always been a happy, close knit family, but once [my sister] died and there was always an empty chair at Christmas, we were never the same and the loss weighed on us all quite heavily.”<sup>569</sup> One man whose father died when he was 16 says: “I think about all the things I plan to do with my children when they are older, and all the things that my father missed out on being a part of, my first legal pint, my graduation, my wedding, his grandchildren being born and my eventual passing of my motorbike test.”<sup>570</sup> Graham Simpson’s father died when he was 30 and so: “My children were born after my father passed away. To them, Grandad is a plaque in the cemetery.”<sup>571</sup>*

For Joyce Wheatley, whose husband Stephen Royle died of end stage liver disease and metastatic liver cancer having contracted Hepatitis C from blood products, when her daughter gave birth *“it was both a joyful and sad occasion. I was naturally overjoyed by the situation but it was also tinged with sadness because my husband should have been there to meet his first grandson.”<sup>572</sup> Clare Foster says of her father’s death:*

*“Emotions were high as my wedding day arrived. I sat in the cemetery for 2 hours talking to my dad, wishing he was with us for this special event. I then went*

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566 Written Statement of ANON para 29 WITN1293001

567 Written Statement of ANON para 29 WITN1292001

568 Written Statement of Gideon Bullock paras 4-5 WITN1731001

569 Written Statement of ANON para 32 WITN0366001

570 Written Statement of ANON para 31 WITN1233001

571 Written Statement of Graham Simpson para 36 WITN1518001

572 Written Statement of Joyce Wheatley para 58 WITN1601001

*home, put my smile on and got married. It destroyed me that dad wasn't there. I loved my husband and was happy but so sad at the same time about my dad. One year later I had my first child, again dad wasn't there which destroyed me again. I became paranoid and didn't want to take my daughter out. I was scared someone was going to take her away or hurt her. I was finally diagnosed with depression 8 months later.”<sup>573</sup>*

### **Misplaced feelings of guilt**

For many people, particularly parents, there is an added layer of guilt. Margaret Madden says: *“After meeting with Dr Jones and trying to get my head round everything, reality came rushing in. I kept blaming myself, ‘I have killed my son’ all because I thought it would make life easier for us to give him Factor VIII. I struggle with this every day of my life. I cannot get to grips with all the pain and suffering this has caused me and my family. Even now I can see Daniel in pain like a video on a constant loop.”<sup>574</sup>* One man, who was infected with HIV and Hepatitis C through blood products, lost his two brothers, also infected with HIV and Hepatitis C said: *“The death of my brothers really hurt me and it really affected my mother because she blamed herself for giving us haemophilia. She never really spoke about it because she couldn't without crying, so she stopped talking about it and we stopped mentioning it. I destroyed any newspapers or documents that came into the house that mentioned contaminated blood or HIV because it hurt her so much.”<sup>575</sup>* He too has died.

One man, whose son died of HIV contracted through blood products, speaks of the impact of his death on his wife (who herself contracted Hepatitis C):

*“With help, my wife nursed our son at home until he died. Her grief was overwhelming, she was weary and exhausted both physically and mentally. She had given her ‘all’ and just ‘gave up’ – she wanted to die. I believe (although I am no longer sure) that, for her own safety, she was sectioned under the Mental Health Act. Over the next couple of years she spent a considerable amount of time in hospital trying to come to terms with the loss, grief, shame, secrecy and the guilt. Guilty for having passed Haemophilia on to her children. Guilt for giving our son treatment that might have been responsible for killing him. Guilt because a significant part of our marriage had been taken from us. Guilt because depression and mental torment has had such a devastating effect on the whole of our family. Guilt that our daughter might not want children because of what she has witnessed and experienced over the years” .*

Over the years, with significant help, she managed to recover but with recurring bouts of depression.<sup>576</sup>

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573 Written Statement of Clare Foster paras 45-46 WITN7439001

574 Written Statement of Margaret Madden para 56 WITN1364001

575 Written Statement of ANON para 49 WITN0265001

576 Written Statement of ANON paras 38-40, para 43 WITN0448001

Another man speaks of his response to his son dying when he was a very young age from HIV: *“I found it very difficult to cope after [his] death and still do to this day. I returned to work but found it very difficult, as my work would take me away and staying in hotels alone just left me time to think about nothing else. I wanted to be home with [my wife] who was also suffering from being on her own at such a time. I blamed myself and still do for the death of my son, it was my job as his father to protect him and I failed him.”*<sup>577</sup>

Ms S administered Factor 8 concentrates to her late mother, who had von Willebrand disorder, and who was infected with Hepatitis C. Nothing was said to her or her husband, or to Ms S, who *“was the one infusing the product”*, about any risks. She struggles still with the fact that it could have been the injections she gave that infected her mum, and she cannot bring herself to tell her father of that possibility: *“How can I say that to my Dad? He loved her to bits. How could I say it? ... I have that huge empathy for people given what they thought was the best thing for their child to use, you know, and I’ve done it to my Mum. My Dad still misses my Mum all these years later. ‘By the way, Dad it could have been me injected it’. No. So I can’t tell him.”*<sup>578</sup>

## Family breakdown

The unnaturally early death of parents led to family breakdown. One woman explains that when her father died of HIV contracted through blood products, *“we lost his side of the family, I think they had a lot of guilt and shame about AIDS and the stigma attached so they disowned us ... When my father died, I not only lost him but the whole of his family. This has destroyed part of my roots. There is no one who can tell me about my father’s childhood. There is no one who can tell me my medical history on my father’s side.”*<sup>579</sup>

Anna-Marie Smith-Clark’s mother was infected with Hepatitis C from a transfusion after a stillbirth in 1980. Her mother became unwell in September 2000 and died of multi-organ failure. Anna-Marie and her family are part of the traveller community:

*“Things changed dramatically for us as a family as well as my father moved us from our home in the traveller’s community to a permanent address next door to my present home and where my older sister still lives to this day. My father could not bear to live in the place he had lived with my mother when she was alive. We stopped being travellers in the usual sense because of my mother’s death and are now settled people. I was quite angry about the decision to move us initially but we have adapted to life in a permanent residence. It has meant however that my children have experienced a reduced connection with the traveller community. Things have been changed for them because of my father’s decision to move away, a decision only made because of my mother’s death.”*<sup>580</sup>

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577 Written Statement of ANON para 39 WITN1042001

578 ANON Transcript 4 July 2019 pp146-147 INQY1000027

579 Written Statement of ANON para 21 WITN1452001

580 Written Statement of Anna-Marie Smith-Clark para 23 WITN0754001



One man lost his mother who was infected with HIV by his step-father, who had himself been infected through Factor 8. He went to live with his aunt and uncle but the relationship *“was strained and quite tempestuous. We did not get on and had arguments. It must have been very difficult for them also; my aunt had lost a sister and had taken on her children as well.”* He and his brother moved to live with their grandparents: *“It was not nice for my grandparents to have two moody, depressed teenagers living in their house. They did not have enough energy to deal with us. It was an extra burden on them. They had already finished raising their children ... They went through ridiculous amounts of pain and were the kindest, most fundamentally decent people I have ever met”*.<sup>581</sup>

Another man describes losing his father at the age of eight and his mother just two years later. His father had been infected with HIV through blood products and had infected his mother. He went to live with his grandmother which he describes as: *“difficult because she was elderly, widowed and a pensioner. My Nan was also experiencing grief from losing her son. She carried the burden of responsibility of my care. She was only receiving a small amount of money for childcare benefit up until the age of 18 when it stopped. I lived with my Nan until my mid-twenties when she still supported me up until that time.”*<sup>582</sup>

Another woman also lost both of her parents. Her father was infected with HIV through blood products and infected her mother. Her father died when she was six, and her mother when she was nine years old: *“Soon after her death, I was traumatised. There was no one to take care of me so I was sent to live with my uncle who lived ... about 100 miles away before moving to my grandmothers and then with another relative. In the space of a few years, my life was turned upside down.”*<sup>583</sup>

Tony Farrugia went into a children’s home when his father became more unwell with AIDS-related illnesses. After his father died, his twin brother David was also put into care but they were *“roughly about 80 or 90 miles apart ... I mean I was in a children’s home and they were lovely, you know ... It was a great place. They were very supportive but there was no – you know, they weren’t geared up for this.”*<sup>584</sup> The twins had limited contact with each other for a number of years.

Both of Lauren Palmer’s parents died of AIDS. Her mum was infected through her dad, who had severe Haemophilia A. Lauren was nine when her parents died, within eight days of each other. Lauren’s two half brothers went to live with a relative from a previous marriage and she went to live with other relatives. She describes the impact of the separation from her siblings: *“It was shattering and up until that point, I always knew them as my brothers. Regardless of if they were from a previous marriage we were a family unit and we should have been together and should have remained together growing up ... It was the hardest thing to deal with being separated from them. Not only did I lose my parents, I lost my*

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581 Written Statement of ANON paras 13-15 WITN1466001

582 Written Statement of ANON paras 16-17 WITN1354001

583 Written Statement of ANON para 16 WITN1508001

584 Tony Farrugia Transcript 18 October 2019 p40 INQY1000044

*brothers who were the next closest thing to me ... I would be grief-stricken for weeks after visiting them. I just wanted to be with them.*" Lauren went to live with other relatives where she says: *"I was very lonely, felt quite alone, isolated, and I was going into a family where I was disrupting things ... I just never relaxed there, never felt like I ... really belonged and could be myself."*<sup>585</sup> She left her relatives at 17 and went to live with family friends nearby.

William Chadwick describes how the loss of both of his parents through HIV *"denied me of my right to a normal, supportive and nurturing childhood that I know others received ... As bad as it is to lose both parents, I was then let down by social services and the man my father selected to be my guardian. I was left under the 'care' of a woman who I now feel had no reason to care for me other than ... on the pretence there may have been money that she would benefit from ... I had to grow up quickly and take yet another different path to my peers, again losing all I had ever known all over again."*<sup>586</sup>

### **Families with bleeding disorders**

The toll of other family members becoming ill and dying was significant for many families with bleeding disorders.<sup>587</sup> Mothers experienced more than one son affected because each had similar treatments; siblings would see each other waste away and wonder if they were next; uncles and cousins as well as fathers and brothers might be seriously ill; sisters and daughters worried about starting families; and women with bleeding disorders who were infected were overlooked because they were not men. Though disease caused by infection is in general no respecter of persons, the brunt of HIV and Hepatitis C infections linked to haemophilia treatment was borne disproportionately by some families.

One man, who was infected with HIV and Hepatitis C through blood products, saw his late brother become unwell: *"I prepared myself to get ill. Everyone was getting ill and dying in hospital so I was effectively just waiting my turn in line. I did not think anything mattered anymore; I always just used to say that I was going to die."*<sup>588</sup>

Suresh Vaghela, infected with HIV and Hepatitis C through Factor 8 products, recalled *"one heavy year where I attended 70 funerals of people who were part of the haemophilia community, one of them being my own brother's. I was very close to my brother. He was like my right-hand man. The heartache was too difficult to cope with. There came a point when I was going to so many funerals you automatically start thinking you are going to be next. It is like playing Russian roulette and after a certain amount of time you know the bullet is going to come for you. Every week there was somebody passing away, one after the other and then another and another."*<sup>589</sup>

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585 Lauren Palmer Transcript 7 May 2019 p14, pp16-17 INQY1000005

586 Written Statement of William Chadwick para 16 WITN3210001

587 Though it can be, and does, sometimes arise spontaneously, it is classically carried by an X-linked recessive gene.

588 Written Statement of ANON para 23 WITN1275001

589 Suresh Vaghela Transcript 18 June 2019 p89 INQY1000021

Another man, infected with HIV and Hepatitis C through blood products, says: *“I am also always anxious about my life expectancy. I feel I am a ticking bomb. Whenever I go to hospital I keep thinking: ‘Is this going to be it for me?’ This was intensified when I lost my cousin to HIV, which he too contracted as a result of treatment for his Haemophilia from blood products. My cousin died in 1988 and it really traumatised me. I never visited him in hospital, because I was too afraid that it could be me in the future.”*<sup>590</sup>

One man, himself infected with Hepatitis C through blood products, describes his brother, who also had haemophilia, testing positive for HIV and Hepatitis C: *“They also tested his wife and found that she had contracted HIV from [him]. It was a really difficult time ... Sadly [he] passed away in 1991 and his wife in 1993. She nursed him for the last two years of his life knowing that the same fate awaited her. [He] died knowing he had passed it to his wife and that she would die too. I cannot think of a worse nightmare. They were just trying to live their lives despite his condition and his treatment by the NHS killed them both ... both angry and terrified and with so much potential unfulfilled.”*<sup>591</sup>

Many people with a bleeding disorder lived with the fear of HIV infection. For example, one man, who contracted Hepatitis C from Factor 9, describes: *“During my teenage years I was fearful of contracting HIV and AIDS. I constantly expected to be told that I had this infection and I tried to prepare myself psychologically for how I would deal with it. I worried constantly about getting HIV and AIDS.”*<sup>592</sup> Judith Howells describes the TV adverts about HIV and says *“It was the most awful advert. I feared Sam had HIV and in my head, I had buried my child already. The hospital did not give us the all clear until Sam was 16 years old. For 11 years I had worried constantly that he may have HIV. In retrospect I know we are lucky because he is still alive.”*<sup>593</sup>

Many families faced agonising decisions when they sought medical treatment for their own children, carrying with them the pain and trauma of what had previously happened to their loved ones. One woman describes when her daughter was rushed to hospital with appendicitis, two months after her husband had been diagnosed with AIDS: *“Dr Savidge told me that she needed FVIII for the operation as she is an asymptomatic haemophilia carrier. I was horrified and said ‘no’ before I was persuaded that she had to have it. It was such a stressful time ... Dr Savidge said that the FVIII was now ‘very pure’ but I have had trust issues with the medical profession ever since and there will always be a worry at the back of my mind.”*<sup>594</sup>

Female carriers faced difficult decisions about whether to have children. One woman says *“During the period between 1980 and 1982 I was carefully considering: a) obtaining advice about whether I was a carrier, b) whether I should have the new amniocentesis procedure, which had a high risk of miscarriage at that time and c) whether I should have children at*

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590 Written Statement of ANON paras 27-28 WITN1489001

591 Written Statement of ANON paras 26-27 WITN0010001

592 Written Statement of ANON para 43 WITN1446001

593 Written Statement of Judith Howells paras 10-11 WITN0344001

594 Written Statement of ANON para 19 WITN1550001

*all ... With the benefit of hindsight, I do now wonder whether I could have been given more information about the emerging risks of viral contamination in 1980 to 1984.” After the birth of her second son, her brother “broke the devastating news to us that he had in fact been infected with the HIV virus. What followed was an incredibly difficult and sad few years until his death in 1990.” She reflects “It was so frightening and sad throughout the 1980s and 1990s to live through the media storms and hear of other sister carriers losing their sons, brothers, cousins, uncles and grandfathers.”<sup>595</sup>*

Another woman, whose father died of Hepatitis C that he contracted through blood products, describes that her “son is a mild haemophiliac and after what happened to my father, I cannot even convey how very nervous I am about my son receiving treatment.”<sup>596</sup> Collette Pigden, whose father died of HIV from blood products, has a son with haemophilia. She says: “we managed to hold off treating him until he was 14 months old. We were faced with having to inject our son with a similar treatment to the one that had potentially killed my father.”<sup>597</sup>

Another woman whose father died of HIV from blood products has a son who has severe haemophilia: “knowing that my father died from an infection that he received from the treatment that was supposed to help him, this always plays at the back of my mind when my son is being treated by the doctors. I always get reassurance from the doctors that the treatment my son is having is safe. However, it never stops me asking questions. I am very vigilant with what happens in the hospital in relation to my son.”<sup>598</sup>

## Impact on family and social life

Many families have lost all “normality” in life. Katie Rendle describes the effect on her brother, who is infected with HIV, Hepatitis B and Hepatitis C:

*“Andrew’s infections have transformed every aspect of his life. The life he could have had if not for these infections would be totally unrecognisable to the life he has forged out for himself. From his teenage years to today he has suffered a barrage of debilitating, crippling illnesses and conditions. His potential to live a ‘normal’, healthy, happy life was stolen. We feel deeply grateful just to have him still alive and with us. The injustice of the life that was robbed from him and from our family haunts us always.”<sup>599</sup>*

Parents were deeply distressed when told of their children’s infections. One man, infected with HIV, says: “My father took my HIV diagnosis really badly and locked himself away for two days. My mother always did and still does feel guilty for my condition. She injected me with the blood products whenever I needed treatment therefore she feels she is to blame for

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595 Written Statement of ANON para 6, para 11 WITN2441001, Written Statement of ANON para 12 WITN2441004

596 Written Statement of ANON para 30 WITN0883001

597 Written Statement of Colette Pigden para 22 WITN0365001

598 Written Statement of ANON para 17 WITN1335001

599 Written Statement of Katie Rendle para 12 WITN3372001

*my illness. As a family, my condition has never been talked about.*<sup>600</sup> Lester Hill explains that his eldest daughter had died in a car accident and when his son told him of his Hepatitis C infection, *“I was so shocked to hear this dreadful news. It was very hard to accept that I will lose another child ... When John died in 2009 it came as a great shock to me and I was deeply upset. No parent should have to lose a child in their lifetime.”*<sup>601</sup>

Andrew Hearne, infected with HIV and Hepatitis C through blood products, explains that his parents *“were and still are devastated and angry about my infections and I believe that both of them have bottled up their real feelings about my HIV for many years. They are two old and sad people who do not have a large social life, and do not have much enthusiasm for life in general, which is very much as a result of what has happened to me.”*<sup>602</sup> Molk Raj Heera says that his Hepatitis C, caused by treatment for Haemophilia B, *“caused great distress to my parents who had no knowledge of what it was. It was a huge concern for them and made them feel guilty and that they had failed as parents.”*<sup>603</sup>

Another man says:

*“My parents suffered a great deal, from back when they were both told of the heart breaking reality that their only child had been given multiple life threatening viruses, caught from a contaminated batch, by the very people they entrusted their son’s well being to. They had no information about the viruses and felt their son’s future had been taken away. They were forced to suffer in silence as they had no one to turn to with the stigma around and they could only talk to the hospital staff; who were the same people who had contaminated their son.”*<sup>604</sup>

Another man explains:

*“The impact of my contracting HIV and Hepatitis C felt by my family has been huge. My parents are still haunted by the trauma of the events surrounding these issues and I do not think they will ever be healed. Since the inquiry began my mother has been re-traumatised and although she sees the inquiry as beneficial I cannot talk to her about it. When the inquiry began we had a brief conversation about it and since then she has been having traumatic flashbacks. I feel powerless to help her. I have tried to coax her into thinking about entering into counselling but to no avail. My father began looking into the Inquiry and when it went live he watched some of it but after a while felt that he could not persevere. The Inquiry simply reminds him of the trauma from long ago and how he felt unable to help me when I was a child.”*<sup>605</sup>

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600 Written Statement of ANON para 12 WITN1501001

601 Written Statement of Lester Hill p4 WITN2345001

602 Written Statement of Andrew Hearne para 57 WITN1281001

603 Written Statement of Molk Raj Heera para 16 WITN1283001

604 Written Statement of ANON para 43 WITN1242001

605 Written Statement of ANON paras 27-28 WITN1006001

A woman explains that the father of her son took his own life “*mainly due to the shock, shame and fear*” of discovering that her son had been diagnosed with HIV. His father’s suicide has “*profoundly affected [her son] for the rest of his life, he is angry and feels the NHS was to blame, not just for his own illness but also for his father’s death, and consequently he feels guilt himself.*”<sup>606</sup>

Judith Braithwaite describes how her then husband reacted to her son’s infection with HIV from blood products:

*“He loved Spencer and was a good dad when sober. However, when the HIV diagnosis came, he was in denial and would not accept it. He stayed out drinking all the time, often from 8am to 12am. He wouldn’t even know I had taken Spencer to hospital a lot of the time. He stayed out late drinking after work and didn’t want to believe it. I resented him because he was on a good wage and I felt that if he hadn’t drunk, I wouldn’t have had to work and I could have cared for Spencer more.”*

Spencer died aged 34.<sup>607</sup>

Life at home changed dramatically when a parent was diagnosed with HIV or hepatitis. The impact on the children has been extensive and complicated, ranging from the loss of a normal childhood, watching a parent suffer intolerably, guilt for being the “*cause*” of the infection where the transfusion was given during childbirth to the death of one or, in some cases, both parents.

Rebecca Gilray’s father was infected with HIV and died aged 28. She says: “*My father would often cry his eyes out at home and in hospital. He could not bear to be around us. He would go away to clear his head and I cannot imagine how lonely that must have been for him.*”<sup>608</sup>

One woman, whose father was infected with HIV, Hepatitis B and Hepatitis C remembers “*a sad and oppressive atmosphere at home*”. She escaped to a friend’s house at weekends and after school: “*I think I spent a lot of time with her family because they were so different from mine. Her family were happy. There was fun and laughter in her household. Fun and laughter were missing from my home.*”<sup>609</sup> Jennifer Jones explains:

*“The impact my father’s illness and subsequent death [from HIV and Hepatitis C through blood products] has had on me has been huge. Before reaching the age of 12, I had experienced my father openly and publicly speaking about his HIV status with all the associated stigma of that time, the breakdown of my parent’s marriage and my father’s death. I was aware my father was dying and for a long time we were waiting for it to happen. My parents thought if my brother and I were more aware of what was happening, we would deal with it better. He went*

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606 Written Statement of ANON paras 14-15 WITN2877001

607 Written Statement of Judith Braithwaite para 40 WITN0112001

608 Written Statement of Rebecca Gilray para 16 WITN2908001

609 Written Statement of ANON paras 14-15 WITN1313001

*into a coma when he developed [pneumocystis carinii pneumonia] PCP and we knew that was the end. It was traumatic”.*

Her fears of having a child with haemophilia also affected her own decisions and she has only had one child.<sup>610</sup> One woman describes the situation with her daughter: “[She] is especially sensitive to what we went through as she was older at the time and remembers so much; me not able to get out of bed, me unable to go to parents’ evening as I couldn’t stand for long periods. She remembers brushing my hair at one point and clumps of hair falling out.”<sup>611</sup> Alex Shenton-Parkin describes that “Both Mum and I took over the cooking from Dad, and I was making meals for the family at about 14 years old. Dad being ill meant that I had to grow up quite fast and do things that other children my age did not have to do. I would never have friends over for sleepovers at our house and I would always go to friends’ houses instead, due to what was going on at home.”<sup>612</sup> Another woman, whose father was infected with Hepatitis C, says that “No child should see illness as normality. My lack of emotion at my Dad’s illness wasn’t because I didn’t care about it but I learnt that emotions weren’t going to change anything. As a result I have been described as cold, even uncaring, but I just buried my emotions because they were too much to deal with.” As a teenager she suffered from frequent panic attacks and was diagnosed with depressive and anxiety disorders at age 16. She continues to suffer from mental ill-health.<sup>613</sup>

Julie Kirkham, whose father contracted Hepatitis C from Factor 9, has “memories of being banished from the kitchen when my father was having his treatment at home. There seemed to be an atmosphere of fear and stress. This was further accentuated if my father cut himself which resulted in my mother shouting orders at me to ‘stay out of the way’. Again, it was only later on in life that my mother told me that they were petrified that I would catch something which is why they behaved as they did and why an atmosphere of fear existed.”<sup>614</sup> One man explains that when his father was diagnosed with HIV, he “became a very difficult man to live with. There was no love and affection there anymore, just his worry and anxiety about his mortality. Through a deep-rooted fear of being contaminated with the disease, I developed OCD related to cleanliness. It was early days and no-one was able to reliably tell our family how (because they didn’t know) to safely protect ourselves from cross-infection. Everyone was worried. I washed myself in bleach and showered three times a day.”<sup>615</sup>

Rebekah Wintle describes the impact of her mother’s infection with Hepatitis C:

*“I remember many times where I have seen my mum extremely upset and on one occasion she did not want to carry on living anymore. On this occasion the family were all at home one evening, and an hour had gone by, and we had not seen Mum. We discovered she was not in the house. It was dark and the middle*

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610 Written Statement of Jennifer Jones paras 17-18 WITN1312001

611 Written Statement of ANON para 29 WITN0105001

612 Written Statement of Alex Shenton-Parkin para 33 WITN6444001

613 Written Statement of ANON para 7 WITN0797001

614 Written Statement of Julie Kirkham para 42 WITN1331001

615 Written Statement of ANON para 13 WITN1475001

*of winter. We searched for her and found her down a dark lane close to a large, deep pond near our home. She was in a terrible state and totally suicidal. The crippling pain I felt seeing her on the edge was indescribable. I was young but all I wanted to do was run up to mum and grab her. No child should ever have to see that, and nobody should have to go through feeling like their life is not worth living.”<sup>616</sup>*

One woman explains that, despite being adults, she and her brother have remained living at home with their dad, who was infected with Hepatitis C: *“I am the only girl in the house and do feel some pressure to stay at home and continue to care for Dad, because apart from what we do in the house, I worry that he would be very lonely without us there.”<sup>617</sup>* Donna Lever’s father was infected with HIV from blood products. As he became progressively more unwell, Donna explains: *“Life was chaotic and plans could not be made. My idyllic country life, where my father had polished my school shoes on a Sunday evening, had seemed long gone. We would grab tea and I would have to sit at people’s tables often to do my homework, I felt there was no routine or support and I felt very frightened and insecure.”* After her father died, her mother *“became emotionally and physically unavailable”* to her. Her life changed from being *“the girl who had her school shoes polished for her on a Sunday evening, did her homework and was almost top of the class academically to demonstrating chaotic behaviour which included jumping out of cars, spitting, swearing and running away. Idyllic early family life had been transformed into horrific teenage years. I was mad at my mother and the world and unable to process the loss of my father.”* She was never offered counselling or psychological assistance.<sup>618</sup>

Many children feel guilt for a parent’s infection. Lucy Parham’s mum, Gill Fyffe, was infected with Hepatitis C and suffers an autoimmune condition from interferon treatment causing severe photosensitivity:

*“By far the biggest impact Mum’s infection has had on me is the mental impact. The difficulty has always been that the story starts with me; everyone else in my family had a life pre-contamination but my life is encapsulated by Mum’s transfusion ... My rational brain of course knew that this thought was erroneous, but I suddenly realised that because my Mum had received her infected blood transfusion at my birth, I had subconsciously linked my birth, my existence indeed, to Mum’s illness and then the photosensitivity and financial struggles that ensued. I realised for the first time that I had been feeling guilty all these years.”<sup>619</sup>*

Lynn Johnson describes how her youngest son feels *“very guilty, because I was infected through a transfusion due to a haemorrhage after his birth. He thinks that if it was not for his birth, then I would not have suffered with Hepatitis C. Of course, I have told him not to think*

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616 Written Statement of Rebekah Wintle para 18 WITN1058001

617 Written Statement of ANON para 10 WITN0802001

618 Written Statement of Donna Lever para 24, para 26, para 36 WITN1762001

619 Written Statement of Lucy Parham para 16, para 21 WITN0687001



*that way and that it was not at all his fault. Regardless, he still carries unnecessary guilt with him.*<sup>620</sup> Demos Papamichael, whose wife Andre died from complications arising from the Hepatitis C infection, says that his daughter “*feels responsible and thinks that it was her fault that Andre died*” because Andre required a blood transfusion after her birth.<sup>621</sup>

Where one parent was infected, the other struggled to give their full attention to their children. Jean Hill’s husband Ron had two liver transplants for Hepatitis C, contracted through blood products. As she followed an ambulance taking Ron to hospital, she:

*“took a phone call from a PC Williams to inform me that the Police were going to prosecute the girls who had been bullying [my daughter] Stacey at school. Up until then, I had no idea that Stacey was being bullied and that she had to endure such an ordeal whilst her father was so ill ... [My other daughter] Hayley had tried to protect me and Ron from what was happening to Stacey by taking on a parental role, liaising with the school and trying to deal with the problem herself. It broke my heart and made me feel terrible and a useless mother not being there to protect my children.”*<sup>622</sup>

Gayner Hallam’s husband was infected with HIV from blood products and died in 1992. Her son, Adam:

*“started taking drugs during the period of Dave’s illness. I did not give him the attention that he was craving. As a mum, I blame myself. I feel guilty. The night after Dave died, Adam went out and caused a lot of trouble. He was kicking off about the government killing his father and the police picked him up and put him in a cell. The police phoned me and asked if his father had just died. I said yes. They said they would not charge him and asked me to come and pick him up. Adam had so much anger in him. I knew that Adam started on drugs because he was trying to find some relief from the situation”* .

Adam tried over the years to free himself from drugs but “*just could not seem to sort himself out. He would phone me and would still be going on and on about what happened. I had always thought that once Dave was gone, I could give Adam the time he wanted. But it was just too late. The damage had been done.*” In 2012, Adam got involved in a fight having taken drugs and died a few weeks later from his injuries.<sup>623</sup>

Parents who were infected experienced severe limitations as to what they can do with their children. One man recalls that the “*severe lethargy*” from his Hepatitis C made it difficult at his children’s sports day: “*Every year, there was a parents’ race. I would watch my wife run and feel proud but I would be thinking ‘Oh no it’s the dads next’. I could never take part and the girls never really understood why. One year I did join in. I came last by a long way*

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620 Written Statement of Lynn Johnson para 29 WITN0026001

621 Written Statement of Demos Papamichael para 41 WITN0037001

622 Written Statement of Jean Hill para 31 WITN1285001

623 Written Statement of Gayner Hallam paras 39-40 WITN0467001

*but it made the girls happy and they were cheering me on. I paid for it for about 2 weeks afterwards. I couldn't get up the next day. I was dead to the world. I was in so much pain.*"<sup>624</sup>

The psychological fear is also considerable. Roger Newman describes that whenever his children become unwell, *"I have an automatic fear that I have contaminated them."*<sup>625</sup>

Antoni Olszewski says that *"The damage this has done to my wife and kids is terrible. The children were too young to understand why I could not spend time with them and why I was always ill"*. His wife Joyce explains that for 12 years following his transfusion he was depressed: *"it turned my husband into someone else and we did not know why for such a long time ... The children did not know or understand what was happening to their dad."* Their sons confirm the impact on them: *"I remember there being lots of arguments, and lots of frustration ... I remember wishing I could spend more time with him. We had bikes we could not go on without him. I did not understand, all I was told was daddy was sick."* *"Mum had to care and do everything for him ... The tension in the home could be felt when Dad was ill."* *"Because of my dad's mood swings and erratic behaviour, we argued a lot ... It became difficult to keep the family together."*<sup>626</sup>

The daughter of a woman infected with Hepatitis C says:

*"Our lives have been completely torn apart; two of my siblings have nothing to do with the family. There has been a lot of resentment and tension from my siblings towards my Mum as she has always been sick ... my Mum doesn't have a life, she just exists. It has meant a lot of arguments in my family that have never been resolved ... I look at the hand [my parents] have been dealt in life and it honestly makes me so sad. My mother was robbed of her life, my father of his wife, and us of our mother. Their grandkids have never known my mother not to be sick or my father not to be a caregiver."*<sup>627</sup>

One man who was infected with Hepatitis C said *"My illness has affected my family a great deal, and I can only describe it as like living with a time bomb, not knowing if I was going to die and what impact that would have on my wife, my children and my parents."*<sup>628</sup>

Friendships have also been affected. One man says: *"I did have quite a decent circle of friends prior to my diagnosis. I have virtually none now. I simply do not cope well in company anymore."*<sup>629</sup> Another woman explains that the Hepatitis C infection, contracted through a blood transfusion had *"made it hard to form real friendships."* She says: *"I cannot be my*

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624 Written Statement of ANON para 29, paras 31-32 WITN0616001

625 Written Statement of Roger Newman para 47 WITN1431001

626 Written Statement of Antoni Olszewski p4 WITN2522001, Written Statement of Joyce Olszewski p3 WITN2524001, Written Statement of Troy Olszewski p3 WITN2523001, Written Statement of Leon Olszewski p3 WITN7216001, Written Statement of Christian Olszewski pp3-4 WITN7217001

627 Written Statement of ANON pp4-5 WITN3166001

628 Written Statement of ANON para 5.5 WITN0110001

629 Written Statement of ANON para 67 WITN0123001

*genuine self. I do not have a social life. The side effects the treatment has left me with, kills my ability to participate.*<sup>630</sup>

Another woman, whose husband was infected with HIV and Hepatitis C, explains: “we were a well known family in our area and so in around September 2001 we moved away from everyone and cut them off as we could not deal with the constant questions. People knew [my husband] was a Haemophiliac and so that would lead to more probing questions. We now have different friends who do not know anything about all this.”<sup>631</sup>

Christopher Mitchell says that the Hepatitis C infection makes him “feel like an outcast” and says “my social life is non-existent. I feel like my life is one big secret and people ask me questions which I am not comfortable answering. I have never had a long term relationship as I feel it would not be fair for someone to deal with the way I am and I would find it difficult to tell someone that I had Hepatitis C.”<sup>632</sup> Another man says: “I live my life as a piece of china wrapped in cotton wool. I have led my life like this to ensure that no one comes close to me.”<sup>633</sup>

## Impact of caring

The impact on family members of having to care for a loved one, and of having to witness their intense physical and psychological suffering, has been profound. As Alan Burgess describes “even though I was the one who got infected, it didn’t just happen to me; it happened to the whole family, and it is still happening to the whole family.” His daughter Laura says she has “never come to terms with my dad’s illness and the way in which he contracted it, and it feels as though my family and I have been living a 30-plus-year death sentence.” His daughter Sarah had to intervene to stop him killing himself and arrange for his admission to hospital: “He was a child, on that day. I was the parent, he was the child. Something I never, ever want to do ever again. That was one of the hardest days of my life, having to do that to him.” His son Liam says: “Growing up I always felt like I had to be an adult. I couldn’t just be a child.” Denise, Alan’s wife, has “never been able to do what I wanted to do because I have had to be Alan’s carer”.<sup>634</sup>

One man describes how his wife’s infection with Hepatitis C following transfusions around childbirth has “completely changed our marriage”. Previously she used to do everything to do with running their home, and he says:

*“Now I do all of the housework, I make sure that [she] has taken her tablets on time and I even help her shower as she is unable to get in and out of the bathtub independently. I am her full-time carer, as well as manager of the house*

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630 Written Statement of ANON para 36 WITN0251001

631 Written Statement of ANON para 39 WITN1274001

632 Written Statement of Christopher Mitchell para 21 WITN1401001

633 Written Statement of ANON para 15 WITN1287001

634 Alan and Sarah Burgess Transcript 28 October 2019 pp43-46, pp59-61 INQY1000045, Written Statement of Liam Burgess para 9 WITN1118001, Written Statement of Denise Burgess para 30 WITN1119001

*... Watching someone I love get worse with illness and become lower in mood has completely drained me mentally. It has been such a stressful experience that I still have trouble sleeping, even now ... [My wife's] infection has left me with mild insomnia, because there are so many things on my mind that I can never fully settle down and relax.”<sup>635</sup>*

Rosemary Wright says “As a partner you have to just pick up the slack. You have to be strong. You’re not always strong, and sometimes you’re impatient, but you also have to be aware of the fact your partner is living with not expecting to live very long”. She describes it as “a big cloud, a big shadow that affects lots of different aspects of your life.”<sup>636</sup>

One woman says that her husband’s infection “has impacted on us in a big way. I expected us to do things together as we grew old together. I always have to keep an eye on him and I feel as if I am nagging him. It’s the things you take for granted that we now cannot do together. I feel almost like a nursemaid to him.”<sup>637</sup>

Lesley Mason’s late husband Chris was infected with Hepatitis C during his third kidney transplant. Lesley said: “I became my husband’s carer and over time, my role as his carer increased ... for the whole family any support has come almost entirely from family and friends rather than from any organisation or official channels.”<sup>638</sup>

## **Marriage and relationships**

Many people felt that they could not pursue romantic relationships after their diagnosis. Graham Berwick says: “I haven’t had many relationships in my life. The thought of having to tell someone about my infection is probably part of the reason why I haven’t pursued it. I’ve just always thought that I’ll carry on as I am and keep it to myself. I would find it incredibly hard to discuss this with someone if I were to have a relationship with them, as the possibility of rejection would be a horrible scenario.”<sup>639</sup>

For some, cultural concerns made relationships more difficult once it was known that they had an infection. For one man, who contracted HIV and Hepatitis C from blood products, the possibility of a marriage was said by his parents to be “a remote possibility”. He says:

*“my status had to be revealed to any marriage prospects ... With my health concerns, it was a lot more difficult to establish a relationship in my own community. It prevented it. The condition had other connotations with it also – death, stigma, being ostracised. It was difficult to find any person who would welcome someone with my medical history into their family ... I had a very hard time getting families to accept me because of my haemophilia status but we did find on 2 occasions*

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635 Written Statement of ANON paras 30-31, para 33 WITN0837001

636 Rosemary Wright Transcript 5 July 2019 pp83-88 INQY1000028

637 Written Statement of ANON para 37 WITN2208001

638 Written Statement of Lesley Mason para 57, para 76 WITN0667001

639 Written Statement of Graham Berwick para 35 WITN0303001

*when I nearly got engaged but when we finally informed them of my HIV, I was rejected ... Eventually, I married albeit outside of my own community.”<sup>640</sup>*

Very many people who were married or in a long-term relationship have faced a transition from partner to carer as their loved one has become more unwell. Janet Root describes this:

*“Becoming a full-time carer was a slow process. You start off accompanying your husband when he visits medical staff. Then you realise there are times when he simply cannot take in the latest news about his condition so you step in on his behalf. You start to make notes, you come home and type them up and refer back to them at the next visit. Then you are the one who is remembering details neither your husband or the medical staff can recall. People start to rely on you and relay information to you so you can discuss it with your husband when he is ready. You become the expert on your husband’s condition, prompting him to go to the doctor as you sense a change in his condition or making sure he mentions something important when visiting consultants. You become the one breaking bad news to your children, to friends and extended family after your husband has received another setback which he doesn’t want to talk about. You are the only witness seeing the impact of another drug trial fail, noticing more symptoms emerge and helplessly observing your husband’s continued deterioration.”<sup>641</sup>*

Robert Mackie said that *“The worst and saddest thing that this disaster has brought to me is that my wife has given up so much and made the ultimate sacrifices in her life. She has given up her right to have children and her career ... Even after my wife has made all these sacrifices, she is still with me after all these years – this most of all to me is the ultimate sacrifice.”<sup>642</sup>*

The strain of ill health told on many relationships. Sue Threakall recalls of Bob, who was infected with HIV:

*“As Bob became more and more ill he didn’t want me to go anywhere or do anything. I think he may have been scared to be alone, but I also think he started to resent the idea that I was off doing something nice whilst he was suffering so much ... On one occasion I signed up for an art session at our local library. It only lasted two or three hours and I loved it, but I recall that Bob was really annoyed that I was away for ‘so long’. On another occasion he got cross because I was chatting and joking with the milkman. It was very unlike the Bob I married who wouldn’t have been bothered at all ... Our relationship was put under terrible strain. I did everything I could to help and support him, but I think we both knew what the final outcome was likely to be and we were scared. Bob was a very, very*

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640 Written Statement of ANON paras 23-34 WITN0254001

641 Written Statement of Janet Root para 11, para 13 WITN1965001

642 The emphasis is given in the original statement. Written Statement of Robert Mackie para 36 WITN2190001

*frightened man. Most of the time he dealt with it all stoically, but whenever he wasn't well I could see the terror in his eyes.*"<sup>643</sup>

For some partners the pressures of caring and facing losses became too heavy. David Moore believes that his father's long ill health and death after contracting Hepatitis C contributed to his mother taking her own life.<sup>644</sup>

Partners who had encouraged their loved ones to seek treatment experienced feelings of guilt. Sue Sparkes' husband Leslie was needle phobic but she would encourage him to go to the hospital for treatment for his Haemophilia B when he was in pain. In 1985, Leslie and Sue were told that he was HIV positive:

*"Professor Bloom said 'don't worry about it but you have antibodies for HIV but it might not lead to AIDS' ... We were told to come to the hospital if Les needed treatment. When we came out of that room Les said to me 'I am never coming back for treatment again'. He went on to say and I remember his words clearly 'I am a murderer; there is something inside me which can kill people.' Our whole world crashed around us; Les felt like he had been given a death sentence. The problem is after we were told he was HIV positive he said that if he had stuck to his guns and not had the Factor IX treatment he would not be in this position with HIV. He made me feel like I was the one who made him have the treatment and I will never forgive myself for that; never, ever ... From the moment Les was told ... until the day he died we did not tell a soul. It was just me and him ... It was something that brought us closer together but also at the same time tore us apart."*<sup>645</sup>

Sex was fraught with difficulty. One woman explains: *"The thing I find hardest about our relationship is to do with kissing, and this makes me very upset. [He] is my love, my soul mate and the bravest, most caring and considerate man that I have ever met ... All this has meant no proper passionate, full-on kissing ... It is a constant reminder that we can't be like others, that these horrible viruses are ruining yet another part of our lives."*<sup>646</sup> Janet Kenny's late husband was infected with Hepatitis C and she said: *"Our lack of intimacy wasn't something we spoke about but was an immense loss to us both. If there was just one thing that could have been avoided throughout his illness, I really wish that we had been able to remain physically close as well as emotionally close, but this was taken from us by Hepatitis C."*<sup>647</sup> Another woman says: *"at times it felt like I was playing Russian roulette by having a sexual relationship with someone with HIV. Although we practised safe sex we still worried that something could go wrong and it definitely affected the intimacy between us."*<sup>648</sup>

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643 Written Statement of Susan Threakall paras 24-26 WITN1564001

644 Written Statement of David Moore para 29 WITN1404001

645 Written Statement of Sue Sparkes paras 14-16, paras 22-23 WITN1713001

646 Written Statement of ANON para 26 WITN0864001

647 Written Statement of Janet Kenny para 79 WITN0338001

648 Written Statement of ANON para 14 WITN1328001

Many others ended their sexual relationship with their partner. One man said that after he had been diagnosed, he never had sexual intercourse with his wife again “for fear of me transmitting the virus to her.”<sup>649</sup> Another man says:

*“When I was told of my diagnosis, my life changed completely. From the very day of my diagnosis, my wife and I did not share intimate relations ... My wife and I continued to share a happy relationship, though it became clear that the lack of physical intimacy had put a strain on our marriage. One weekend 3 or 4 years after my HCV diagnosis, I had been to Scotland on my own to visit family. When I returned to the family home, my wife had prepared divorce papers and left them on the table. I had no idea that she wanted a divorce.”*<sup>650</sup>

### **Fertility, childbirth and being unable to have children**

Many people felt obliged to decide that they could not start a family. Sam McMahon explains that once told he had contracted Hepatitis C, he was “convinced that I would never be able to have a relationship or children. This was extremely damaging to my self esteem. To this day it has been a factor in deciding not to have children. I do not want them to go through what I went through.”<sup>651</sup> Louise Veale says: “When I discovered I had contracted HCV, I decided to have an operation to be sterilised because I would not want to put a child through that. The potential risk of the child being born with the infection was too much to contemplate.”<sup>652</sup>

Another man records that he decided on a vasectomy from a young age. He says this was because “I feel it would be unfair on them [the children] if their father were to die young.” His infections have “had a profound impact on what my family life could have been. The same applies for [my wife] who had to make significant decisions about her future by choosing to be with me.”<sup>653</sup> For one woman infected with Hepatitis C, “The thought of passing on the infection to potential children horrified me. My husband and I decided the risk was too great. I look back on my life and it is with great sadness, I am childless.”<sup>654</sup>

Martin Beard lived with his partner happily for a year but says: “However, I always knew there were going to be problems because in the future she would want children. It was not the fact that I was against the idea of children; it is just that I knew it was going to be problematic ... I made the decision for us to separate so that hopefully she could go off and have children, which thankfully she did and she seems happy. After this I went into a downward spiral.”<sup>655</sup> Another man also made the decision not to have children for fear of passing on the Hepatitis C infection which resulted in his relationship ending.<sup>656</sup> A woman, whose late ex-husband was infected with HIV and Hepatitis C, says that “The strain of living

649 Written Statement of ANON para 41 WITN4313001

650 Written Statement of John Devine paras 31-33 WITN4871001

651 Written Statement of Sam McMahon para 18 WITN1386001

652 Written Statement of Louise Veale para 65 WITN5212001

653 Written Statement of ANON paras 60-61 WITN0376001

654 Written Statement of ANON para 22 WITN2084001

655 Written Statement of Martin Beard paras 79-80 WITN0012001

656 Written Statement of ANON para 25 WITN1407001

*with HIV destroyed our marriage and we eventually divorced ... The regret of listening to flimsy advice not to have children has remained with me and haunts me every day as I see my friends busy with their children and grandchildren. I feel enormous sadness that I wasn't given the opportunity to have my own family.*"<sup>657</sup>

Andrea Peach and her late husband, who had HIV, "*had dreams of starting a family*". She says:

*"We had put our names down on the waiting list for Assisted Reproduction / IVF treatment at the John Radcliffe Hospital, Oxford. In November 1993, we were notified that a treatment appointment had become available. Sadly, Leigh was very unwell in hospital when I got the call. I decided it would put too much stress on us to go through with the treatment at that time, so reluctantly declined the appointment. Leigh's condition never improved, and he died 2 months later."*

He was 27 years old. Andrea did not meet anyone else "*significant*" until she was 42 years old and has never had children.<sup>658</sup> Janice Whitehorn-Cox received treatment for Hepatitis C, having been infected through her mother, and was not warned of any risk to her fertility. However, she was later told that she was almost infertile and IVF treatment was not an option.<sup>659</sup>

Some couples made the decision to terminate a pregnancy, on the advice of doctors, because of the risk of passing on the infection to the baby. Frankie describes two terminations because of infection with HIV, transmitted by her then husband who had been infected by blood products. Of the second, late stage termination, she says: "*I was made to feel like I was a murderer by them, and that is how I continue to feel to this day. I was even told by one of the doctors that people like me should be sterilised. I was told afterwards that my baby was a boy ... I was offered no counselling or support throughout this time. I have since seen many counsellors and try to meditate to forgive myself. I have nowhere to go to mourn for my baby.*"<sup>660</sup>

Richard Warwick's wife Tina became pregnant and was advised to have a termination: "*It was explained to us in very strong terms that it would be best for Tina to abort her unborn child as there was a high probability that the child could be born HIV positive ... I had been lucky to date but was living on borrowed time ... There was absolutely no treatment available for HIV at the time. We were both heartbroken.*"<sup>661</sup> Another woman whose husband contracted HIV from blood products recalls:

*"When my son was around 18 months old, I fell pregnant again. I had been told that due to all the risks around at the time, any more children I had were guaranteed to be infected, as would I. Due to fear I therefore decided to get a termination and I regret that to this day. It was, and still is heart-breaking to see*

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657 Written Statement of ANON para 27 WITN1290001

658 Written Statement of Andrea Peach para 20, para 25 WITN7128001

659 Janice Whitehorn-Cox Transcript 11 October 2019 pp43-45, p59 INQY1000040

660 Written Statement of Frankie paras 25-26, paras 28-29 WITN1388001

661 Written Statement of Richard Warwick para 16 WITN1592001



*other couples with multiple children and I used to break down when I saw other children. I never wanted to get a termination. It makes me so angry about it just thinking back to the appointment with Professor Bloom before [my child] was born and the information he gave us about having children.”*<sup>662</sup>

One man, infected with HIV and Hepatitis C through blood products, describes how his wife was pregnant around the time he was diagnosed with HIV and says: “*we were forced to terminate the pregnancy. We were advised by Dr Savidge that the risk of the mother and child being infected was extremely high and that it is best she has an abortion ... We were so excited to start a family, but this was taken away from us due to my HIV infection.*”<sup>663</sup>

Mr and Mrs V took the “*horrendous decision*” to go through with a termination, due to the fear that the baby would be infected with Hepatitis C, and later decided not to try for children again for fear that the child “*might not have a dad after two/three years*”. It remains “*a bloody knife through the heart*” listening to people at work talking about their children.<sup>664</sup>

As scientific understanding developed, assisted conception that minimised the risks of transmission of infection became available. However, this was often fraught with difficulty. Perry Evans described sperm washing and IVF as “*A physical and highly emotional journey*”.<sup>665</sup> Since giving evidence to the Inquiry Perry has died. Matthew Merry’s wife became pregnant on the second attempt using sperm washing but: “*Three years later, we wanted another child and Lewisham Primary Care Trust refused to fund it because our circumstances were ‘not exceptional enough’! ... We had to self-fund for another cycle of assisted conception*”.<sup>666</sup> His brother also had to self-fund a second round of IVF in order for his wife to conceive their second child because they did not meet the “*exceptional need*” criteria.<sup>667</sup>

Another woman explains that she and her husband had their son before being informed of his HIV infection and then “*explored every avenue*” to have further children: “*After months of stress and disappointment I came to the conclusion that I couldn’t put myself through this process any longer and to be grateful for our son. All my dreams of having a large family were over and this important episode in our lives was done as if we were ashamed of what was happening. All of this was done in secret ... The party line became ‘we didn’t want any more children, we were happy with one’ but inside my heart longed for more.*”<sup>668</sup>

The stigma associated with the infections affected how mothers were treated when giving birth. One man describes that when his wife gave birth to their first child “*she was treated very badly by the hospital staff. Although she was not infected, she was put in isolation so that she was not around the other mothers. I felt like this was all my fault and I could not do*

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662 Written Statement of ANON para 13, paras 15-16 WITN1274001

663 Written Statement of ANON paras 24-26 WITN1365001

664 ANON Transcript 8 July 2019 pp122-125 INQY1000029

665 Written Statement of Perry Evans para 24 WITN1212001

666 Written Statement of Matthew Merry para 47 WITN1389001

667 Written Statement of Simon Merry para 68 WITN1390001

668 Written Statement of ANON para 5.10 WITN2487001

anything. I felt awful so I can only imagine how bad she felt.”<sup>669</sup> When Moira Oldfield gave birth to her first son, her husband’s HIV infection meant she was put:

*“in a room on my own with a yellow sign outside the door saying ‘do not enter’. They gave me food on paper plates and plastic cutlery. The doctor also came in wearing gloves and the nurses were wearing long robes and goggles, which I was quite embarrassed about. They even removed the shelves, trollies and other equipment out of the room and just left a bed for me inside the room. Everything they could move they moved so that they could clean the room with bleach once I had given birth. This came as a shock for me as I was not infected with HIV and the doctors and nurses were fully aware of this.”*

The same thing happened when she gave birth to her second son just over a year later. Her husband died a month after this.<sup>670</sup>

David Pescod was diagnosed with Hepatitis C a few weeks before his wife gave birth to their son. He says:

*“I was desperate to be at the birth of my son. The doctors remained ambiguous about whether I was allowed to attend the birth and told me it was subject to negotiation ... When I was later told that I would not be allowed to attend I was absolutely devastated. I swore at the doctors with words I rarely use in public and I was overcome with emotion. I had been so intent on being there for the birth ... that we had not made any back-up plans for other attendants to be with my wife; my wife therefore had to give birth alone.”<sup>671</sup>*

Kathryn Croucher’s late husband was not allowed to be in theatre for the birth of their son by caesarean section because he had been infected with HIV and Hepatitis C.<sup>672</sup>

## Fear of infecting others

The fear of infecting others, particularly children, partners or grandchildren has been immense for many of those infected with HIV or hepatitis. Sean Nevin has described *“the day to day issues of living with haemophilia and Hepatitis C have been a nightmare. Before I cleared the virus I worried about every small bleed ... as they all presented the opportunity to leave spots and smears of contaminated blood around.”<sup>673</sup>* Joseph Pisharello describes his worry about infecting his children: *“I held back in being affectionate with them. I was cautious enough not to even kiss and cuddle my own daughter.”<sup>674</sup>* One woman describes how her son *“stopped talking and started communicating by writing things down instead*

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669 Written Statement of ANON para 25 WITN1399001

670 Written Statement of Moira Oldfield para 24, para 26 WITN1443001

671 Written Statement of David Pescod paras 19-20 WITN1464001

672 Written Statement of Kathryn Croucher para 17 WITN1346001

673 Written Statement of Sean Nevin para 48 WITN1425001

674 Written Statement of Joseph Pisharello para 21 WITN1469001

*because he was worried that he would infect one of us with HIV through spit or air. He was silent for two and a half years.” He died aged 29.*<sup>675</sup>

Maria Mooraby was diagnosed with Hepatitis C: *“I felt infectious and dirty. I went over and above what I was advised to do because I was terrified of transmitting the virus to others. I was caring for grandchildren then and I became obsessive with cleaning and not sharing utensils, cutlery and plates. This also extended to not sharing towels, razors and toothbrushes with my husband.”*<sup>676</sup> One man describes how once he was diagnosed with Hepatitis C, *“I had to have my own things such as cutlery, towels, toothpaste and my clothes were washed separately. I felt like a leper, even though unbeknown to anyone I had had the virus for years.”*<sup>677</sup> Edward Rippingale-Combes was not told about the Hepatitis C infection until the mid 1990s. He subsequently self-cleared. Nevertheless: *“I remember I had an accident cutting out a wooden duck in woodwork at school (in year 8 or year 9) and bleeding everywhere. I break out in a cold sweat when I think of how I would have put others at risk.”*<sup>678</sup>

One man describes his wife discovering she had been infected with HIV by a former partner who had been infected through blood products. When she gave birth to their son, they both became unwell and tested positive for HIV. She and their son died shortly afterwards. He says: *“[my wife] had a constant feeling of guilt that she had passed the infection on to [our son]. It was life changing and the focus was on the two of them for however long it was going to be, by the time they passed away I was prepared for it, in those days the diagnosis was a death sentence anyway, so it was just a matter of how long ... The diagnosis took a great mental toll on [my wife] as she could never overcome the guilt of infecting our boy.”*<sup>679</sup>

The wife of a man who had been infected through blood products discovered she had Hepatitis C during her pregnancy with their second child. He says:

*“I was responsible for her infection, and the clinicians supported this, telling her that I had been the source. I felt dreadful, one of my longstanding fears, that of passing an infection on to another, had come to fruition. My feelings weren’t helped when my wife, having been told of her HCV diagnosis, told me that she felt she had been handed a death sentence. Guilt metaphorically crippled me, it was a really tough time in our lives and I continue to hear her words to me to this day.”*

The marriage ended some years later.<sup>680</sup>

Catherine Moy’s brother was infected with HIV and Hepatitis C through blood products:

*“Over the course of Andrew’s treatment of Factor VIII he met his wife, Tina. Unaware that he was HIV and hepatitis C positive, he infected Tina. Around 1994*

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675 Written Statement of ANON para 59, para 75 WITN3772001

676 Written Statement of Maria Mooraby para 23 WITN6155001

677 Written Statement of ANON para 58 WITN4864001

678 Written Statement of Edward Rippingale-Combes para 14 WITN7025001

679 Written Statement of ANON paras 14-15 WITN7235001

680 Written Statement of ANON paras 123-124 WITN0325001

*Tina began to lose a lot of weight and became very unwell. Tina died from AIDS in June 1995. Although Andrew was unaware that he was HIV positive when he met Tina, I know that he would have felt very guilty having infected her. They had been dating each other for a while and had married only 6 weeks before she died. After Tina's death, Andrew was absolutely devastated and began to see a counsellor. It must have caused him a tremendous amount of anxiety to witness her death knowing that his health would deteriorate in the same way.”<sup>681</sup>*

One woman describes the death of her brother, infected with HIV and Hepatitis C:

*“The physical effects of the AIDS on my brother were profound and devastating. In the few years from when he was told about his infection until his death he experienced a massive decline in his condition. He was bloated because of all of the drugs, he was in a wheelchair, he had a fungal infection in his lungs, he lost a lot of weight and was emaciated towards the end. My brother's infection also had a severe psychological impact on him, he knew that he was dying and he was deeply worried about his wife [who had been infected with HIV through him]. My brother died thinking that his wife may die of the same thing.”<sup>682</sup>*

One woman describes her husband, who was infected with HIV from Factor 8, fearing she would also become infected with HIV: *“The mental effects of [my husband's] infection were very traumatic for both of us ... [His] infection appeared to us to be a death sentence. [He] worried that our children would be orphaned and what would become of them.”<sup>683</sup>*

Some people never felt able to tell their partners about their infections. Bernadine Rushton was infected with HIV by her first husband, Kevin. She attended a routine appointment with him and told the doctor that they were getting married. She was advised to have an HIV test; this was the first time she knew that Kevin was HIV positive. Her HIV test came back positive. She says: *“I could not believe that Kevin had infected me with HIV, that he knew he had HIV before he met me, and that he had withheld this information. I was distraught, mad and I lost my temper with him ... He was aware of his diagnosis, but I do not know what he was told by doctors in regard to infecting others. He would not wear a condom.”* Bernadine was pregnant at the time of her diagnosis and states that she was immediately told she had to have a termination and was not given any choice in the matter. She was also sterilised.<sup>684</sup>

## Stigma

### HIV

The stigma experienced by people infected with HIV and their families was devastating and continues to this day. The adverts on TV and in other media warning people about AIDS

681 Written Statement of Catherine Moy paras 16-17 WITN0879001

682 Written Statement of ANON paras 22-23 WITN0128001

683 Written Statement of ANON paras 5.1-5.2 WITN0047001

684 Written Statement of Bernadine Rushton paras 10-11 WITN0134001

meant that anyone known to be infected was socially isolated and at times, subjected to dreadful treatment. Comments from well-known figures were expressed in extreme terms. The impact on mental health, and personal and family lives was appalling. Very many families did not admit that their loved one had HIV, which added to the already substantial psychological burden. Parents would sometimes keep it secret from their own children; when acquaintances asked about apparent ill health, it might be described as cancer, to avoid the stigma that came with HIV or hepatitis. Infected individuals would hide it from their own parents. To many it felt like living a lie – indeed, it was just that although for entirely understandable reasons. Concerns about the consequences of being open about their illness meant that they had all the added pressures of hiding it from others. Many people have – understandably – chosen to remain anonymous during the Inquiry process because they continue to keep their infection a secret. Some have explained that they dare not, even now, let those who live close to them become aware that for years they have struggled with the infection.

One man, infected with HIV and Hepatitis C from blood products, describes being diagnosed with HIV as *“like being given a life sentence and my life changed overnight. HIV/AIDS was on the cover of every newspaper with celebrities’ deaths reported regularly. I vividly remember one story in a newspaper suggesting that all those infected should be moved to the Isle of Wight!”*<sup>685</sup> Mr AK felt unable to tell his parents of his infection with HIV – his mother *“would have felt so guilty because she would have thought it was her fault, even though it wasn’t”*; he did not tell other family members for years, or friends: *“My life since infection has been a lie.”*<sup>686</sup>

Helen Martin, speaking of the deaths of her brothers and fiancé from infected blood products, says that: *“A phrase that was in popular use was, ‘Good AIDS and Bad AIDS’, i.e. poor souls like my brothers who did not deserve it whilst others whose lifestyle choices somehow meant they did, could suffer and die without anyone caring. The reality was society at large ... really didn’t give a damn which group you were in, you had it and therefore must be shunned, consequently you said nothing. Let’s face it, good or bad you were just as infectious and dangerous to know and were of course going to be just as dead.”*<sup>687</sup>

One woman describes how she and her late husband were told his diagnosis at the height of the Government’s public health campaign:

*“The absolute horror of being told, along with having to keep quiet, was difficult. We didn’t tell anyone of [his] HIV status for 5 years, not even his mum or dad ... It was only in the last 12 months of his life when there was definitely no mistake of his condition, that we told them. We lived a lie for 5 years, lying to friends and family. The weight of the secret was a strain in its own right and unfortunately put pressure on our own relationship ... It is difficult to capture that moment*

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685 Written Statement of ANON para 9 WITN1430001

686 ANON Transcript 11 October 2019 pp188-190 INQY1000040

687 Written Statement of Helen Martin para 81 WITN0085001

*in time; the stigma associated with HIV/AIDS and the resulting overwhelming social isolation.”*<sup>688</sup>

Another woman, whose late husband was infected with HIV from blood products, describes how *“Living in silence due to the media pressure, fear of discovery, stigma and prospect of ostracisation, due to the diagnosis, was a further burden to carry. The campaigns which were undertaken by the Department of Health created hysteria, to the extent that sufferers were ostracised in the community if their diagnosis was made public.”*<sup>689</sup> Ian Jones said: *“The stigma associated with HIV and Hep C was devastating. I would deny having HIV and just bottled it up. When it came to light that haemophiliacs had been infected, I just lied and said I was one of the lucky ones that was not infected. At the time my children were starting school and I did not want it to affect them.”*<sup>690</sup> Since giving his statement Ian has died.

One woman was questioned *“in the local village shop if I had AIDS and the girls were asked the same thing at school. They often came home crying. To protect myself and my daughters I just told people that [my husband] had died of leukaemia.”* Her husband had died of AIDS, contracted through blood products for severe Haemophilia A.<sup>691</sup> Laura Lysons describes that *“a rumour later went round the school that my Dad was a drug dealer because he wasn’t working and people didn’t know how he got his money. It was humiliating for me and I felt very isolated throughout my time at school.”* Her father had been infected with HIV and Hepatitis C through blood products.<sup>692</sup> For Janette Johnson, it was *“heart breaking”* to see her son, Graham, *“come home upset after school, and in tears, every day because the other children had been so cruel to him. They used to call him Rock Hudson.”*<sup>693</sup> His sister was also *“taunted because her brother had AIDS.”* He died aged 15 from AIDS. He had been infected with HIV through blood products.<sup>694</sup>

Another woman, infected with HIV through transfusion, describes how worried she was about people finding out she was HIV positive: *“HIV isn’t like other illnesses. People always think ‘what has she been up to?’”*<sup>695</sup> Another man, coinfecting with HIV and Hepatitis C, explains how he will *“constantly worry if my post is delivered mistakenly to another person on my street. I worry that my neighbours will mistakenly open my letters from the hospital and find out about my medical condition. I worry about what people would say and how they would react if they find out about my situation. In an ideal world I would want to move somewhere where it is just me by myself.”*<sup>696</sup> Alison Bennett said that their neighbours’ two

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688 Written Statement of ANON paras 35-36, para 38 WITN1470001

689 Written Statement of ANON para 16 WITN0597001

690 Written Statement of Ian Jones para 38 WITN1316001

691 Written Statement of ANON para 43 WITN1403001

692 Written Statement of Laura Lysons para 11 WITN1358001

693 Rock Hudson, the film star, was an early victim of AIDS.

694 Written Statement of Janette Johnson para 27, para 29 WITN1755001

695 Written Statement of ANON para 10.2 WITN0021001

696 Written Statement of ANON para 36 WITN1345001

boys were “*constant companions*” of both her children but once their parents learned of her son Alistair’s diagnosis with HIV from infected blood products “*they cut us off totally.*”<sup>697</sup>

One woman, infected with HIV from a blood transfusion in childhood in 1981, learned that she was HIV positive when a university student in the 1990s. Attending the HIV clinic, she would be tested for syphilis and other sexually transmitted infections, which “*made her feel awful ... they insinuated that it was her lifestyle that caused the HIV infection. We could never understand where it came from, and every medical professional we spoke to refused to acknowledge that it could have been a result of the transfusion she had received.*” Her experience was that “*When you tell people that you have been diagnosed with HIV, they either treat you like a biohazard or run a mile.*” For years she blamed herself, until it was finally confirmed in 2019 that the transfusion was the cause.<sup>698</sup>

Social isolation once people knew about a person’s infection was profound. One woman describes that after her late husband’s diagnosis with HIV: “*His friends cut him off once they heard about his infection. He didn’t tell them, but word got around in our village and so he became ostracised very quickly. People even used to say nasty comments to him so he simply stopped going out.*”<sup>699</sup> Graham Lawton was infected with HIV through blood products and says: “*I told my friends as soon as I was told I had HIV. The word soon spreads. I recall having a drink just after I was told at a pub run by friend’s girlfriend’s parents. I looked back into the kitchen after he had collected our glasses and saw him drop my glass into the bin. He did the same with my next drink.*”<sup>700</sup>

Adrian Goodyear, who was infected with HIV through blood products while attending Treloar’s, says:

*“I fell out further with my mum because I didn’t want to go out because of the taunts. My mum didn’t appreciate this. When I had told my mum about my infections, she went and told everyone on our home street that I was infected ... When I went home for leave weekends, half terms and the school holidays, I was taunted with daily chants of ‘hey Ade, you got AIDS yet’ and ‘Live AIDS coming’ which was a pun on my name ‘Ade’. Others shouted at Mum ‘we know what your sons got’, ‘G.A.Y – Got Aids Yet?’ which brought shame on the family. I didn’t know what to do; I was so isolated and alone that it was heart breaking if it was happening to another, let alone it happening to me. I could no longer go out in the surrounding areas ... It was relentless but I kept that a secret due to embarrassment.”*<sup>701</sup>

Another man says:

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697 Written Statement of Alison Bennett para 5.5 WITN0553001

698 Written Statement of ANON para 19, paras 52-53 WITN0929001, Written Statement of ANON paras 41-43 WITN0930001

699 Written Statement of ANON para 29 WITN1347001

700 Written Statement of Graham Lawton para 21 WITN1341001

701 Written Statement of Adrian Goodyear paras 57-58 WITN1243001

*“Other than my parents (now deceased), only my Haemophilia Centre and my specialist Dental Hospital (built alongside my Centre) knew of my co-infection. It was in fact, only in very recent years that I felt it was time to confide in my local GP, bearing in mind I live in a small market town ... This resulted in many decades of secrecy, barefaced lies, and suffering in silence. Even to this day, my elder brother is wholly unaware of my co-infection, my treatment regime, and the side effects ... As soon as I was told of my HIV positivity, I resigned myself to a life of living alone, ending close friendships and probable relationships. I would not have a wife and children, no daughter-in-law and grandchildren for my parents, and no nephews or nieces to grow up alongside, play and interact with my brother’s children.”*<sup>702</sup>

In some communities, there were additional difficulties relating to cultural differences. Nayna Alonso describes that for her husband:

*“Coming from an Indian background and living in an Indian community, he was looked down on just for having Haemophilia. If people knew about his HIV infection he would have been excluded, it became our biggest secret. There was a lot of incorrect information around and people were scared. To this day Praful’s parents do not fully understand the consequences of HIV ... I think a lot of the problems came from our culture. In the Indian community Haemophiliacs and other disabled people are considered to be less and are looked down on by certain members of the community. Some even consider them to be cursed people and that the illness occurred as a result of Karma for something bad that the family did in the past.”*<sup>703</sup>

Sheila Patel describes losing her husband, Girish, to HIV and says *“In Indian society, you lose a certain level of respect when you lose your husband, and I felt that his family began to look down on us a little bit.”*<sup>704</sup> Another man has told his parents of his HIV infection but says *“The issue of my HIV status is taboo and not discussed outside of the family. We have kept it to ourselves because of the stigma and out of fear of being ostracised and/or abused. My HIV status would not be understood or tolerated within my culture.”*<sup>705</sup>

Mark Ward and Richard Dudley-Smith reflected on the particular challenges for Mark of being a gay person with haemophilia who was infected with HIV and the lack of acceptance of his sexuality and Richard’s existence as his partner in their interactions with the health service: *“The institutionalised homophobic attitudes, who never even recorded their existence, is as relevant today as it has ever been. Judging people based solely on others’ beliefs is unacceptable ... I was effectively abandoned, isolated and seen as a figure of hate by some.”*<sup>706</sup>

702 Written Statement of ANON para 25, paras 27-28 WITN0218001

703 Written Statement of Nayna Alonso para 15, para 17 WITN1075001

704 Written Statement of Sheila Patel para 44 WITN3146001

705 Written Statement of ANON para 16 WITN2760001

706 Mark Ward and Richard Dudley-Smith Transcript 17 October 2019 p130, p138 INQY1000043



Even within families, HIV was kept secret: one woman, whose husband was infected with Hepatitis C through blood products, describes that “we were shocked when [his brother] died as we later found out that his death was due to HIV and HCV. [His brother] had told no one about his infections.”<sup>707</sup> Another man has never told his sons about his infection and describes that: “Now I have to hide this big scandal from my sons which is very hard for me and my wife. When anything related to this Inquiry is on TV, I have to keep my feelings and emotions hidden. I have kept it a secret since I was 14 years old which has been playing on my mind and is very stressful.”<sup>708</sup> One woman’s husband decided not to tell anyone about his HIV infection: “[He] did not want to tell any family members about his infection. I do not know whether this was because he was ashamed or because he just didn’t want them to know he was ill. He put it all on my shoulders and I did not know how to deal with it. We had a very close family but I could not speak [to] them ... Or confide in them about it. Not even [my husband’s] mother knew anything about his infection until the day he died.”<sup>709</sup>

At times, the treatment of people who were infected was brutal. Margaret Madden, whose young son was infected with AIDS, says:

*“We lived in the farmhouse for about 6 months. One day I received a letter from the farmer asking us to vacate the property immediately. Apparently, someone had told him that Daniel had AIDS and he was worried that he could contaminate his stock of 2000 turkeys. I did not know how the information got to the farmer as the only people that knew about his condition were the social security and the local social worker. A couple of days later my car was vandalised and my tyres were slashed. The word AIDS was daubed down the side of it ... We were homeless for about two weeks and lived in my car. Eventually I found a property to rent and we were able to move ... We stayed for approximately three months and then we were back to the same situation as we were at the farmhouse. The neighbours found out about Daniel’s illness and were making our lives hell. We had the word ‘AIDS’ sprayed on the front door and someone even tried to set fire to the house whilst we were in ... Again we were homeless and searching yet again for a place to live. This was becoming a recurring nightmare and in total it happened 4 times. I remember going to the local shop and I was served first, so I would not contaminate anyone. The shop keeper tipped the change into my hands from height, so he did not have to touch me. Sometimes the money would fall to the floor and I would scrabble around the floor to pick it up. I was treated as though I had leprosy.”<sup>710</sup>*

Colin Smith described people finding out that their young son, Colin, had HIV, and “I got up one morning and there ‘AIDS dead’ written across the side of the house in good six foot letters, so I’m painting that out. The following day there was ‘AIDS dead’ scratched into the

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707 Written Statement of ANON para 8 WITN1278001

708 Written Statement of ANON para 21 WITN1286001

709 Written Statement of ANON para 21 WITN1537001

710 Written Statement of Margaret Madden paras 64-69 WITN1364001

*front door with a big cross ... Then 'AIDS dead' scratched on the car. Constant phone calls day and night, he should be put down, put on an island, shouldn't be allowed to sleep with his brothers. It just went on and on ... we decided to move.*"<sup>711</sup>

Alison Morris explains what happened around the time of her brother-in-law's death from HIV and Hepatitis C: *"Before and after Jeff died we received loads of silent phone calls. We had over 20 silent phone calls; all hours of the day and night. We had to tell the children not to answer the phone. I bought a whistle and left it by the phone and then whenever the phone rang and no one spoke we would blow the whistle! We never found out who did this but it must have been someone we knew, who knew that we had to answer the phone in case we were needed."*<sup>712</sup> Helen Northwood's late husband Gary was infected with HIV and Hepatitis C through blood products. They sought to keep his HIV infection quiet but she says:

*"it obviously was realised in the community that Gary was a person with Haemophilia and possibly that he had developed AIDS. Then the notes started coming through the letterbox with the words 'AIDS' on them, 'Scum'. In addition, notes came through with 'Homo', 'Homosexual' etc. Even on one occasion, dog faeces was put through the letterbox. No greater sense of social isolation, ostracisation and condemnation by a community can occur to any family than what occurred to us during that time. It emphasised Gary's illness, his different situation, exacerbated our fears and caused huge concerns in relation to our children's welfare."*<sup>713</sup>

Sandra King describes the stigma she and her husband Jon faced in their neighbourhood after she was dismissed from her job when the business owner discovered he had HIV:

*"The next day I got a call from the owner ... who ... told me that the girls [at the business] weren't comfortable working with me and not to bother going in. We went to the press as we were so outraged that I had lost my job as a result of this, but I regret doing that now. We were completely hounded by the community who threw eggs and flour at the house. People would point at us in the street and avoid us in town; we had abusive letters put through the letterbox. I wish I still had the letters to demonstrate just how nasty they were, but Jon ripped them up at the time. Eventually we pulled the phone socket out of the wall because of the abusive phone calls we were getting."*<sup>714</sup>

Many people consider that the media has a lot to answer for in stirring up the stigma and ostracisation they suffered. One woman, who was infected with HIV after her husband was infected through blood products, recalls a day in 1986-88 when she says: *"I had a call from Dr Peter Jones 'There has been a leak'. He called me and [her husband] and said 'the press could be outside your door. Do not answer the door. Just call the centre. We are not 100%*

711 Colin Smith Transcript 24 July 2019 p19 INQY1000034

712 Written Statement of Alison Morris para 18 WITN0759001

713 Written Statement of Helen Northwood paras 32-34 WITN1046001

714 Written Statement of Sandra King paras 26-27 WITN1678001

*sure if your name is on it'. All we knew was that somebody may have said something to the press or that someone had got data and information about those infected with HIV. I had a new baby and this was very worrying.*"<sup>715</sup> Rebecca Ward has provided a statement about her partner, David who died of a cerebral haemorrhage, having been infected with HIV and Hepatitis C by blood products. In her statement, she has provided notes that his dad, Tom, wrote before he died:

*"As a child, young boy and teenager the mental anguish resulting from taunts by his peers was massive. Ignorance and press coverage has a lot to answer for. I lost count of the number of times David came home from school, either in tears or very upset as a result of name calling ... I even visited the Royal Grammar School on two occasions to complain about the behaviour of some of his classmates resulting in David wishing to leave the school ... It is almost impossible to communicate how traumatic the impact of being infected with HIV [and] HCV was. Not only did his friends, school peers and acquaintances almost treat the condition as a form of leprosy, but every newspaper was running scare stories, comedians on TV regularly told jokes about AIDS, TV advertising was running ads to scare people. There was no escape from a constant and negative stream of information, most communicating that to be HIV positive was like a death sentence."*<sup>716</sup>

The stigma extended to how people infected with HIV were treated by health professionals. One person says: *"I noticed a bright red sticker on my medical notes. I believe this was a warning for the doctors to show that I had HIV. I understand why they needed the warning, but it made me feel very isolated."*<sup>717</sup> Another man describes his mother discharging his father from hospital when he was dying of AIDS *"because of the way he was being treated by the medical staff when he was in hospital. Whenever anyone came to treat him they would wear full gowns, gloves and masks. My mother told me she used to hear the staff talking about us. Our whole family were treated like we were infected and dangerous."*<sup>718</sup> Jane Campbell struggled to find carers to come in and help her (she has a degenerative condition) or her husband Graham, who had AIDS: *"I chose to tell people [about Graham's AIDS] and mostly they didn't want to work for us ... we had actually very little support and Graham would struggle to help me and I would struggle to help him. We struggled on together really. It was hard."*<sup>719</sup>

Elaine Feterston's brother was infected with HIV from blood products and was admitted into hospital after a fall. When she went to visit him, she says:

*"I had to wear a mask, gown and gloves to enter the room, and the entrance to the room had a prominent sign on it warning that Kevin was an 'infection risk' or*

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715 Written Statement of ANON para 26 WITN0424001

716 Written Statement of Rebecca Ward para 24 WITN0870001

717 Written Statement of ANON para 29 WITN1282001

718 Written Statement of ANON para 23 WITN1250001

719 Baroness Jane Campbell Transcript 9 October 2019 pp163-164 INQY1000038

*something similar. My auntie was also there and told us that she had to clean the room before we got there because it was covered in swabs, plasters and bandages. She had made a complaint to the hospital about this before we arrived. The next day, I returned to visit Kevin with Mum and the room was disgusting again. My auntie said this was unacceptable and again made a complaint to the hospital. When she did so, she was told that one of the cleaners had learnt of Kevin's HIV status and had refused to clean his room, presumably the rest of the cleaning staff followed suit. I was heartbroken by the state of the room. I was disgusted that no one would clean it except his own family."*<sup>720</sup>

A father describes the treatment of his son:

*"[He] had numerous hospital admissions in The Royal Liverpool Hospital where he was treated very badly and received extremely poor standards of care. It was horrendous. It was as if the nurses had nothing but contempt for the patients. It was necessary for me to visit him every day to ensure he was eating properly, he was washed properly and that he was receiving and taking his medication. There were many times his medication was strewn all over the floor and I would have to make arrangements to get it replaced. I would shower him when he was too weak to do it for himself and change his bed sheets after he had soiled himself and was lying in the dirt for hours at a time."*<sup>721</sup>

When Amanda Weaving's dad died of HIV, he wore gloves to hold her mum's hand. She says: *"In your dying days to have no human contact must be awful. It ripped the family to pieces."*<sup>722</sup>

There were also practical implications of speaking up about having the infection in terms of losing insurance or mortgage cover. Amanda Patton's brother Simon was infected with HIV and Hepatitis C through Factor 8 treatments. He was a radio presenter and *"He would talk openly about haemophilia but he could not talk about the HIV infection, particularly when it became associated with AIDS. He was known to have a 'long-standing illness' and nothing more. He would not mention AIDS publicly for fear of nullifying his life insurance."*<sup>723</sup>

## Hepatitis B and C

Hepatitis also carried and continues to carry stigma. This is largely because of the association in peoples' minds of hepatitis with HIV, or with promiscuity, intravenous drug use or alcohol addiction.

One woman who contracted Hepatitis C from blood transfusions during jaw surgery, says: *"I did not want anyone to find out as we live in a small village and I was scared that if people did find out they would think I was an ex-drug addict and would avoid all interaction*

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720 Written Statement of Elaine Feterston paras 32-34 WITN7657001

721 Written Statement of ANON para 31 WITN1147001

722 Written Statement of Amanda Weaving para 29 WITN1595001

723 Written Statement of Amanda Patton para 38 WITN0042001

*with me.*<sup>724</sup> Catherine Guthrie, who contracted Hepatitis B from blood transfusions, says that in her small town it was well known that she had hepatitis: *“I recall that people would cross the street away from me and I was treated like a leper”,* with people saying *“don’t go near her, she’s got Hepatitis’.*<sup>725</sup> John Thorneycroft also relates his reticence about telling anyone about his condition to his belief that *“people related those infected with Hepatitis to sharing needles and drugs.”*<sup>726</sup> As Lee Coverdale describes, *“people automatically assume you have it from drug abuse. Even now when I tell people I have had liver transplants they assume it must be because I drink a lot.”*<sup>727</sup>

For Paul Walker, infected with Hepatitis C through treatment for von Willebrand disorder:

*“The diagnosis came as a shock and was a huge blow at the time. In those days not much was known about HCV, but it was very much associated with drug abuse and promiscuous sex. The latter came into the mix for myself, as I am gay ... Being gay made everything much more difficult, and contributed to my decision not to be open about my infection with HCV. People would have thought it was because of all the wrong reasons. The stigma around HIV had moved on a little bit at the time but it was still around. I therefore kept my diagnosis to myself, unless I had to.”*<sup>728</sup>

Charles Dowden’s wife, Gilly, had been told she was an alcoholic for seventeen years until a doctor confirmed there was no apparent reason for Gilly’s supposed alcoholism: *“Over the years ... I had turned the house upside down looking for hidden alcohol, but never found anything. Furthermore, by this point, Gilly had been in hospital for 2-3 days and the nurse was saying that she was still showing signs of being drunk.”* The doctor agreed to review her notes fully then tested her for Hepatitis C and she was positive.<sup>729</sup> Alison Brooks was infected with Hepatitis C from a blood transfusion during an emergency caesarean section. She says: *“People usually assume that hepatitis has come from IV drug use, so I feel like I have to justify myself to people. However, I don’t think I should have to give people such personal information just to prove that I’m not at fault for having this virus.”*<sup>730</sup> Kathleen Locke states that she *“felt that there was a stigma attached to my father’s condition and this began when he was accused of being an alcoholic”*. In fact, he was suffering from cirrhosis, arising from Hepatitis C that he contracted from blood products used to treat von Willebrand disorder.<sup>731</sup> Another woman describes how as her father’s Hepatitis C infection progressed and his liver became more damaged: *“on his bad days he would be very yellow with jaundice and people would automatically assume he had an alcohol addiction and so his condition was brought on by himself. I found it very frustrating as people would comment and presume my dad was*

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724 Written Statement of ANON para 20 WITN0314001

725 Written Statement of Catherine Guthrie para 21 WITN7499001

726 Written Statement of John Thorneycroft para 29 WITN0329001

727 Written Statement of Lee Coverdale para 38 WITN3220001

728 Written Statement of Paul Walker para 22, para 37 WITN0275001

729 Written Statement of Charles Dowden para 21 WITN1867001

730 Written Statement of Alison Brooks para 48 WITN3693001

731 Written Statement of Kathleen Locke para 55 WITN0049001

*an alcoholic.*<sup>732</sup> Richard Kellett-Clarke's brother was "found to have cirrhosis of the liver but to add to the distress of his ordeal he was treated ... as though he had brought the condition on himself through alcohol abuse."<sup>733</sup>

One man who has died since giving his statement said he would have "liked to be told about the stigma around HBV so that I could be prepared for that ... Mentally, I have always felt as if I was carrying a secret. I was always ashamed of having to keep the infection secret at work and with friends but have to declare it to sexual partners."<sup>734</sup> Another man infected with Hepatitis C through blood products says that "I generally feel ashamed of my infection; I have been made to feel as though I have done something wrong."<sup>735</sup>

One woman who was infected with Hepatitis C following treatment with blood products for von Willebrand disorder was stigmatised when she gave birth to her first child in 1995:

*"I was given my own side ward and my own bathroom with 'Hazard' in big, bold writing on yellow signs placed on the doors, and I wasn't allowed to eat with the other ladies. I had to eat and stay in my room, basically, and do everything I had to do in there. All my bedding was put into hazard bags. All my son's bedding was put into hazard bags, even though at this point he hadn't been tested, and then specifically one night I hear crying. All the children were always put in the nursery at night-time and I looked out of my door and my son was in the corridor. And when I asked why he was in the corridor I was told he had a slight cough, which he didn't have."*<sup>736</sup>

Due to the stigma, many people chose not to tell others about their infection. One man, who had a transfusion after being set upon by a gang and requiring facial reconstruction, says: "When people find out that you have HCV, they don't want to know you. They are scared to touch you. There is unquestionably a stigma associated with HCV. I don't hug or kiss people because of the fear of transmitting the virus. As a result I chose not to tell people that I had HCV. I was always careful around people, being mindful not to physically touch other people ... HCV made me feel and most likely appear socially awkward."<sup>737</sup> Linda Kitson, who was infected with Hepatitis B from a blood transfusion in 1979 but not diagnosed until 2017 says "I do think there is still a stigma around having hepatitis. As I began to tell people about my infection, a few people started to look at me differently and appeared to be worried they would catch it ... I keep it to myself now."<sup>738</sup> Another man says that he avoided suffering from stigma "because I did not tell a soul about my Hepatitis C and I shied away from intimate relationships until I cleared the virus."<sup>739</sup>

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732 Written Statement of ANON para 17 WITN1419001

733 Written Statement of Richard Kellett-Clarke para 24 WITN1323001

734 Written Statement of ANON para 12, para 19 WITN1951001

735 Written Statement of ANON para 22 WITN1457001

736 ANON Transcript 21 May 2019 p89 INQY1000009

737 Written Statement of ANON para 42 WITN4313001

738 Written Statement of Linda Kitson para 34 WITN2641001

739 Written Statement of ANON para 21 WITN1441001

One man says *“For over 35 years my wife, children and I have been unable to talk openly with family and friends about what I went through; it still worries me what they might think about me should they find out and I am still concerned about the stigma associated with having HCV.”*<sup>740</sup>

Derek Wherry states that *“Trying to live through the stigma and maintain a positive image for myself was very difficult. I wonder if sometimes I used the virus as an excuse and blamed a little too much on it. I sometimes look back on my life and question the decisions I have made. It is only recently that I have managed to get stability. Hepatitis C defined me for 25 years of my life. I have always felt completely ostracised from society because of it. I have always felt so alone.”*<sup>741</sup> A man who was infected with Hepatitis C through blood transfusions after a road traffic accident was advised not to tell anyone about his infection: *“Because of these concerns, only my mother, sister, ex-wife and present partner know about my infection ... I have put away this ‘secret’ and kept it in a box. It has been a constant cloud hanging over me which has had a debilitating and corrosive effect on my entire life”*.<sup>742</sup>

Other people faced overtly aggressive behaviour from their community. One man explains that he and his brothers *“grew up on a council estate and it often came up on the news that haemophiliacs had HIV and Hepatitis in the mid 80’s, we had shit thrown at our door. Where I live now there was a local petition for me to be moved. There was panic and ignorance, it was a terrible time.”*<sup>743</sup>

The treatment of people with Hepatitis C in hospitals often emphasised the stigma. Valerie Hipwell recalls: *“[I was placed in] an isolation ward when I was in hospital for operations or treatment for fear that I would infect other patients or the hospital staff ... In my presence, [hospital staff] were instructed to wear all the protective gear and in a very public and humiliating way.”*<sup>744</sup> Paul Ledger says that *“it also used to bug me that I had to have a yellow sticker with red writing on my medical notes which stated ‘Risk of Hep C’, I felt as though I was black listed. That message was always on my notes. When I was at Basingstoke and North Hampshire Hospital, I used to be put in a room on my own as I was a risk for transmitting infection. This added to my feelings of [being] isolated and labelled.”*<sup>745</sup> Jonathan Colam-French, who is gay, says that he was referred to a hepatologist in relation to his Hepatitis C and that *“the attitude of the consultant was appalling. The NHS had caused my infection but the consultant appeared to have a problem with my sexuality and considered that it was more likely the infection had been caused by my lifestyle.”*<sup>746</sup>

Many liver clinics did not differentiate between people who had been infected through blood and blood products, and people infected through other routes. Many Inquiry participants

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740 Written Statement of ANON para 27 WITN1718001

741 Written Statement of Derek Wherry paras 57-58 WITN0097001

742 Written Statement of ANON paras 11-12 WITN0215001

743 Written Statement of ANON para 24 WITN0006001

744 Written Statement of Valerie Hipwell para 5.15 WITN0080001

745 Written Statement of Paul Ledger para 39 WITN0151001

746 Written Statement of Jonathan Colam-French para 18 WITN2736001

found that this added to their feelings of stigma and ostracisation from society. One woman says she *“hated going to the liver ward at King’s. There were always people that were obviously alcoholics; quite regularly there were prisoners handcuffed to prison warders and once there was a woman covered from head to toe in tattoos. I hated being considered one of them. I felt dirty; really really dirty.”*<sup>747</sup> David Rogers, who has mild haemophilia and was infected with Hepatitis C, describes that *“Later, when I began attending the liver clinic for regular blood tests with my wife, the waiting room was full of people from prison and drug addicts. It was an awful experience and in the beginning I felt that I was treated as if being infected with Hepatitis C was my own fault. Also my notes when I went for blood tests always had a yellow sticky note on it which said ‘Danger infected’. This was awful to see.”*<sup>748</sup>

Other agencies did not help with their response to managing the disposal of bodily fluids. One man who required a liver transplant having contracted Hepatitis C had a bad experience with his council:

*“After I had my liver transplant I had a bag attached to me collecting bodily fluids. One night the bag burst flooding the mattress which became sodden. I called the Council to take it away and [my wife] explained I had HCV as I was worried about others being infected. They arrived in a huge truck with a big ‘Bio Hazard’ sign on it and they parked right outside my house. They came into the house wearing masks and hazard suits, cut the mattress up, put it in plastic bags and took it away. They were not discreet about it and some of the neighbours must have seen and I felt really contaminated.”*<sup>749</sup>

The stigma suffered added significantly to people’s psychological burden, both for those infected and their families. David Tonkin explains that the stigma was also felt by his children: *“My daughter often came home crying as kids at school told her I had HIV and she shouldn’t be at the school because she could infect people. My wife and I had to go into the school and speak with her Head of Year and Headmaster to try and deal with the abuse she was receiving.”*<sup>750</sup>

In some communities, the stigma was an additional element to that which they already faced because of their background.

Peter Gardner says that *“Coming from the traveller community, my wife and I are used to being stigmatised. This is something we have had to live with. We don’t label ourselves with this tag, we are just normal people ... Therefore any stigma from having hepatitis, just compounded a general stigma from wider society because we are travellers.”*<sup>751</sup>

Andre Andreou describes the difficulties she and her late husband faced with his infection with Hepatitis C: *“Mario was already disheartened about the fact that he had beta thalassaemia*

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747 Written Statement of ANON para 54 WITN0277001

748 Written Statement of David Rogers para 14 WITN1496001

749 Written Statement of ANON para 71 WITN1853001

750 Written Statement of David Tonkin para 50 WITN1567001

751 Written Statement of Peter Gardner para 46 WITN6222001



*major; there was a big stigma attached to having it and a lot of ignorance around it, especially from his own cultural background. He could not bear the thought of having to tell people that on top of the blood disorder, he had become infected with HCV. Mario developed severe depression in the end”.*<sup>752</sup>

Another woman, infected with Hepatitis C from a blood transfusion during childbirth describes the particular stigma she has suffered in the context of being part of the Asian community and being in a mixed-race marriage:

*“I have experienced further stigma from within the Asian community in relation to my Hepatitis C infection ... Within the Asian community, Hepatitis C and AIDS are often associated with having been with an ‘unfavourable’ partner or lots of partners or with needle use ... It is already difficult to deal with contentious subjects, but the Hepatitis C infection makes it worse ... I feel that there is an unseen burden as a person of colour in needing to subtly adapt in society to make myself seem acceptable sometimes. I have felt like I don’t want to make myself ‘more different’ by bringing up my Hepatitis C infection and health issues because of it. It has added to the effort I feel I need to expend in order to make myself ‘more acceptable’ to people.”*<sup>753</sup>

Two witnesses described the particular difficulties within their communities and with the medical profession. Waqar Ahmad said that he felt *“Ethnic minority, especially from India, Pakistan, Bangladesh, Asia people, as most of their first language has not been English, I think they have been let down ... a lot of times [other patients from my community] have been given a lot of refusal from the hierarchies, from the doctors and that thing, and they have been let down a lot.”*<sup>754</sup> Ghufrana Qureshi said that for her mum:

*“I think in terms of the doctors, they didn’t show any attitude that mum came from Pakistani background or anything like that, ... but what I would like to highlight is that nothing was put in place as a support for mum ... Whether that was because we come from an ethnic minority, because now when I look back, you know there’s lots of support groups, there’s lots of peer support, there is a lot happening now, but why not for the [Black, Asian and minority ethnic] BAME community? Why not for people who don’t speak English? Why not for people who come from a background or come from a country that they don’t know what is available? Nothing was put in place.”*<sup>755</sup>

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752 Written Statement of Andre Andreou para 25 WITN1821001

753 Written Statement of ANON paras 10-12, para 18 WITN0580004

754 Waqar Ahmad Transcript 30 September 2022 pp57-58 INQY1000250

755 Ghufrana Qureshi Transcript 30 September 2022 pp59-60 INQY1000250

## Wider impacts

### Education

One woman says of her son, that when he “*left school at 16, he found it difficult to cope with the fact that he had been infected with contaminated blood. There’s not much incentive to focus on your studies when you have been told you have a death sentence.*”<sup>756</sup> Another woman says that the news of her son’s HIV diagnosis, “*had a devastating psychological effect ... His school attendance was poor and he stopped bothering. He developed a school-related phobia.*”<sup>757</sup>

Another man describes doing very well at school but then dropping out after he was diagnosed with HIV: “*I did not see the point of having an education as the doctors told me that I would be dead before I was 21.*”<sup>758</sup> A man infected with HIV and Hepatitis B says: “*I thought that exams were a waste of time as I would not be around for very long. I attended a few of my O level exams but did not turn up for many of them. My parents received a letter about my exam truancy. They didn’t mind, given the circumstances. I got a B, 3 C’s and 2 F’s in my O levels. I didn’t bother with maths.*”<sup>759</sup> One man was diagnosed with HIV and subsequently Hepatitis C and says: “*Being 17 and being told that you have got eight years left to live is devastating, you don’t feel like there is any point in pursuing a career or going to university.*”<sup>760</sup>

Ill-health also affected people’s ability to complete their education. One man who is infected with HIV and Hepatitis C says: “*pneumonia caused me to have a lot of time off school, which led me not to be able to sit my GCSE exams, as I was unable to study. Therefore I did not finish my GCSEs. I just have a certificate stating I attended the school for 5 years, but I have no official qualifications.*”<sup>761</sup> Mark Harding, who was infected with Hepatitis C, struggled with brain fog:

*“I definitely think my infection had a big impact on my education. All of my school reports stated that I had a lot of promise but just couldn’t stay focused or remember what we had been learning. We could spend 8 weeks on a topic and when [we] came to the exam a month later I had forgotten everything. When I was preparing for my GCSE exams revision was a real struggle. I couldn’t remember anything long term and in the end just revised for things the night before the exam as if I tried to remember things for longer than that I simply forgot them.”*<sup>762</sup>

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756 Written Statement of ANON para 25 WITN2911001

757 Written Statement of ANON para 17 WITN3260001

758 Written Statement of ANON para 37 WITN1282001

759 Written Statement of ANON para 81 WITN1297001

760 Written Statement of ANON para 15 WITN2212001

761 Written Statement of ANON para 27 WITN1465001

762 Written Statement of Mark Harding paras 24-25 WITN1271001

Many children faced bullying at school because of their infections. One man, infected with HIV and Hepatitis C, “suffered terribly” at school. His mother had been “upfront with my headmaster at the junior school and told him about my viruses”. He was bullied and “children would shout ‘he’s got AIDS’ and I was subjected to other horrible things”. When he moved to secondary school, they were not told about his infections and he “managed really well” there.<sup>763</sup>

Richard Newton was bullied at school because of his brother Mark’s infection with HIV/AIDS: “The other kids would shout at me that I had the ‘lurgy’. There was so much ignorance and general lack of awareness. Even the teachers gave me a wide berth.”<sup>764</sup> One woman whose father had Hepatitis C, says: “I experienced bullying at school because of my father’s illness. All sorts of rumours were circulating about my father’s infection and illness, where it had come from and this resulted in me being very much left apart and isolated from everyone. In turn, this impacted my self-esteem and confidence growing up. These are important years of a child’s life when a personality is developed, but this situation has left me traumatized.”<sup>765</sup>

The daughter of a man infected with HIV says that “My school eventually found out about dad having AIDS ... I had to drop subjects or change classes because certain teachers wouldn’t teach me. I had to take months at a time off school partly to visit dad and partly because the school was deciding whether it was safe to have me attend.” After her father’s death she was her mother’s main carer, as a result of which she was unable to complete her university education. Nine and a half years later her mother took her own life.<sup>766</sup>

## Work

Infection with HIV or hepatitis has severely impacted upon people’s ability to secure or remain in employment. A significant number of people faced obstacles to obtaining work because they were required to declare their infections.

Madeleine Blanchard worked for ICI for a number of years but then the family moved. She says: “I struggled to get another office job because the Hepatitis C would not allow me to pass the medical insurance requirements. When the medical insurance turned me down, so would the job. I eventually found a job at the MOD [Ministry of Defence].”<sup>767</sup>

Another woman says that after her late husband was made redundant and:

*“tried to find another job, he hit a major problem in that all of the application forms required him to declare whether he had been exposed to HIV. He was afraid of disclosing his HIV status so he had to take a self-employed role ... which meant that he was not entitled to either sick pay or a pension. This meant that every*

763 Written Statement of ANON paras 16-17 WITN1247001

764 Written Statement of Richard Newton para 11 WITN6897001

765 Written Statement of ANON para 13 WITN6607001

766 Witness Statement of ANON para 43, para 47, para 49 WITN2643001

767 Written Statement of Madeleine Blanchard para 35 WITN0214001

*time he had to attend a hospital appointment, he lost income. As time went on he had to have more and more time off due to his infections. This negatively impacted him in two ways. Firstly, it seriously reduced his income and secondly because he couldn't say why he had time off, he started to look unreliable.”<sup>768</sup>*

Another man explains he has *“never been able to work because of my health. It is difficult in any event to find an employer willing to take you on when you have HCV, liver cirrhosis, severe haemophilia and (potentially) vCJD. It would cost a company a fortune to insure me.”<sup>769</sup>* A woman describes applying for jobs and disclosing Hepatitis C: *“but having done so, [I] didn't even receive replies, certainly no calls back. I applied to do anything and everything. Eventually after what must have been a hundred failed job applications in which I'd told the truth, I decided to leave the condition off the application forms. Almost immediately I was offered a position.”<sup>770</sup>* Paul Fitzsimmons was infected with Hepatitis C through Factor 9. When he was at university he applied to become a Special Constable as he *“wanted so desperately to follow my father and uncle into the Police Service when I eventually graduated”*. His application was ultimately declined because of his Hepatitis C: *“I was absolutely devastated. I cannot describe the feeling and it's incredibly painful to recall.”* He was able to join as a Special Constable many years later.<sup>771</sup>

There were difficulties in obtaining work because of the long periods of sick leave sometimes needed. Despite having a computer science degree, one man, infected with HIV and Hepatitis C as a child, has never been able to work: *“As a result of my infections I missed big chunks of my life; my education was disrupted, and there are huge gaps in my CV due to not holding down a job in adulthood being severely disrupted because of illness and constant appointments.”<sup>772</sup>*

Others could not move country for work because of their infections. Andrew Mowat was refused a work permit in Saudi Arabia where he was about to take up a new position because he had Hepatitis C markers in his blood.<sup>773</sup> When management in Mark Denner's organisation decided to do HIV tests on all staff, he felt he had to leave his job. He describes getting job offers as an engineer in Kazakhstan, Algeria and Japan: *“Unfortunately, these offers were rescinded when I submitted full disclosure of my medical issues.”* He has been unable to work since then and is now reliant on benefits: *“When I was effectively forced to stop working at 51, I was earning more than Tony Blair! I had at least ten years of work ahead of me.”<sup>774</sup>*

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768 Written Statement of ANON para 38 WITN1303001

769 Written Statement of ANON para 34 WITN1521001

770 Written Statement of ANON paras 50-51 WITN0324001

771 Written Statement of Paul Fitzsimmons para 23 WITN1219001

772 Written Statement of ANON paras 29-30 WITN0354001

773 Written Statement of Andrew Mowat para 41 WITN0665001

774 Written Statement of Mark Denner para 31, para 43 WITN0371001

Another man, infected with HIV and Hepatitis C as a child, describes being offered:

*“a very exciting and lucrative position in America to manage the biggest car collection in America at the Imperial Palace in Las Vegas; however I was unable to go as I could not enter the country as a result of my infection. This was heartbreaking for me. I have been offered another exciting job in the last few years but was advised by my doctors not to take it as I would be too ill. I have not only lost out on a career, but the feeling of being useful in life. This has all been taken away from me through no fault of my own.”*<sup>775</sup>

Similar difficulties meant that many people stayed in the same role rather than seeking promotions or broader professional experience. One man, infected with HIV and Hepatitis C, says: *“I could have ‘flown freer’ both in relationships and in my career. Career-wise, having HIV meant that I was least likely to take a risk in the job market so it made me risk averse.”*<sup>776</sup> Paul Kirkpatrick says that he *“stayed with the same company in Northern Ireland for 30 years. I was offered more senior roles in the company but they were global roles and I had to decline them as I was aware the Hepatitis C virus limited my mobility within the company. I clearly feel I have missed out on promotions due to my Haemophilia and Hepatitis C.”*<sup>777</sup>

Neil Weller describes that until his treatment for Hepatitis C he was *“mentally sharp and had a career in accountancy.”* He explains: *“I would travel abroad to France, Holland and Germany to undertake job assignments. After the treatment I struggled to get professional jobs and hold down the jobs I acquired because I was worn down and depressed and struggled with a lack of focus and concentration”.*<sup>778</sup>

Some people gave up their jobs because they no longer met the health requirements or feared that they could not comply. A woman describes how her late husband had to give up his job as a senior scientific officer because he had to have three monthly blood tests as a radiation worker. He could not tell the nurses about the HIV infection and did not want them to take blood from him and risk cross-infection. He left his job and took a sales role.<sup>779</sup> Denisia Gray worked as a nurse but contracted Hepatitis C from blood products for a (predominantly) Factor 10 deficiency. She said: *“Shortly after being diagnosed as having Hepatitis C, I was asked to leave ... When it was revealed that I had contracted Hepatitis C I was effectively shown the door ... [It] was deemed that I was medically unfit to be a nurse.”* She missed nursing greatly.<sup>780</sup> Since giving her statement Denisia has died. Another woman, who was infected with HIV by her partner, was also working as a nurse. The infection meant that she could no longer continue working in that capacity. She says:

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775 Written Statement of ANON para 34 WITN1387001

776 Written Statement of ANON para 27 WITN0022001

777 Written Statement of Paul Kirkpatrick para 29 WITN1333001

778 Written Statement of Neil Weller para 24 WITN1598001

779 Written Statement of ANON paras 27-28 WITN1234001

780 Written Statement of Denisia Gray paras 15-16 WITN0404001

*“there was a recall of all patients who had been operated on whilst I was in theatre ... Thankfully none of the patients came back positive which brought me an extreme amount of relief. I decided to take retirement from my post in 2003. I qualified for early retirement on ill-health grounds. Even though Occupational Health staff were aware about the reasons for my retirement, they had to have letters from my consultant. I felt terrible and ashamed. I still feel ashamed to this day that this happened to me. I was a professional nurse and I could not believe that I let this happen to me ... When I could no longer continue working ... I felt that my career had been snatched away from me. I was young at the time, only 39. I enjoyed my job ... I qualified in 1985 and the HIV diagnosis was the end of my career and vocation.”*

She subsequently returned to nursing but in a different role and in a part-time junior position, rather than her previous full time senior role resulting in significant financial loss.<sup>781</sup>

Very many people became too ill to work. Maureen Hayes was infected with Hepatitis C and explains: *“At the age of 62 I decided to take early retirement as I felt I could no longer work. I was unwell and constantly exhausted. As a rural community support worker my job was both physically and mentally draining ... I found my job very rewarding and despite not having worked for 10 years now, I still miss it very much. Taking early retirement meant that my income was reduced by almost £1000 per month. This reduction in income hit us very hard financially.”*<sup>782</sup> Another man, infected with HIV, Hepatitis C and Hepatitis B states:

*“In the early 2000s my energy levels started to drop considerably, this was attributed to the Hep C and work became more difficult. My hospital and clinic appointments were becoming more and more frequent and it was getting to the point where I was fitting work in around them instead of the other way round. In 2007 I took the painful decision to stop working, I was starting to falter mid job and began cancelling projects at the last minute. This was having an impact on my reputation and I felt unprofessional ... [Not working] I had completely lost sense of who I was. I felt worthless.”*<sup>783</sup>

Neil Ogden says Hepatitis C *“greatly affected my professional work. The loss of memory meant that I would visit a site to give a quote on construction or roofing work and then forget what I had said. I used to travel to a job that I had previously been to and forget how to travel there again.”*<sup>784</sup> Kate Ashton received blood transfusions during her twenties during treatment for leukaemia and contracted Hepatitis C. She lost her job with a medical transcription company when she sent a patient letter to the wrong hospital or GP on three occasions over 18 months. She accepts this was *“because of lack of concentration ... I was definitely at fault. This is not something I would normally do and it upset me. I was suffering*

781 Written Statement of ANON paras 18-20, paras 29-31 WITN1384001

782 Written Statement of Maureen Hayes paras 14-15 WITN3412001

783 Written Statement of ANON para 22 WITN0034001

784 Written Statement of Neil Ogden para 37 WITN0318001

*from fatigue and concentration problems. Unfortunately this was a consequence of what had happened to me; my depression and Hepatitis C. It was very upsetting. When I was dismissed from the company this had a knock-on effect on how I was feeling at the time.*<sup>785</sup>

Jacqueline Raynel was infected with Hepatitis C by a blood transfusion in 1990. Before she was diagnosed, she was working:

*“In my role, I was responsible for looking after projects valued between £50 million and £100 million pounds. My job was demanding and I often worked a 60 to 70 hour week but I loved it. I had always prided myself on my ability to manage both a demanding job as well as take care of my children and husband and keep a tidy home. It started becoming hard to balance both home and work life. I was exhausted all the time. I couldn’t lift my head off the pillows and I struggled to get up in the morning. At the time, I put the exhaustion down to stress. I wasn’t coping. It was like a complete fog had come over my brain. I wasn’t able to keep up at work and I was falling behind in my family duties. I was forgetting to do the shopping, forgetting to pay bills. It all became too much and I came to the decision to ask for a redundancy. I walked away from my job and took a year off to try and recoup.”*

Jacqueline was diagnosed with Hepatitis C in February 2017 after her health worsened.<sup>786</sup>

Nicola Leahey was infected with Hepatitis C through blood transfusions given between 1975 and 1980. She was diagnosed in August 2009:

*“The impact on my career has been significant. I used to work as an NHS clinical governance and audit manager. That included lecturing to doctors and nurses on clinical governance and audit and how to do audit. I was in charge of 20+ staff and responsible for three hospitals; I held a Grade 8 post and was very senior ... I retired in December 2006 when I was 55 ... If I had not had to stop working I would probably be a Director by now. The Trust have even offered me part-time work for when I finish my term as a [unpaid] governor; they want to keep me on but I don’t want paid work because of the tiredness, so I keep saying no.”<sup>787</sup>*

Some employers were understanding. Ruth Spellman’s husband contracted Hepatitis C through leukaemia treatment. His liver gradually started to deteriorate from 1992. He was a teacher and she says: *“He would often go to work, come home and go straight to bed not getting up until the next morning. Bill stepped down as Head of Science to work part time around 2001 because of his deteriorating health. That was very difficult for him, as he loved his job which also helped him to stay strong through everything. He also clung on to his*

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785 Written Statement of Kate Ashton para 28 WITN1416001

786 Written Statement of Jacqueline Raynel paras 11-13 WITN0217001

787 Written Statement of Nicola Leahey paras 82-87 WITN0223001

work and had a great relationship with the school. He worked the whole time, up until four weeks before he died.”<sup>788</sup>

One man describes what he and his wife faced in their business:

*“With regards to the financial effects, my wife and I have suffered greatly due to me being infected with HCV. My wife and I owned our dream house and grounds in Devon. We had holiday cottages in the grounds and ran a bed and breakfast in the house which was physically demanding. Once we knew, everything changed drastically. The property and grounds were too large for us to continue to run. We had to sell the property which meant we gave up our sole income as my wife would not have been able to handle the property if I died and I was feeling too fatigued to cope with the workload. My father in law helped us out and we stayed at his for 2 years on no income and with all our belongings in storage. We had to prepare for the short term as we didn’t know how long I had to live. This caused a massive upheaval in our lives with the financial repercussions still felt today.”*<sup>789</sup>

As John Lister became more unwell with Hepatitis C, he was no longer able to run his greengrocer business: *“My business went into liquidation in or about 1992. We were unable to pay the mortgage because I could not work and eventually the family home was repossessed. I was left with no option other than to claim benefits which I found shameful as someone who was a hard worker and had recently owned a successful business.”* The family were allocated social housing which he was unable to cope with and he attempted suicide.<sup>790</sup> Graham Knight describes Hepatitis C having:

*“a drastic impact on my working life. The problems started at least five years before my diagnosis. My wife and I had just completed buying our small high-end tooling firm from my former employers, a project I had worked on for about ten years. Because of my tiredness, I felt I had no choice but to wind up my business. If I had not done this, then the bank would have wound up the business for me. I was losing money because my brain was not functioning. I only realised this later on. To me this is where I feel like a failure. Things seemed too complicated for me at the time and I couldn’t cope.”*<sup>791</sup>

Trevor Marsden worked on his farm which had been in his family for six generations. He says: *“I have lived there my whole life. Due to my hepatitis C infection, I had to give up full time farming 20 years ago, which devastated me. I have let out the farm over the years and my son in law has now taken it over. I do bits to help here and there which I enjoy, but nothing like I once did.”* He used to own 112 acres but had to sell parts of it when money

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788 Written Statement of Ruth Spellman paras 18-19 WITN0179001

789 Written Statement of ANON para 27 WITN1535001

790 Written Statement of John Lister para 27 WITN1350001

791 Written Statement of Graham Knight paras 130-133 WITN0216001



became tight: *“Selling the land was not something I had ever envisaged doing and it was very much a last resort for me.”*<sup>792</sup>

The loss of work had a significant impact on people’s mental health. Sharon Tonkin says of her husband, David, that since he was infected with Hepatitis C, he has *“changed as a person and when a black mood comes there is nothing that I can say or do; I just have to put up with it”*. This is partly because *“what has happened to him has made him feel worthless and like less of a man because he hasn’t been able to provide for his family.”*<sup>793</sup> Another man describes watching his partner leaving for work every day and says: *“I would be in floods of tears thinking to myself that I am supposed to be the man of the house and that I can’t possibly retire at the tender age of 44.”*<sup>794</sup> In 1994 one woman’s husband *“had to give up his job with the civil service due to his health which was really hard for him as it gave him more time to think about the state of things. In the early days, when he knew he had HIV, he didn’t see the point of living. We also told the neighbours that he was working from home so that they wouldn’t speculate.”*<sup>795</sup>

The careers of partners and other family members were also affected. After her husband Steve’s death, from HIV and Hepatitis C when she was aged 32, Louise Hughes stopped work as an associate partner in an accountancy firm:

*“I suffered severe exhaustion and it became necessary for me to re-evaluate my life ... I intended to take 6 months sabbatical but started to work for myself out of our home. My income was much reduced over the level of income that I previously achieved, but I needed the time to come to terms with Steve’s death. I believe that if Steve had been in good health and I had remained in the accountancy firm concerned that I would have been a partner in that firm or a similar type firm.”*<sup>796</sup>

Colin Smith Sr lost his job *“as soon as it was discovered that there was AIDS in my family”*. His young son, Colin had been infected with HIV through blood products. Colin Sr got another job but on his first day, he says: *“I was told not to bother coming in because they found out about Colin’s infection. I went to the Job Centre where I was told I was unemployable”*. A week after Colin died, aged seven, Colin Sr received a letter from the Job Centre *“telling me to go back to work as I was no longer unemployable.”*<sup>797</sup>

Eileen Dyson contracted Hepatitis C during childbirth and describes the *“devastating”* impact on her career. When her health briefly improved she obtained work in international tax as an expatriate tax manager. The expectation was she would progress to being a partner, earning around £240,000 per year. However, when she became unwell again she was required to attend a private medical assessment. When the partners of the firm were

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792 Written Statement of Trevor Marsden para 58, para 60 WITN1372001

793 Written Statement of Sharon Tonkin paras 39-40 WITN1716001

794 Written Statement of ANON para 37 WITN1310001

795 Written Statement of ANON paras 44-45 WITN0145001

796 Written Statement of Louise Hughes paras 22-23 WITN0238001

797 Written Statement of Colin Smith paras 9-11 WITN1781001

told she had Hepatitis C: *“they refused to give me a staged return to work and made me redundant ... I was never able to return to my profession as each management position which arose required a medical which I was told informally, would not accept an applicant with the Hepatitis C virus. It could be equated to a prison sentence.”*<sup>798</sup> When a woman working part time at a pharmacy was diagnosed with Hepatitis C, her employer *“later came to see me and told me that the other girls [in the pharmacy] no longer wanted to work with me because I had Hepatitis. This really upset me. I still do not know if it was the girls I worked with or simply that he didn’t want me to be there.”*<sup>799</sup> Another woman who was working as a primary school teacher informed her headteacher that her husband had tested positive for HIV and she was being tested. She says: *“He told me he didn’t want me back in the school. I was devastated, I felt like a leper. People thought that only drug addicts and gay people were affected by HIV.”* She spoke with a doctor who spoke to the headteacher and he then agreed that she could return to work after the tests were completed and she tested negative.<sup>800</sup>

Another man with Hepatitis A, B and C took voluntary redundancy when he heard from colleagues that *“the managers did not want me working there anymore”*. He then retrained and applied for jobs *“but I was not successful. I never actually received any replies. I do not know if this was because I had to declare my Hepatitis C on application forms.”*<sup>801</sup>

Knowing that he would be unable to get life insurance or a mortgage, and worried about his life expectancy, Stephen Nicholls sought a job with tied accommodation: *“After about 2 years, they one day saw the disabled badge on my car and found out that I was a haemophiliac. Staff were worried about the link between haemophiliacs and HIV/Hepatitis. The personnel department told me that if I left the job immediately, they would give me 6 months’ pay and provide a council flat. I felt that I had no option other than to accept the offer. I did feel bullied, angry and somewhat ashamed.”*<sup>802</sup>

For others the experience of work was more positive. Anne Kings, who was infected with Hepatitis C at the age of 7, describes the impact of her infection in the workplace:

*“I have experienced some of the stigma associated with Hepatitis C. I am an open and honest person so, once I was diagnosed, I told my work colleagues. I did not weigh up the consequences of telling them. I saw on their faces that question of how I had come to be infected and they almost took a step back from me. I found there was a lack of sympathy for my infection. I have consequently avoided saying anything unless it was necessary. As the working environment gossips a lot, I felt I had to explain to my colleagues how I would manage the*

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798 Written Statement of Eileen Dyson paras 37-38 WITN2130001

799 Written Statement of ANON para 20 WITN0077001

800 Written Statement of ANON paras 22-23 WITN1309001

801 Written Statement of ANON paras 38-39 WITN1326001

802 Written Statement of Stephen Nicholls para 46 WITN1432001

*illness and avoid infecting others, but I felt after the initial shock everyone was fine with me.”<sup>803</sup>*

One man, infected with Hepatitis C,

*“didn’t tell anyone at work about my infection until I began treatment because I was worried about the stigma associated with it ... I told my line manager that I was infected with HCV and needed to go for treatment for the same. I really did not know how the news would be received. However, she was really good about it and said I could take as much time away from work as I needed. I have no idea if she told anyone else, or whether she shared that information with anyone more senior than her, but no one ever treated me any differently from that day on.”<sup>804</sup>*

One woman tried to continue with her work as a nurse, but eventually had to give up. She did not want her colleagues or patients to know about her Hepatitis C status: *“I had to lie about my reasons for leaving my job ... Leaving my job left me on the bread line ... The career I loved as a Senior Practice Nurse was ruined and cut short.”<sup>805</sup>*

## Finance

The financial struggles faced by many people have often stemmed from difficulties at work or an inability to work due to ill health or their partner’s death. Karen Millard describes facing a financial struggle when her husband Russell became too ill with HIV to work. That struggle, she says: *“was exacerbated following Russell’s passing and I sought and held down three jobs so that I could keep a roof over mine and the children’s heads. It was only about five years ago that I was able to drop back down to having only one job.”<sup>806</sup>*

One woman, who described herself as a stay-at-home mum, had to start working full time despite being her husband’s principal carer, when he was forced to take early retirement at age 49. She says: *“we needed more money. All these worries impacted on my physical and mental wellbeing. Our children also lost out on normal family activities such as days out”<sup>807</sup>* Frederick Bates explains: *“As we were not financially stable we were unable to purchase a house, which we would have loved to. Due to my infections, my health deteriorated which meant my work and earning potential decreased significantly. Money became very tight and earnings dropped from £148 p/w to £45 p/w. With 2 children to support and me being the breadwinner in the house, life became difficult.”<sup>808</sup>*

Simon Beddow’s father was infected with HIV and Hepatitis C. His health gradually deteriorated until he could no longer work. Simon explains:

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803 Written Statement of Anne Kings para 27 WITN0947001

804 Written Statement of ANON para 48 WITN1298001

805 Written Statement of ANON paras 49-51 WITN1974001

806 Written Statement of Karen Millard para 42 WITN1396001

807 Written Statement of ANON paras 32-33 WITN0102001

808 Written Statement of Frederick Bates para 61 WITN0393001

*“We used to live in a brand new detached house and my father had a fairly new BMW and a company car. However, all of this suddenly changed when my father could no longer work. The company car and the BMW were collected; my father had paid for the BMW but he needed the money so had to cash it in. I remember that I had to miss school trips and used to have to wear ‘charity clothes’ on non-uniform days so I stuck out like a sore thumb at school. We could no longer afford fashionable clothes. We basically went from having an affluent and ‘flush’ lifestyle to living completely on the ‘breadline’.”<sup>809</sup>*

Robert Fraser describes the stigma of Hepatitis C affecting his working life and finances: as word of his illness spread at work, people began avoiding him (“*for instance, they would get out of the lift when I got in*”) and his employers began a termination process. His intention was to take his case to an employment tribunal but he could not afford to continue to fight and was forced to settle out of court: “*The illness not only impacted my mental health and consequently all my relationships but it affected me financially as well.*”<sup>810</sup>

Marjorie James’ husband, Chris, was diagnosed with Hepatitis C in 1992. He

*“was a financial partner in a city firm but had to retire in the late 1980’s as he became increasingly tired. He was very lethargic but didn’t know why. He had always been a man who paid real attention to detail but he started to lose his concentration. I could see it was making him very unhappy so I encouraged him to take early retirement ... Chris had disability insurance cover so if he had been made aware of his infection, he would have been able to take medical retirement and received long-term disability insurance payments. Instead he was left with significantly less income than he could have received.”<sup>811</sup>*

Wayne Gambin, who was infected with Hepatitis C and Hepatitis B, was very unwell during his second treatment for Hepatitis C. He says:

*“I ended up losing my job and was unable to obtain any type of insurance or pay the mortgage ... My wife was forced into taking on the role of bread winner which put excessive strain upon our relationship ... Financially, life has always been a struggle. I had to claim as many benefits as I could when I was declared bankrupt during my second Hepatitis C treatment. I remember attending numerous medicals in relation to verifying my eligibility for benefits which I found very unfair given the mode of my infection. I also felt like I was begging which was not a nice feeling.”<sup>812</sup>*

Andrew Thomson’s father Bryce was infected with Hepatitis C. He had worked in a physically demanding job but was eventually unable to continue: he “*was on benefits and had no*

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809 Written Statement of Simon Beddow para 2, paras 17-18 WITN1089001

810 Written Statement of Robert Fraser paras 8-9 WITN2136001

811 Written Statement of Marjorie James paras 18-19 WITN1304001

812 Written Statement of Wayne Gambin para 25, para 34 WITN1226001

*savings. I remember he phoned me up one day crying, he said he had no money to pay for his funeral. He said, 'I'm sorry son, but I can't even afford to die'. He said that it was the biggest shame of his life. He would often phone me up apologising that he couldn't pay for his funeral."* Bryce died in 2006.<sup>813</sup>

The costs of being unwell, and caring for those who are unwell, can be very high. Gillian Currie, whose husband died of Hepatitis C, states: *"I spent a significant part of my life travelling long distances to visit Barry every day and many other family members do the same to visit their sick loved ones. The travelling expenses, fuel and parking tickets add up over the years ... I feel commuting to visit sick loved ones is an overlooked issue. It is a tax in terms of cost, time and emotions. Hospitals are doing great work in treating the patients, but people really need assistance from the government."*<sup>814</sup>

One woman experienced symptoms of tiredness, lethargy and general ill health for years following a transfusion before finally being diagnosed with Hepatitis C. Her husband explains that this had *"a huge impact on our family finances. Only being able to work part [time] for the majority of her life has meant lower earnings ... under normal circumstances she would have gone back to work full time and knowing my wife, would have excelled in her chosen career. It has even impacted on our long term finances as she only has a limited pension."*<sup>815</sup>

Financial difficulties and the loss of work often resulted in people turning to the benefits system. This was rarely a positive experience. Joan Edgington recalls being assessed by the Department of Work and Pensions ("DWP") during the year she was recovering from Hepatitis C treatment:

*"I just remember being pretty distressed and trying to explain that I was still dealing with chronic fatigue. I just found the whole benefits system horrendous ... I was occasionally met with kindness but the whole structure was awful and I did meet a whole lot of people with a 'jobs worth' attitude. Because the treatment was not chemotherapy they did not believe that it was that bad ... I found the whole process of applying for benefits and attending the assessments really demeaning."*<sup>816</sup>

Margaret McIlwrath applied for Disability Living Allowance on three separate occasions. She says *"[I] was always turned down which made me very angry. The Government gave me my infection, but would not care for me. I think the fact that I looked normal was enough for the powers that be to always reject my claims. An ignorance about the disease also prevailed."*<sup>817</sup>

Another woman, describing her brother's situation, explained that he had never had difficulties in obtaining money from the schemes set up to provide financial assistance. However:

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813 Written Statement of Andrew Thomson para 26, para 32 WITN2678001

814 Written Statement of Gillian Currie para 41 WITN0810001

815 Written Statement of ANON pp4-5 WITN2334001

816 Written Statement of Joan Edgington para 36 WITN0065001

817 Written Statement of Margaret McIlwrath para 47 WITN1382001

*“there have been some issues with the money given to him interfering with his benefits. If he has too much money in his account then his benefits stop so he has to take the financial support for his illnesses out of the bank. Furthermore, he has to go to the job centre every year to prove he is disabled, which is embarrassing going with the alcoholics and druggies and having to have a medical when his condition will never improve. On occasion the individuals processing his case have no knowledge of his circumstances so he has to tell them everything from scratch which can be hard, especially telling them about the infections.”<sup>818</sup>*

Another man says:

*“The Skipton Fund payments are not state benefits. They are to be treated independently and/or disregarded by the DWP but that does not happen in practice. I have been targeted by the DWP and have been called into the local benefits office on three occasions for questioning on the matter. They knew what was in my account. I have been grilled as to the source of the funds, what I have spent it on and why I receive it. On one occasion I was informed by the female investigator that I was going to be prosecuted for fraud. Upon turning off the tape recording she went on to say that if it was up to her I would get a prison sentence. I was suffering already and then I thought I was going to go to prison. It was only when the Centre’s social worker intervened that I was told my case would be dropped. I complained but I did not get an apology. I tried to speak to the Head Investigator to make sure the same thing did not happen to anybody else but I was told he was not available as he was ‘a very busy man’.”<sup>819</sup>*

HIV and hepatitis come with other “financial penalties”. One man explains: *“I have for example experienced difficulty in getting a mortgage and discovered there were only a limited number of lenders who were available to me. I have never been able to get, and still do not have life insurance, and travel insurance has always been significantly more costly for me than for other people. This is due to the need to declare both the Haemophilia and the HCV.”<sup>820</sup>* David Pescod contracted Hepatitis C after having previously had a mortgage approved. However, when he informed an assistant that he had Hepatitis C, a week later he *“received a letter withdrawing the offer and refunding all payments.”<sup>821</sup>* Another man recalls that when he and his wife bought their flat in 1991: *“Because we couldn’t tell the building society about my HIV status, [she] assumed full responsibility for the mortgage and insurances. The girl we saw for mortgage advice was surprised at [her] insistence that she earned the most and would therefore do it herself (without me).”<sup>822</sup>*

One person explains: *“Due to Hepatitis C, I am not able to get ANY life insurance for my family even after being cleared of Hepatitis C. This means that if something should happen*

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818 Written Statement of ANON para 31 WITN0416001

819 Written Statement of ANON para 36 WITN1521001

820 Written Statement of ANON para 55 WITN0066001

821 Written Statement of David Pescod para 25 WITN1464001

822 Written Statement of ANON para 20 WITN1230001

*to me then my family have no support and would have to go begging with ‘cap in hand’ to [the England Infected Blood Support Scheme] EIBSS. If something were to happen to me, I would want my wife and children to be supported.”<sup>823</sup> One man says: “the financial security we thought we had was gone when the life insurance we had was cancelled and not renewed. We could not find another insurer to take us on.”<sup>824</sup> Another man “decided not to declare information about my infections” because until then he had “always had to pay more for insurances like travel insurance and always had issues with getting a mortgage”. He has never got life insurance.<sup>825</sup> Stephen Stubbs states: “I cannot get life insurance and I feel bad about that. I don’t have the ability to protect my wife and family in the future. I don’t believe it’s fair that I cannot have the same safety net others have.”<sup>826</sup>*

Kim Law explains that, despite having successfully cleared Hepatitis C, she continues “*to be discriminated against with regards to insurance companies, despite being declared clear of HCV since 2004, the wording of forms often includes phrases such as ‘have you ever been tested for HIV/HCV’. I feel this is particularly prejudicial and never allows me to be free from the past infection.*”<sup>827</sup>

People’s experiences of the trusts and schemes were mostly negative. There was a very strong feeling amongst those who were able to obtain financial assistance that it was too little, too late.

## Housing

Financial difficulties and ill health affected housing decisions, often requiring house moves out of necessity rather than choice. Terence O’Hora says:

*“At the time of my second treatment [for Hepatitis C], I had just bought a house and everything was looking up. I had approximately £130k savings. When I started the second treatment I was unable to keep up with the mortgage payments and my savings kept going down and it was all too much to deal with. I had to sell the house and buy a smaller property. I lost money on the house as there was a financial crash but I had no choice but to sell the house. I then considered that the safest thing to do was to rent somewhere on my own which would give me less responsibilities. I am still currently renting.”<sup>828</sup>*

One woman describes how her husband contracted Hepatitis C and required a liver transplant. Around three years later, he deteriorated suddenly and died of liver cancer. When he had become too unwell to work they had financial difficulties. She says: “*We made contact with our mortgage company at that time and they put us on to an interest only*

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823 Written Statement of ANON para 33 WITN1289001

824 Written Statement of ANON para 17 WITN0005005

825 Written Statement of ANON para 32 WITN1242001

826 Written Statement of Stephen Stubbs para 54 WITN0432001

827 Written Statement of Kim Law para 16.3 WITN0013001

828 Written Statement of Terence O’Hora para 40 WITN1438001

*mortgage. I could really do with moving to a bungalow now but that is no longer possible as I have no mechanism with which to repay the capital I owe on the mortgage.*<sup>829</sup> Martin Sloan describes how his ill health made him “*simply unemployable ... My marriage struggled greatly as I could not provide, I could not buy my home ... I couldn’t do anything to give my wife a home.*”<sup>830</sup>

Another woman had to move house after her husband’s death from HIV and Hepatitis C: “*not because I wanted to but because I couldn’t afford to live there anymore. At the time I was getting no help from the MacFarlane Trust. It broke my heart. I had a lovely home, full of memories – my youngest daughter was born there – [my husband] and I bought the house in 1974 when it was little more than a wreck. Through our own hard work and determination, we turned it into a place to be proud of.*”<sup>831</sup> Stacey Lewis had to move house after her father died because her mother could not afford the mortgage repayments and says “*Leaving our family home was like losing my father all over again ... all of my memories of my father were there.*”<sup>832</sup> One woman’s husband was infected with Hepatitis C and after unsuccessful treatment, he developed serious mental health difficulties and turned to alcohol. He left the family home and she was unable to continue to pay the mortgage: “*I loved my home, it was the first home [he] and I had bought together ... Ultimately I had to sell the house and I now live in a housing association flat ... You can see my marital home from my flat window. I often look over and wonder what might have been.*”<sup>833</sup>

Elizabeth Hooper was married to Jeremy, who had Hepatitis B and C from blood products. He died in December 2008 when oesophageal varices haemorrhaged and Elizabeth says “*Before I could face up to the loss of the man I had loved for 26 years and confront his horrific death, I had to go into survival mode ... I had to sell the house ... It was a wrench for me and [my son] Lewis to have to leave our family home at such a traumatic time.*” Elizabeth later met and married Paul, who had contracted HIV and Hepatitis C from blood products. He died in December 2017. After his death, Elizabeth was unable to afford the mortgage and says “*I lost my home again after a second bereavement. The building society were patient but it took me a year to sell and I had to drop the price of my home due to the risk of repossession ... I have downsized again to a leasehold maisonette.*”<sup>834</sup>

## Travel

Certain countries have operated, and continue to operate, a ban on people with certain infections from entering the country. This has restricted people travelling and increased the feeling of stigma. One man says:

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829 Written Statement of ANON para 18 WITN1373001

830 Written Statement of Martin Sloan page 9 WITN2443001

831 Written Statement of ANON para 25 WITN1450001

832 Written Statement of Stacey Lewis para 24 WITN2923001

833 Written Statement of ANON para 38 WITN2288001

834 Written Statement of Elizabeth Hooper paras 40-41, para 64 WITN3514001



*“In 1995, a friend was working in the United States and both myself and another friend arranged to visit him. I realised that due to my HIV status, I was required by virtue of U.S. Federal Law to complete a Waiver Form, but I was assured that it would be alright to travel even though I had not received confirmation of the waiver. I arrived at Newark, New York with my travelling companion (who I had not told of my HIV diagnosis). My friend went straight through Customs but I was pulled to one side and because the Waiver had not yet been processed, I was refused entry into the United States and sent back to the UK on the next plane. I spent time in a holding cell during the period it took to arrange my repatriation to the United Kingdom. On my return, it was deeply embarrassing having to attempt to explain away what had happened where I had to be less than candid to friends and colleagues as to why I had returned home whilst my companion remained in the United States ... That scenario meant that I now lived life on the edge for fear of discovery.”<sup>835</sup>*

Another man explains:

*“in 2003, I went to visit my best friend who was in Los Angeles. I went to get my visa at the US embassy and was interrogated like I was attending a police interview. I was asked the same questions again and again as if they were trying to see if I changed my story. Before going in, I was in a room with others of a similar age to myself. Many of them were travelling to the US for summer/sports camps and were also attending visa interviews. Many of them were chatting about what they were going to do. I was petrified someone would ask me what I was going to do, so I kept my head down and ignored everyone. Even now, whilst there is no requirement for me to have a visa, there is a marker on my passport when I travel to America. My wife and I were getting the boat from Victoria, Canada to Seattle; travellers have to clear US customs before they get on the boat. We were first to arrive at the terminal and last to board the boat due to me being interrogated in respect of my HIV. I was taken into a separate room with my wife where I was once again questioned ... There was no privacy and whilst the officers were trying to be pleasant about the whole situation, it left us with bad memories of what had otherwise been an excellent holiday.”<sup>836</sup>*

Susan Harrison discovered that she had been infected with Hepatitis C from a blood transfusion when she and her husband tried to obtain a temporary residence card in Northern Cyprus. This required them to have blood tests and her results showed that she had Hepatitis C: *“I was informed by the police that I had to report to a local police station. [The person] who owned and ran the laboratory knew I was married and explained to my husband and I about HCV but the information was not adequate. I attended the local Police station on a Friday and was told to surrender my passport and that I had to remain in custody until I was deported”*. Susan passed out due to shock and was told she could go home until

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835 Written Statement of ANON paras 36-37 WITN0173001

836 Written Statement of ANON paras 69-70 WITN0125001

she was deported by the Army. She and her husband arranged a flight home and the police organised for her passport to be delivered to the border post where they intended to cross into Southern Cyprus. She explains that *“We arrived at the border and I had to then sign a document in Turkish, with the only English stating that I was an ‘undesirable immigrant’ to obtain the return of my passport”*.<sup>837</sup>

Even if travel to a particular country is not barred, the cost of travel insurance is exorbitant. One man says: *“Insurance companies are very bad about [Hepatitis C]. It is prohibitively expensive for me to get travel insurance and life insurance. We do have a family package but I am not covered by it.”*<sup>838</sup> A woman, whose husband is co-infected with HIV and Hepatitis C, says:

*“We have had to disclose his HIV status when making applications and this has dramatically increased the premiums of the available policies. When we apply, we have to take out separate policies. Finding an appropriate policy for my husband is difficult as there is a very small pool of suitable insurers. There are some specialist companies that cover people with HIV but their policies come at an exorbitant premium. The fact that [my husband] has had hepatitis C and liver damage raises the risk and therefore the costs.”*<sup>839</sup>

Colin Catterall explains:

*“I struggle financially to get travel insurance. It can cost approximately £1,600 for travel insurance for a single holiday. I have not been able to afford this. I have been on previous holidays without travel insurance and my wife and I would get into arguments as a result. I would always worry that I would fall ill abroad, but it was a risk that I took because I could not afford the travel insurance. I would just take my medication with me and hoped nothing would happen. I cannot just sit back and wait to die, I want to enjoy my life.”*<sup>840</sup>

## Former blood donors

Some people discovered they were infected with a virus after giving blood for many years and feared they had unknowingly passed on the infection. One woman received blood transfusions in 1972 prior to surgery to remove a fibroid. She says *“I started to donate blood in the 1980s and continued up until sometime in the 1990s. I feel terrible because I had no idea I had HCV. I received a certificate for giving blood for 10 years. Then I was told there was something wrong with my blood.”*<sup>841</sup>

Genevieve Jones was given plasma after the delivery of her first child and subsequently donated blood: *“Something that has been playing on my mind is the fact that I had been*

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837 Written Statement of Susan Harrison paras 8-12 WITN0625001

838 Written Statement of Peter Frith para 88 WITN4118001

839 Written Statement of ANON paras 31-32 WITN0240001

840 Written Statement of Colin Catterall para 39 WITN1145001

841 Written Statement of ANON para 7 WITN0260001

*giving blood following the plasma I had received in 1979, between 1982 and 1989. I decided to give blood as I had received it and I believed it saved my life. I wanted to give back and tried to do a public service. The thought that I may have potentially infected other people makes me feel very guilty, as I was trying to do a good thing”.*<sup>842</sup>

Another woman received two transfusions after childbirth in 1972 and 1981. She gave blood regularly thereafter until she was informed in 1992 that her blood had been tested and Hepatitis C had been detected:

*“I had been donating blood regularly for 19 years, from 1973. However, I also realised that by doing so I had been passing on the virus myself and infecting others. I have a great amount of guilt about this ... I also still find it very hard to know that in trying to do good by being a blood donor, I would have infected / killed a number of people in the 19 years I was a donor. I try to tell myself that it was not my fault but it doesn’t change the outcome. It would have been good if the transfusion service could have counselled us donors about this but it was never offered or spoken about. I try not to dwell on it.”*<sup>843</sup>

For some people, not knowing whether or not they infected other people has also been difficult. Graham Bee was infected with Hepatitis C through multiple blood transfusions after a road traffic accident. He decided to give blood regularly as he was grateful for the blood he received and “*wanted to pay it forward.*” However, he says “*I feel guilty that I had given about fourteen pints of blood before I was diagnosed with HCV, and I worry that some other person has contracted HCV through my blood. I gave blood in good faith, but it has been a worry for me over the years.*”<sup>844</sup>

Barbara Savage was a blood donor before and after her blood transfusion in 1978 and says “*I feel really awful that I was a blood donor in all the years that I carried Hepatitis C. I probably gave blood for at least four years after the birth of Jonathan. Unbeknownst to me, I could potentially have infected others as blood was not screened during this time.*”<sup>845</sup>

Another woman says that she was a “*frequent blood donor*” after her transfusion at birth: “*I can’t know how many people I have infected by donating my blood in the 1970s and 1980s, I don’t know their names and I will never know what happened to them. Some of those people may have become more ill than I ever was and some may not even know that they have the infection to this day. It’s a horrible thought that I have to live with.*”<sup>846</sup>

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842 Written Statement of Genevieve Jones paras 57-58 WITN0465001

843 Written Statement of ANON paras 10-12, para 20 WITN1826001

844 Written Statement of Graham Bee para 15, para 57 WITN5952001

845 Written Statement of Barbara Savage para 35 WITN4770001

846 Written Statement of ANON para 10, para 16 WITN4186001

## Wider impacts on medical treatment

At the height of the AIDS crisis, some people experienced poor hospital care because of the stigma attached to the infection. Graham Russell describes visiting his brother Malcolm who had been *“admitted to an isolation unit at Churchill Hospital around 5 weeks before he died ... we found him in a toilet in a distressed state plastered in diarrhoea. He said he had been there for a long time and nobody had been in to check on him ... It was obvious that nurses were fearful and scared of AIDS and, most likely, avoided patients.”*<sup>847</sup>

Kim Law describes how she was treated following a miscarriage: *“I was virtually quarantined due to my HCV to the extent that nursing staff would throw towels at me from the doorway to avoid any contact. As can be imagined this was a horrendous experience especially as I was already traumatised by the loss of my child.”*<sup>848</sup> When Neil Walker, infected with HIV and Hepatitis C, was admitted into hospital around 1985, he recalls: *“my room was horrible as the cleaners were not allowed in, so bed pans and urine bottles were piled up. My bed sheets would get incinerated along with anything else that came into contact with me. Blood samples were taken from me with people having 3 pairs of gloves on and they were shaking and so nervous which just made it harder to take blood and made it more uncomfortable for me.”*<sup>849</sup>

Even today, many people face treatment that they experience as stigmatising. One man describes being put in a separate room whenever he was admitted into hospital because of the Hepatitis C:

*“This has led to me isolating myself even further. Having these special measures makes me feel very alone – it got to a stage where if I was put on a normal ward I would shut the curtain around me. It does make you feel marginalised ... Dentists and surgeons wouldn’t touch me because they were scared of touching haemophiliacs with HCV – they were ignorant of it. All they knew was this person was a ‘bleeder’ and has a dreadful disease. A lot of people were frightened of interacting with me.”*<sup>850</sup>

One woman describes how after her husband was infected with Hepatitis C through plasma exchange used to treat kidney disease, he was isolated during his dialysis treatments. He had to have his treatment in a room alone, rather than alongside others receiving dialysis: *“When this decision was made we did get asked a lot of questions from the other patients, as to why we were segregated which was an awkward situation”*. There were also difficulties in getting an engineer out to fix their home dialysis machine and in undertaking dialysis at a different hospital when he was away visiting family.<sup>851</sup>

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847 Written Statement of Graham Russell para 32 WITN3261001

848 Written Statement of Kim Law para 16 WITN0013001

849 Written Statement of Neil Walker para 16 WITN1587001

850 Written Statement of ANON para 28, para 30 WITN0006001

851 Written Statement of ANON para 38 WITN0507001

Another woman recalls an episode at Wakefield Hospital when she was having treatment for carpal tunnel syndrome and her daughter asked when the doctor would see her. The nurse *“replied ‘Not with what you’ve got, you will be last!’ My daughter replied to her: ‘Well, why don’t you tell all the ward then!’ It was an awful experience. I could have walked out at that very moment; it wasn’t nice at all.”*<sup>852</sup> Despite having cleared the hepatitis infection a number of years earlier, one woman describes having to answer questions about drug use and her sex life. She says that for a colonoscopy: *“They even mentioned that they would use the ‘dirty scope’, which was reserved for people with HIV, even though I have documentation proving I am negative, which is highly infuriating.”*<sup>853</sup> A man describes requiring shoulder surgery after diagnosis with Hepatitis C. In advance, he recalls being told:

*“precautions would have to be taken to protect the clinical team, precautions which I may find distressing. Although they had told me what to expect, I hadn’t been prepared for what I saw and it all came as a bit of a shock – the clinical team, all wearing full protective equipment, including visors (looking like Hazchem suits). I found this upsetting, but understood the rationale for it, and I had been told, but nevertheless it made me feel diseased and ‘unclean’, my posing a tangible danger to others.”*<sup>854</sup>

Others have had more positive experiences of NHS care since their infection and David Lowles describes his care as *“phenomenal ... they have treated me with the utmost respect and dignity.”*<sup>855</sup>

## Dental care

Very many people were unable to access their normal dental care once they disclosed their infections. Hilary Power describes how her mum, Shirley, told her dentist about her Hepatitis C infection: *“the dentist did not want to treat her. She did not receive dental care. When she died she had hardly any teeth. She could only eat squashed up jacket potato.”*<sup>856</sup> One man attended a local dentist who *“found out I had HCV and politely asked me to leave his practice.”* Since then he has been treated by the hospital dentist.<sup>857</sup> Another man who has died since giving his statement said he had avoided going to the dentist for any treatment *“as I would have to declare I had hepatitis C and it is not a subject I want to talk about. I do not believe I have been to the dentist since my diagnosis.”*<sup>858</sup>

Others were treated but found the precautions taken excessive. Paul Kirkpatrick is one of many who describe always being treated as the last appointment of the day, and says: *“Any instruments which were used in my treatment had to be thoroughly cleaned and it felt like*

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852 Written Statement of ANON paras 31-32 WITN0117001

853 Written Statement of ANON para 41 WITN0140001

854 Written Statement of ANON paras 69-70 WITN0351001

855 Written Statement of David Lowles para 25 WITN1356001

856 Written Statement of Hilary Power para 5.7 WITN0039001

857 Written Statement of ANON para 27 WITN1352001

858 Written Statement of ANON para 26 WITN2106001

*I was in a bomb disposal unit because the dentists were covered in ‘bomb disposal suit’ overalls which included full face masks. I found the whole procedure very embarrassing and it was very scary seeing the dentists like this and I believe that this had a significant impact on my mental health.”*<sup>859</sup> Frederick Dawes recalls attending the dentist and says “*The nurse said they wouldn’t be long. When I went in, everything in the room, up to the lights, was wrapped in cling film. They didn’t know what to do. Even the clock was cling filmed. Everything was cling filmed ... I couldn’t believe it. It made me cry. It made me feel like a leper and like I was unclean.*”<sup>860</sup> Since giving his statement Frederick has died.

### Loss of trust in the medical profession

Very many people describe a loss of trust in the medical profession. Louise Marsden, whose husband Trevor was infected with Hepatitis C, explains: “*Our faith in the medical profession has been shattered by everything that has happened to Trevor. Trevor now refuses to see a doctor. They lied to him when they told him he may have HIV in 1983, they failed to inform him of his positive Hepatitis C test in 1991 and they lied about treatment. We have no interpersonal relationship with our doctors. Trevor is cautious about what else doctors could be hiding from him.*”<sup>861</sup> One person infected with HIV through blood transfusions during leukaemia treatment, says that “*Due to being infected by the NHS. I have hardly any trust in the service, even though I have no choice but to rely upon the NHS to keep myself alive.*”<sup>862</sup> Alan Kirkham describes the strong bonds that as someone with haemophilia he had with his treating team: “*Therefore, try to imagine the emotional effect of finding out that these people, in whom we had a deep and long term trust, had been the cause of a potentially life destroying blood, and further [the] more we find out, bit by bit, they have lied to us and in some cases caused this illness when it would appear they could have avoided it.*”<sup>863</sup>

Karen Mclean describes a similar situation with her husband Stuart, who was infected with Hepatitis C after being misdiagnosed as having a bleeding disorder. She says: “*Stuart now has an anger towards, and deeply held mistrust of, the medical profession which simply was not present before his diagnosis. Unfortunately, following his diagnosis, Stuart’s doctors have done nothing to rebuild trust and Stuart continues to have negative experiences of doctors*”.<sup>864</sup> Andrew Tarren, infected with Hepatitis C through blood products, says: “*I definitely have trust issues with medical professionals due to the contaminated Factor VIII that I was given and as a result of my interactions with Dr Adelman. Being constantly misled has affected my outlook and the way I have dealt and deal with things in life; this lack of trust has transferred to a lot of other areas in my life.*”<sup>865</sup>

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859 Written Statement of Paul Kirkpatrick para 35 WITN1333001

860 Written Statement of Frederick Dawes para 75 WITN4465001

861 Written Statement of Louise Marsden paras 100-101 WITN1371001

862 Written Statement of ANON p5 WITN0296001

863 Written Statement of Alan Kirkham para 27 WITN1332001

864 Written Statement of Karen Mclean para 14 WITN0654001

865 Written Statement of Andrew Tarren para 26 WITN0274001

One woman, infected with Hepatitis C following a transfusion in 1985, and only informed of her diagnosis in 2010 (at which point she “was accused of being a junkie”), has lost all faith in hospitals: “I wouldn’t trust anyone in the medical profession anymore ... Unless I am dying, I won’t go to the doctors”.<sup>866</sup>

### Counselling and psychological support

The lack of psychological support for people infected through blood, blood products or tissue transfer had a profound detrimental effect. Robert Hodgkins was diagnosed with HIV when he was around 15 years old and was unable to be in education from age 16-21 because of his illnesses: “At that time my life was very bleak. I was unemployed and had no direction in life. I felt unable to speak with anyone about my HIV because I did not know how they would react. I was not offered any counselling or any other form of help. This is a time when I really needed support and guidance but there was no one there to help me.”<sup>867</sup>

One father speaks of his son who, having successfully graduated from university despite being infected at a young age with HIV and Hepatitis C, was not kept on at work and then “Mentally, ... deteriorated drastically”. His son refused treatment for both his HIV and Hepatitis C. His father says:

*“There were many occasions when [my son] self-harmed by cutting himself. He used to say that he could not help himself, he would feel an overwhelming sense of rage and frustration, and the only way he could stop it was by getting a knife and cutting himself ... When [my son] first self-harmed in 1989, the doctor was unsure whether to admit him as an inpatient or not. They decided to treat it as a one-off episode of self-harm and hope that would be it, but unfortunately that was not the case. He briefly had outpatient treatment but it was completely inadequate for his needs. With the amount of pain [my son] was in, he became addicted to his painkillers, which he used to take with vodka. It is our belief that if [my son’s] mental health could have been properly addressed then he may have been persuaded to take treatment for his HIV and HCV, and to go for regular check-ups. He was a young man with definite views and he got stuck in the mind-set of not trusting the medical profession.”<sup>868</sup>*

Jennifer Reid’s son died of HIV and she says “We were never offered any counselling and I’m not even sure if it was available at that time but it was very difficult to come to terms with Sean’s death when there was nobody to talk to about it.”<sup>869</sup> A man whose son died says that his son was not provided with any counselling or psychological support. He believes: “had he been offered such support, he would have been able to manage his fears and worries

866 Written Statement of ANON para 16, para 20 WITN2253001

867 Written Statement of Robert Hodgkins paras 36-37 WITN0009001

868 Written Statement of ANON paras 28-29, para 48-49 WITN0995001

869 Written Statement of Jennifer Reid para 27 WITN1485001

*and he may not have felt as tormented.*" The father received counselling for just six months through his GP surgery after his son died.<sup>870</sup>

Other people reflect that the understanding of mental health issues was not as developed as it is today. Rupert Miller recalls that counselling was discussed with him in relation to his brother, Julian's HIV infection and subsequent death but he says, "*we had the 'there is nothing wrong with me' stiff upper lip mentality ... If you were a man, to show signs of needing help, that was viewed as a weakness back then, for a man to cry was unheard of back then, it was very much frowned upon, psychiatric support, well that was for nutters, not for me ... was how I viewed it.*" He thinks his brother's view was the same.<sup>871</sup>

By contrast, a woman whose brother died of AIDS describes him receiving counselling through the Terrence Higgins Trust which he found very helpful. Nevertheless, she says: "*I do not believe that the provision of psychological support should have fallen upon a charity to provide, but that it should have been provided as a matter of course by the NHS to those affected. This would, and should, have included [his] broader family, his wife, my siblings and I, and our parents as an example.*"<sup>872</sup> Susan Hall's late husband, Ian, was infected with HIV and Hepatitis C through blood products: "*Ian had a very good counsellor called Arleta. She was fantastic and we remain friends today. I was not offered any counselling either during the times when Ian was told that he was suffering from HIV and Hepatitis C or when he passed away. I feel that the system overlooked me. As far as I am aware, neither of my daughters were offered any type of psychological support.*"<sup>873</sup>

One man infected with Hepatitis C says: "*I have never been offered any counselling or psychological support. It has never been made available to me in consequence of what happened. I was never told that it was an option. I should have been offered counselling, I believe it would have helped me.*"<sup>874</sup> Jason Ward describes being told there was nothing more that could be done for him after interferon treatment was unsuccessful. He says "*I was not offered any counselling or psychological support and it felt that I was being ejected by the NHS as the treatment had not worked. I experienced feeling very low and distressed, I was only 50 years old and had been given a death sentence*".<sup>875</sup>

Another man says: "*I wasn't offered any psychological support as regards my having been infected with HCV or to assist during the course of its treatment. Looking back, I think that this would have proven very helpful had it been offered, not only for me but for my wife as well, not least because we had nowhere to turn to, we knew no one who was going through the same thing.*"<sup>876</sup> Alan Campbell, who became severely depressed following treatment for Hepatitis C and felt suicidal at times, was never offered any counselling or psychological

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870 Written Statement of ANON para 44 WITN1544001

871 Written Statement of Rupert Miller para 35 WITN7234001

872 Written Statement of ANON para 119 WITN7625001

873 Written Statement of Susan Hall para 44 WITN1264001

874 Written Statement of ANON para 48 WITN0428001

875 Written Statement of Jason Ward para 17 WITN1992001

876 Written Statement of ANON para 48 WITN0327001



support: *“I do feel that I would have benefited from counselling. I really needed to talk to someone regarding what had happened to me. I had to deal with it on my own and as a result I became clinically depressed.”*<sup>877</sup> Karen Bolton reflects: *“better psychological help should have been provided. I received counselling through work. I have never found it hard to find someone to talk to. What has been hard is to find people to talk to who understood what I was saying and going through. People who would not just listen but understand.”*<sup>878</sup>

Maria Mooraby was offered counselling at Queen’s Medical Centre in Nottingham but she declined it. She felt that her hepatology consultant and specialist nurse were *“like counsellors to me. I received a lot of support from them and I am forever grateful for this.”*<sup>879</sup>

Some of those who have subsequently engaged with psychological therapy have found it helpful: *“It wasn’t until ... our marriage was on the rocks that I approached the hospital for counselling ... I should have done it sooner. It should have been offered to me when I was told about the infection. It makes me wonder if I could have saved my marriage if I had the help earlier.”*<sup>880</sup> Simon Tonkin sought counselling a year before he wrote his written statement and says, in relation to his father David’s infection: *“The ball of worry hadn’t stopped rolling for more than two and a half decades, generating emotional troubles and personal problems ... Through having counselling, I can finally talk about it and have the tools to move forward. Two years ago, I would have been unable to convey 10% of what I am able to speak of now.”*<sup>881</sup>

John Aubrey has been diagnosed with post-traumatic stress disorder since his engagement with the Inquiry and has received psychological support which has helped significantly. He says that preparing his written statement was *“like a Pandora’s box opening”*. He continues to have panic attacks but his flashbacks are slowly reducing.<sup>882</sup> Another man was offered counselling three years ago and he found that it helped *“to take quite a lot of things off my chest. It also helped me to realise that I should not blame myself for what happened as it was not my fault. I believe my life would have been different now had counselling been offered a lot earlier, when I was told that I tested positive for it.”*<sup>883</sup>

## Commentary

The impact of a single life story can be immense.

This chapter is not a single story. It is more – much more – than that. In this chapter people have described their experience in their own words. Their voices, individually, are more powerful than any third-party commentary. Collectively, they present a picture of a treatment

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877 Written Statement of Alan Campbell para 21 WITN2672001

878 Written Statement of Karen Bolton para 51 WITN0463001

879 Written Statement of Maria Mooraby para 53 WITN6155001

880 Written Statement of ANON para 42 WITN1633001

881 Written Statement of Simon Tonkin paras 16-17 WITN7152001

882 Written Statement of John Aubrey paras 4-5, para 10, para 15 WITN0071002

883 Written Statement of ANON para 38 WITN1784001

disaster. Though the extracts had to be selected, over four thousand statements are available to read for anyone who wishes to do so: and they will find, repeatedly, the same themes. The way those themes are expressed is in the person's own words, or their words as relayed by an intermediary, or by those who have supported them and in too many cases cared for them as they died. But the powerful weight of their shared experience, time and time again, tells its own tale.

It is essential to recognise this commonality of experience. That experience is not that of one particular horrific event, nor those of any particular section of society. It is the collective experience of a large number of people, from different walks of life, in a variety of different social circumstances, over a long period of years stretching over decades, and affecting almost every aspect of their lives.

It is an account of how people have been failed, not once but often repeatedly, by their doctors, their communities and by their government.

Time has made matters worse, not better.

As Mr M, giving evidence anonymously in Leeds, said: *“the suffering ... is not frozen into time. We are none of us moving on, none of us putting distance between then and now. There is none of that, ‘time is a great healer’. There is no healing. Time is just adding insult to injury for most of us.”*<sup>884</sup>

The personal accounts in this chapter speak for themselves. They do not need any third party to speak for them, or to add weight to what has been said. What Professor Sir Jonathan Van-Tam said at the conclusion of his evidence should speak for those who have not experienced what people who have been infected and affected have been through. He said: *“I can only really begin to scratch the surface of the deep anguish, suffering, and loss that you have experienced as a result.”*<sup>885</sup>

## Consent and risk

Given this material, two conclusions are incontrovertible. First, nothing properly informative was said to patients or parents about risk. The risks that factor concentrates brought with them (whether for Haemophilia A or B, or von Willebrand disorder) were hardly addressed, if at all. Nor were the risks of transfusion (where they could reasonably have been expected to be discussed). There was no evidence that any effective choice of treatment was offered where one was available: the thrust of the evidence is clear that it was not offered.

Without an adequate discussion about the risks of treatment, or the alternatives available, no proper consent could be given to the treatment. It was worse, in some cases. There are examples in the chapter of people who were unwilling to have a transfusion or a blood

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884 ANON Transcript 14 June 2019 p81 INQY1000020

885 Deputy Chief Medical Officer for England (2017-2022). Professor Sir Jonathan Van-Tam Transcript 18 November 2022 p70 INQY1000265

product,<sup>886</sup> who nonetheless were given one: presumably because the clinicians concerned were dismissive of the risks or the patient’s reservations. That these are not the only such cases is shown in other chapters.<sup>887</sup>

It was worse, too, in that there are repeated accounts that when queries were raised, or misgivings expressed, assurances were given which turned out to be misleading. Other chapters show that not only were these assurances unjustified in the event, but that those giving them either did know, or should have known, at the time assurances were given that there was no adequate basis for them. In particular, the risks of HIV, Hepatitis B and Hepatitis C infections were downplayed, or ignored.

It is also clear beyond question that people were tested for the presence of HIV infection, or for indicators of, or the presence of, Hepatitis C infection without knowing of this.

## Communication

To discover, as many people did, that a test had been carried out without knowing that you had been tested for an infection never having consented to such a test, that the test had shown that you were infected, and your clinician had not shared this life-changing information with you immediately, could be brutal. The absence of consent is shown by the very fact that group meetings were called – in Edinburgh, in Belfast, in Cardiff, in Treloar’s – to tell people that they (or at least some of them) were infected with HIV. The fact that such meetings were called was a recognition in itself that the people asked to attend had not been told that they had been tested (for otherwise, they would have asked, “what are my test results?”). The clinicians involved had not made the effort to speak individually to each person on a matter which deserved – demanded – to be kept entirely confidential between clinician and patient.

This approach was not only wholly inappropriate, but it left some unclear as to their status.

The reluctance of doctors to tell people their HIV status is truly shocking. Very many people have reported not being told for some time after the clinician must have known. It would not necessarily have been easy for clinicians to have informed each patient individually as soon as they knew the result, but the interests of the patient and safeguarding of public health must come first. The failure to tell patients has contributed to a loss of trust in the NHS.

Informing people about the infections need never have caused the significant degree of distress it did. If a person had been told – and had agreed – that they were being tested for HIV or Hepatitis B or C, or both, they could then have been asked how they would like to be notified of the results. In most cases, the communication of the result could have fitted the individual. Because there was an absence of knowledge, generally, of testing, the autonomy

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886 Written Statement of Carol Carruthers paras 6-11 WITN1850001, Written Statement of Gillian Fyffe paras 2-2.19, para 5.27 WITN0363001, Written Statement of Lesley McEvoy paras 4-10 WITN1934001 and Written Statement of ANON paras 7-16, para 28 WITN1823001

887 See *Treloar’s, Haemophilia Centres: Policies and Practice* and *Blood Transfusion: Clinical Practice*.

of the patient was not respected as it should have been in allowing them to express their choice, and then observing it.

Delays in informing patients of their diagnosis of Hepatitis C were common. The effects of this were to risk the further spread within the community of Hepatitis C; to deny patients the opportunity of treatment in time to prevent further liver damage; and the loss of opportunities to adjust lifestyle and diet.

Witness after witness has confirmed the lack of real counselling at a time when information, sensitively given, was needed in the first place, and appropriate psychological support was essential. Even as long ago as the 1980s it should have been obvious to anyone that a young person told they had no future except a lingering death should be offered significant support. So too should others suddenly staring death in the face.

I limit my comments to these two areas – consent, and communication – as people have spoken for themselves. It is enough to say that, following the principle of placing individuals at the heart of this Inquiry, the rest of this Report has the substance of this chapter, and all of the other accounts which it has received, very much in mind.

On a personal note of my own I would like, again, to acknowledge – and admire, and respect – the courage of everyone who brought themselves to give evidence of such a personal nature so publicly whether by giving evidence orally, or in writing, or in talking privately to an intermediary.

## 2.2 Treloar's

This chapter focuses on what happened to infect almost 90 children at one boarding school. It evidences how research objectives often outweighed the individual best interests of the children. It relates pupils' experiences and the stark way in which pupils were informed of HIV diagnoses. It describes multiple areas of wrongdoing including indiscriminate use of commercial concentrates, despite knowing that it was likely to transmit infection, lack of informed consent, lack of consultation with parents and insufficient support offered to pupils after diagnosis.

### Key dates

**1960s** pupils identified as potential research subjects.

**By 1974** records indicate four completed research studies, prophylactic treatment study nearing completion and two further research projects planned.

**April 1977** Dr Kirk's study finds "*all cases of clinical hepatitis and most cases of asymptomatic hepatitis are confined to recipients of commercial concentrates*".

**1978/1979** haemophilia centre at Lord Mayor Treloar Hospital relocates to Treloar's School.

**March 1979** Dr Aronstam emphasises "*necessity*" of research "*as the concentration of haemophiliacs found at Treloars is unique within Britain*".

**1981** Dr Aronstam's thesis: "*Hepatitis has always been a risk*", but "*the risk increased markedly with the introduction of pooled concentrated preparations of factor VIII*".

**February 1983** pupils are being examined for any signs of the "stigmata of AIDS".

1984 concentrate usage at Treloar's is recorded at its highest level yet.

**December 1984** Dr Aronstam continues prophylaxis treatment with unheated concentrates.

**February 1985** Dr Aronstam records that 37 pupils had tested positive for HIV.

### People

**Dr Peter Arblaster** director (1972 - 1977)

**Dr Anthony Aronstam** director (from 1977)

**Dr Peter Kirk** senior clinical medical officer

**Alexander Macpherson** headmaster (1974 - 1990)

**Dr Seymour Rainsford** research fellow

### Abbreviation

**UKHCDO** United Kingdom Haemophilia Centre Directors' Organisation

## Introduction

The haemophilia centre at “Treloar’s” – the Lord Mayor Treloar Hospital and College at Alton in Hampshire – may on one level be regarded as a haemophilia centre, like many others. However, it has particular significance which demands giving it a chapter of its own. First, children with bleeding disorders were treated there. Second, throughout the 1970s and 1980s there was a large number of such children: around 50 or just over at any one time. Third, these children were boarders. In the late 1970s the school came to house the haemophilia centre, making pupils who had haemophilia essentially residents of their local centre. It was the only haemophilia centre of which this was true. Partly as a result, the pupil cohort was regarded as a prime subject for research into haemophilia, its treatment, and outcomes.

A sad, but compelling and fourth, reason for paying it particular regard is that of those pupils who attended Treloar’s in the 1970s and 1980s very few escaped being infected. The Inquiry was told that 122 pupils with haemophilia attended the school, following the introduction of concentrate therapy, between 1970 and 1987, of whom only around 30 remain alive.<sup>888</sup>

The tragedy that was Treloar’s both illustrates and highlights the nature of, and many of the reasons for, the national treatment disaster which was infected blood.

## Brief history of Treloar’s

In 1908 Sir William Purdie Treloar, former Lord Mayor of the City of London, established a school and hospital to treat children suffering from non-pulmonary tuberculosis. Children could attend school, and learn a trade, whilst still receiving necessary medical treatment and care. It became part of the Lord Mayor Treloar Trust, a charity which supports young people with physical disabilities and is now no longer focused centrally on tuberculosis. The NHS took over running the hospital in 1948, absorbing 75% of the Trust’s funds in doing so. The institution – both hospital and school on the same site – continued until the hospital closed down in 1994. The school and college continue, accepting students with physical disabilities from around the UK, aiming to support them in achieving independence both socially and academically.

The school moved to premises at Froyle in 1953.<sup>889</sup> The first pupils with haemophilia entered the school in 1956. The numbers grew quickly. By the 1960s, it was seen as the only school in the UK which accepted large numbers of boarders suffering from Haemophilia A, Haemophilia B and von Willebrand’s disease. It helped children with haemophilia to learn alongside others with the same condition. It avoided the isolation of a pupil with haemophilia on his own in mainstream education. So popular was it with local education authorities and parents, and so favoured by some haemophilia clinicians, that by 1971 or so there were 40 pupils, and this increased to some 53 by the autumn of 1974.

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888 Collins submission 16 December 2022 p94 SUBS0000063

889 It came to occupy premises at Holybourne as well, became co-educational, and in due course the junior school was at Froyle and the upper school at Holybourne.

The nearest hospital, Lord Mayor Treloar Hospital, was then at Alton. A haemophilia centre was established there in 1972 under the directorship of Dr Peter Arblaster. It catered for all people with haemophilia in the area, though the greater and growing proportion of its patients were boys attending the school. Dr Anthony Aronstam, who had taken up a post as director of the centre in 1977 in succession to Dr Arblaster, argued that it would avoid detriment to the children’s education if the haemophilia centre were relocated to the school (which already had a 10-bedded sick bay). As a result, in 1978/79, the haemophilia centre was relocated to the school, though still providing for the needs of others in the local community.

Apart from Dr Aronstam, and his predecessor as director Dr Arblaster (director 1972-1977), other notable members of the staff dealing with haemophilia were Dr Seymour Rainsford, a research fellow; Dr Mounir Wassef, who was senior clinical medical officer from the late 1970s; Dr Peter Kirk,<sup>890</sup> who worked in the mid 1970s;<sup>891</sup> Dr Michael Painter, who was briefly involved as a medical registrar for 15 months between May 1977 and September 1978; and Dr Ashok Roy, who worked as a haematologist from 1986 to 1990. Neither Dr Painter nor Dr Roy had managerial or decision-making responsibilities. For a time, in the 1970s, Dr John McHardy was a medical officer.

## Research

Research was a fundamental part of the activities of the Alton centre. This began in the 1960s when the Lord Mayor Treloar Trust began to feel that the “*nearly 40 haemophiliacs in the College*” provided “*an opportunity for research*”. It was encouraged by “*the very valuable help of Dr. Rosemary Biggs [of the Oxford Haemophilia Centre] and of Dr. K. M. Dormandy [of the Royal Free Hospital, London]*”.<sup>892</sup> It successfully applied for a research grant to enable this in 1967, which materialised in 1968 with the appointment of Dr Rainsford specifically to conduct research.<sup>893</sup> Alexander Macpherson, the headmaster of Treloar school, said that Dr Rainsford was at the sharp end of introducing better treatment for haemophilia, and was “*experimenting, in a way, with the use of Factor VIII.*”<sup>894</sup>

A meeting of the Wessex Regional Health Authority in March 1979 records Dr Aronstam’s emphasis on the “*necessity*” of research “*as the concentration of haemophiliacs found at Treloars is unique within Britain.*”<sup>895</sup> He spoke of the “*need for continuous monitoring of the levels of Factor VIII given to haemophiliacs in order to compare the relative effectiveness of different dosage levels*” and that he believed that both the benefits of intensive prophylaxis and the effectiveness of desmopressin (“DDAVP”) in the treatment of mild haemophilia should be further investigated.

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890 Dr Kirk declined to provide a statement to the Inquiry and since he was living in Canada he could not be compelled to do so.

891 Certainly from July 1974 to June 1976.

892 Letter from the warden of Lord Mayor Treloar College September 1967 p2 WITN7547002

893 Aronstam *Bleeding Episodes in Severely Affected Adolescent Haemophiliacs and Their Management with Replacement Therapy* p90 TREL0000517”.

894 Alexander Macpherson Transcript 24 June 2021 p12 INQY1000134

895 Minutes of Wessex Regional Health Authority meeting 28 March 1979 p1 HHFT0001066\_002

The reasons for an intense focus on research are not difficult to understand. Dr Rosemary Biggs, a central figure in haemophilia care at the time, observed in December 1970 that “*the collection of 49 haemophilic patients at the Alton School makes this a unique opportunity to study the disease.*”<sup>896</sup> She implied that Dr Rainsford had organised the getting together of a group of boys specifically to research them: it was, she said, in itself a major research objective to define “*the essential organisation required to treat boys gathered into one school*”, and this had been achieved. By then Dr Rainsford had already initiated seven other research projects of which she knew. It was only shortly later that a report said: “*This concentration in one residential centre of patients needing repeated transfusions has provided a good opportunity to study the incidence of Australia antigen and antibody in a vulnerable group.*”<sup>897</sup>

By 1974 it was being said that Treloar’s “*is also the only establishment in the United Kingdom which can provide the opportunity and the facilities for extensive clinical trials of various kinds of treatment. This type of research cannot, at present, be conducted anywhere else.*”<sup>898</sup> The same document speaks of a trial of prophylactic treatment then nearing completion; of four completed projects; and of two which were ongoing with two more planned for the future.

Dr Rainsford’s research position was extended beyond 1975. Each year a number of studies were in progress. Indeed, so many trials or research projects were carried out that on one occasion it was noted in respect of a proposed project that: “*This trial will need to be arranged so that it does not interfere with any future trial of prophylactic therapy.*”<sup>899</sup> Dr Kirk was also appointed specifically to conduct research. When Dr Aronstam, who had been associate director beforehand, became director in 1977 he too was interested in research: he aimed to collect data “*in depth*” on every bleeding episode thereafter.<sup>900</sup> Liver function tests were carried out at regular intervals on blood samples collected at the time that infusions of concentrate were given to boys. It was said “*an attempt will be made to trace the source of infection in every instance of hepatitis however mild clinically.*”<sup>901</sup>

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896 Letter from Dr Biggs to Duncan Guthrie 14 December 1970 p1 AMRE0000012\_004

897 The Incidence of Australia Antigen and Antibody in Boys Suffering from Coagulation Disorders p1 HHFT0000053\_001

898 Proposed Research Programme at Lord Mayor Treloar College p1 AMRE0000011\_021

899 The words “this trial” relate to a study dividing the boys into two groups – one getting tranexamic acid for the first three days with their therapy, the other not; Dr Kirk was to be lead researcher since he had shown “*great initiative, competence and responsibility*” when he had worked as a senior house officer at the Alton centre and was already engaged in many of the other research projects in progress. These studies were said to include one of antithrombin levels in patients and another was the study of hepatitis. Report from Treloar’s College requesting funding for a research fellow p6, p7 AMRE0000011\_006

900 He said so in the preface to his book: Aronstam *Haemophilic Bleeding: Early Management at Home* 1985 p11 RLIT0000666

901 Report from Treloar’s College requesting funding for a research fellow p5 AMRE0000011\_006. Despite this, in a letter of 3 November 1982 to the Royal Free Hospital, Dr Aronstam said: “*We had stopped recording the batch numbers of the transfusions because of the enormous amount of work this entailed for all our boys three times a year.*” Letter from Dr Aronstam to Peggy Britten 3 November 1982 TREL0000116\_139. This would in effect have made it very difficult to trace the source(s) of any infection, and given the importance of record-keeping in helping to control serum hepatitis recognised since at least 1952 – where the World Health Organization recommended this amongst



Research, then, was conducted at Treloar’s to an extent which appears unparalleled elsewhere. Four themes of central importance emerge from this. The first is the knowledge held by those in charge of the centre of those risks into which research was being conducted; the second, whether or not the children who were subject to this intensive research and their parents were informed about the very fact of research being proposed, its purposes and the risks it involved and were asked to consent to them; the third, the ethical implications of the particular study or trial and the individual pupil’s involvement in it (in other words whether there were aspects of that particular bit of research or study which might have led to the pupil being treated for haemophilia in a less than desirable or in an unsafe fashion, or in a way which increased the risk of exposure to viral infection); and the fourth, whether a focus upon research as a primary objective of educating a group of young people with haemophilia in one place, at Treloar’s, may have contributed to a mindset of seeing pupils as objects for research and study rather than as individuals.

## Knowledge

As to the first of these themes, knowledge goes hand in hand with research. Research implies familiarity with the current state of knowledge. What was the state of knowledge relevant to Treloar’s and research conducted there during the period after 1968? As was to be expected, it grew from year to year.

Thus, by early 1968: (a) it was well known<sup>902</sup> that “*a minute fraction of a millilitre of virus-laden blood was enough to cause hepatitis ... and it was for this reason that the production of large-pool plasma, made from the contributions of more than 300 donors, was abandoned in favour of limited pools derived from not more than ten donors*”;<sup>903</sup> (b) a practical method of using cryoprecipitate therapeutically<sup>904</sup> to treat haemophilia, initially reported in December 1965, had by 1968 been enthusiastically and widely adopted for clinical care; (c) an antigen associated with serum hepatitis had been discovered (“the Australia antigen”) in 1965.

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other measures – this may amount to a dereliction of duty by Dr Aronstam. World Health Organization Expert Committee on Hepatitis First Report 1953 p20 RLIT0000215

902 Amongst virologists and hepatologists, and possibly more generally – see the next footnote.

903 On the material before the Inquiry this was well understood. If reference is needed, one example of the knowledge is in an article *Complications of Blood Transfusion*, published in August 1965 in *The Practitioner* by Dr Jean Grant, the director of the regional transfusion centre in Oxford quoting research by Murray in 1955. Grant *Complications of Blood Transfusion* The Practitioner August 1965 p6 PRSE0003897

904 This is often referred to as the “discovery” of cryoprecipitate. In fact, the actual discovery of a protein-rich sludge after controlled thawing of fresh frozen plasma (“cryoprecipitate”) occurred in 1959 – but its suitability for treatment was not realised until there were developments in the design of plastic blood bags, which had only recently superseded glass bottles, and Dr Judith Pool realised that a closed bag system allowed for both the sterile separation of cryoprecipitate from supernatant fluid and its immediate re-freezing for successful storage and later re-use. The discovery that this was “how to do it” might as well have been the discovery of cryoprecipitate for all practical purposes of treatment for haemophilia.

By 1970 the discovery of the Australia antigen led to the finding of the “Dane particle”<sup>905</sup> which enabled the virus (known as Hepatitis B) to be fully identified. This then led on to a screening test for all domestic blood supplies being adopted by 1972.<sup>906</sup> These facts too were known.

After 1970, the researcher would also have known that factor concentrate manufactured commercially (in the US and Europe) began to be used in the UK on a named patient basis.

It was well understood generally from the late 1960s that factor concentrates were manufactured from pools of plasma contributed to by a number of donors. The larger the pool, the greater the risk that it might contain a contaminated donation. It was understood that there was little, if any, dilution effect: rather, a single donation might contaminate a large pool. And it was realised that it necessarily followed that the greater the number of batches the greater the risk; and that the more those batches were of different origin the more that risk was bound to be.

It was also understood that if a pool was drawn from a population which had a lower incidence of infection it would be less risky than one drawn from a population where infection was rife. It was understood, therefore, that NHS concentrates were inherently likely to carry less risk of viral transmission than commercial concentrates, especially those manufactured from paid donors who came from poorer urban districts of the US.

There can be little doubt that, first Dr Arblaster and Dr Rainsford, then Dr Aronstam and colleagues working under their leadership,<sup>907</sup> were well aware of this, since Treloar’s was conducting as much research as it was throughout the time that cryoprecipitate and factor concentrates were given to pupils. Though some suggested at the time that it was “*not yet proved*”<sup>908</sup> that commercial Factor 8 was much more dangerous from the point of view of causing hepatitis than other preparations, and that larger pools may also contain antibodies effective in reducing the extent of serum hepatitis,<sup>909</sup> and the vices of commercial

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905 Virus-like particles of 42 nanometres in diameter in blood with Australia antigen. In April 1970 this was reported as almost certainly being the complete virus. The particle was named after the UK clinician who discovered it.

906 The Blood Products Laboratory (“BPL”) – then an operation of the Lister Institute – started using it from 1970 to test the plasma supplied to it for making blood products.

907 Dr Kirk, Dr Painter, Dr Wassef, and possibly Dr Pat Tomlinson.

908 Dr Biggs. Minutes of Haemophilia Centre Directors meeting 1 November 1974 p6 HCDO0001017

909 Dr Rainsford’s 1970-73 hepatitis study had the conclusion: “*As antibody is evidence of previous exposure to serum hepatitis, it probably also indicates immunity and it is not surprising that clinical hepatitis is uncommon in adult haemophiliacs.*” The Incidence of Australia Antigen and Antibody in Boys Suffering from Coagulation Disorders p4 HHFT0000053\_001. In addition, a study published in the *British Journal of Haematology* in 1977 and authored by Biggs and others noted that the theoretical danger of exposure to infection increased with the number of donations contributing to the doses of treatment material used but said that severely affected and multi-transfused patients did not have a high incidence of clinical illness associated with jaundice and suggested that large pools might contain Hepatitis B antibody which might reduce infectivity. Biggs *Haemophilia Treatment in the United Kingdom from 1969 to 1974* British Journal of Haematology 1977 DHSC6887729\_105. These observations are valuable in an historical context: but cannot be applied more generally without caution, since the article by Biggs was submitted in 1973, and thus at a time when commercial concentrates had only just been licensed for the first time so that experience was limited, when cryoprecipitate was often still the treatment of choice, when “large pools” were very much smaller

concentrate were the subject of some debate,<sup>910</sup> it seems clear that most, if not all, who contributed to this debate thought there to be risks from their use, even if this had not been **conclusively** proved.

By 1973, researchers knew that what had previously been known as “infectious hepatitis” (Hepatitis A) was identifiable such that a test for that too became available. And, finally, no competent researcher could have been unaware that there were concerns about the increased risks of infection from using blood from paid donors as opposed to blood from voluntary non-remunerated donors.<sup>911</sup>

## Significant research projects

The safety of research projects conducted after 1970 falls to be considered against this established background knowledge.

Of particular note were three sets of research at Treloar’s: prophylactic therapy; hepatitis; and appropriate dosage regimes for different target joints. The fact that this Report now concentrates on aspects of those three should not mask the fact that, as already noted, there were many other research projects being conducted at any given time.

### 1. Prophylactic therapy

There were three trials of prophylactic therapy.<sup>912</sup> The idea was relatively simple. If a level of Factor 8 sufficient to provide for effective clotting was maintained in the bloodstream of a pupil with haemophilia, they would not suffer crippling bleeds. Factor 8 had a half-life<sup>913</sup> of 12 hours. A person with severe Haemophilia A could make little or no clotting factor of their own. Given the short half-life, maintenance of an effective level in the bloodstream of

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than they were shortly to become, and when testing for the presence of Hepatitis B antibody was in its infancy and comparatively unreliable. Further, the article covered 37 centres. The quality of reporting from various centres at this time is likely to have been poor, since one of the features of the evidence more generally has been that there is a wide margin of error around the reported figures at least until later.

- 910 At the 1974 UK Haemophilia Centre Doctors’ Organisation (“UKHCDO”) meeting, for instance, Dr John Craske reported on an outbreak of hepatitis in Bournemouth following use of a batch of commercial product. Dr Charles Rizza said that there had been 11 episodes of hepatitis in Oxford patients since January 1974 and it was not easy to identify which material had caused it. Dr Biggs hoped that commercial concentrate would not get an unnecessarily bad name. She said it was in fact clinically invaluable while the NHS supply was so limited. Dr Craske said he felt that a wholly NHS concentrate was likely to be safer when that was available. Minutes of Haemophilia Centre Directors meeting 1 November 1974 pp5-6 HCDO0001017
- 911 See for example: Titmuss *The Gift Relationship* 1970 HSOC0019917. In its original chapter 8 it describes that this was the conclusion of several earlier studies. The book describes how a “gift” – blood or plasma donated by voluntary non-remunerated blood donors – is intrinsically safer than blood sourced from donors who are paid.
- 912 The first was approximately 1973-74: Aronstam et al *Prophylaxis in Haemophilia: A Double-blind Controlled Trial* British Journal of Haematology 1976 NHBT0000091\_036; the second, 1975-76: Aronstam et al *Twice weekly prophylactic therapy in haemophilia A* Journal of Clinical Pathology 1977 RLIT0000084; the third, 1976-77: Aronstam et al *Transfusion requirements of adolescents with severe haemophilia A* Journal of Clinical Pathology 1979 RLIT0000093
- 913 ie the level of Factor 8 in the blood provided by the treatment reduced to half after 12 hours.

that person required constant topping-up. Only then might such a pupil be spared the worst effects of their condition. Large doses were needed for this approach to be effective.

To test whether this idea worked,<sup>914</sup> it was proposed for the first trial that those receiving treatment could be divided into two groups: one to receive a high dose regularly; the other to receive a placebo dose (in this case a low dose, rather than one with no effect at all) at the same intervals. Neither group would be told which was which.<sup>915</sup> The UK Haemophilia Centre Doctors' Organisation ("UKHCDO") discussed this proposal at its meeting in October 1972,<sup>916</sup> and thought it ethically problematic to conduct such a trial at any haemophilia centre in the UK. However, Treloar's was prepared to undertake it. Records do not identify the ethical concerns. It may be speculated that they concerned the considerable use of a scarce resource (NHS concentrate) for some patients, at the expense of depriving other patients elsewhere of sufficient treatment, if it deprived those others of the minimum amount of factor concentrates necessary to treat them effectively; it may be that the high-dose group were to be exposed to a surfeit of blood products manufactured from large pools and thus the risks of a recipient contracting post-transfusion hepatitis or other transmitted viral infections were multiplied;<sup>917</sup> but it is more likely that concerns arose because in order for the trial to be effective, half the children involved would get only a low dose,<sup>918</sup> which would be less than they were likely to need to prevent bleeds (although these were to be treated normally as and when they arose<sup>919</sup>). Thus those pupils were to receive additional injections which were

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914 It was not in itself a novel idea – the UKHCDO discussed in 1971 that a number of centres treated a few of their patients prophylactically, but it was more difficult for Haemophilia A than for Haemophilia B, so it was considered that a controlled trial would be useful. At that stage, Treloar's had not yet been selected as a location for this. Minutes of Haemophilia Centre Directors meeting 5 April 1971 p11 HCDO0001014

915 The trial was supposedly "double blind".

916 Minutes of Haemophilia Centre Directors meeting 27 October 1972 pp5-7 HCDO0001015. An internal Medical Research Council ("MRC") note of this meeting shows that the problems (which Dr Biggs is identified as speaking of in the minutes without those minutes specifically saying that these problems were ethical in nature) records as follows: "*Dr Biggs said that it was clear that no individual Haemophilia Centre could organise a trial of this type – for ethical reasons apart from anything else – but the Lord Mayor Treloar College at Alton were able to undertake it, and any other centres who could do so were welcome to join. Several points concerning the designs of the trial were discussed, and it became apparent that some of the Directors present either had reservations about it or disagreed with particular points.*" Note to Dr H W Bunje on Haemophilia Centre Directors meeting 27 October 1972 MRCO0000065\_022. It may be that the fact that the boys were under close daily observation for prolonged periods enabled such a trial – a suggestion found by reference to the same meeting in: Appendix III: Future Research AMRE0000007\_019

917 The only answer to this at the time could have been the supposition that after receiving a threshold amount of concentrate a person would inevitably have been exposed to infection; that they would already have succumbed if they were going to; and that no further exposure would add to the severity of that infection. None of these could be regarded as established fact at the time. An additional understood risk at the start of the 1970s was that units of US-made commercial concentrates were more likely to be infectious than units of NHS product, both because of the greater prevalence of infection in the donor pools used and the larger size of such pools.

918 The protocol described the "placebo" dose as an infusion of no more than 20 units of factor VIII concentrate, dissolved in a heat-inactivated sterile 1% albumin solution. Prospective Study of Preventive Treatment in Haemophilia p2 MRCO0000065\_008. The report on the trial described using a concentrate produced by BPL to raise the Factor 8 level by no more than 0.01 international unit/ml. Aronstam et al *Prophylaxis in Haemophilia: A Double-blind Controlled Trial* British Journal of Haematology 1976 p2 NHBT0000091\_036

919 According to the protocol in: Prospective Study of Preventive Treatment in Haemophilia p4 MRCO0000065\_008

(by design) likely to be of little positive value, whilst by virtue of the injection alone there would be some risk to the child,<sup>920</sup> let alone exposing that child needlessly to something which would add to the viral risk he faced without intending any proper therapeutic benefit. Handwritten annotations to one of the two copies<sup>921</sup> of this proposal which the Inquiry has obtained show that Dr Aronstam thought that “some form of concentrate” would be necessary, and referred to approaching a commercial organisation. The following words are attributed (in manuscript) to him: “*Very<sup>922</sup> doubtful that the trial would be ethically acceptable at a Haemophilia Centre.*” Yet despite this apparent view, the trial proceeded, without (it seems) any participant or their parents being alerted to the fact that the way they were treated was ethically of “very” doubtful acceptability elsewhere. In the end, the Blood Products Laboratory (“BPL”) provided a sufficient supply of NHS factor concentrate for the study.<sup>923</sup> This was one of the contributing causes for Treloar’s using a disproportionate quantity of NHS concentrate compared to other centres, and thereby (though inadvertently) adding to the risks faced by people with haemophilia being treated at those other centres when it was well known that there was insufficient supply of NHS concentrate across the country.

The trial was unpopular with many of the boys. In a report prepared for the Medical Research Council (“MRC”) on its progress, the Oxford Haemophilia Centre<sup>924</sup> reported “*many unforeseen problems have arisen. For example, the statistical plan lead [sic] to many boys being allocated to the control group in the first term. This gave the “treatment’ a bad reputation with the boys.*”<sup>925</sup>

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920 The evidence for drawing this conclusion is that the original proposal (in the early 1970s) was set out in a ten-page document: Prophylactic Administration of Cryoprecipitate in Haemophilia: A Controlled Trial DHSC0100026\_155. It talks throughout of using cryoprecipitate (in high or low doses), and not of using factor concentrate: save in one respect. That single respect relates to treating bleeds of the pupils on the study therapeutically when they arose between doses of the cryoprecipitate. The emphasis on cryoprecipitate suggests that large pools were not in consideration when ethical concerns were anticipated; nor would the use of cryoprecipitate, which was readily produced locally, deprive others patients of the chance of being supplied with the safer domestically sourced factor concentrates which were becoming increasingly available. Further, a conclusion that the ethical problem related to giving children injections of limited or no therapeutic value, in addition to those injections they needed to treat their bleeds as and when they arose, is indicated by Dr Arblaster’s comments recorded in manuscript: “*Some doubt whether a placebo should be used – local ethical committees have agreed*” (an ambiguous phrase but in context suggestive that those committees were doubtful whether this was ethical). Prophylactic Administration of Cryoprecipitate in Haemophilia: A Controlled Trial p10 MRCO000065\_025. It must be remembered that giving any infusion of cryoprecipitate risked stimulating an inhibitor reaction, and thus for this reason alone posed some risk to the child.

921 Prophylactic Administration of Cryoprecipitate in Haemophilia: A Controlled Trial DHSC0100026\_155, Prophylactic Administration of Cryoprecipitate in Haemophilia: A Controlled Trial MRCO000065\_025. They each have different handwritten annotations. The note recording Dr Aronstam’s views is written on the latter.

922 The use of “very” is worth noting.

923 See the report of the research: Aronstam et al *Prophylaxis in Haemophilia: A Double-blind Controlled Trial* British Journal of Haematology 1976 NHBT0000091\_036

924 Dr Biggs.

925 Progress Report 1967-1973 of the External Staff at the Oxford Haemophilia Centre 14 September 1973 p11 MRCO000039\_015. In the same month, one father wrote saying that he wished his son to be withdrawn from “*any further use of the treatment referred to in your letter of 21st March*”. Letter from Anon to Dr Arblaster 10 July 1973 TREL000065\_015. Six months later, Dr Arblaster reported on some of the practical difficulties: Minutes of Haemophilia Centre Directors and Blood Transfusion Directors meeting 31 January 1974 p4 CBLA0000187. A theme to which he returned at the end of

In the end, Dr Aronstam reported to the MRC that: “*We have now gone as far as we can with this trial, in the face of, I may say, enormous difficulties which I feel were a direct result of using a placebo for this study.*”<sup>926</sup> When he and his team reported the trial in the *British Journal of Haematology* for 1976, the last paragraph began with the words: “*We found many problems in this trial*”, and concluded: “*In our view, future trials should compare only probably effective prophylactic regimes, and should not include placebo doses.*”<sup>927</sup>

### *Second and third trials*

The first trial of prophylaxis had involved weekly injections, given to nine boys. The second prophylaxis trial involved four of the nine boys from the first trial receiving either Kryobulin or cryoprecipitate twice weekly. There was no low dose “placebo” – but instead prophylactic infusions were given in two different strengths – one intended to raise the level of Factor 8 in the bloodstream to 15% (which was less than the level aimed at to treat a bleed into a joint,<sup>928</sup> which was 20%), the other to 30%.<sup>929</sup>

A third prophylaxis trial, after the first which had involved weekly injections, and the second which had involved twice-weekly injections, was one which sought to give alternate day/ three times a week injections. The published study compared the effect of five boys receiving a dose twice a week in 1976, with thirteen who had doses three times a week in 1976 and 1977.<sup>930</sup> This showed that there could be a significant lessening in the number of bleeds, but to achieve it would require amounts of concentrate which were simply unavailable in such quantities.

However, an unpublished study<sup>931</sup> was also conducted which is described as “*the third prophylactic study*”, but does not appear to correlate with the trial just described. This

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1974: Minutes of Haemophilia Centre Directors meeting 1 November 1974 p7 HCDO0001017. Boys had withdrawn for various reasons.

926 Letter from Dr Aronstam to Dr Bunje 22 July 1975 MRCO0000065\_005

927 Aronstam et al *Prophylaxis in Haemophilia: A Double-blind Controlled Trial* British Journal of Haematology 1976 p8 NHBT0000091\_036

928 This might seem hard to fit with Dr Aronstam’s express view in his report of the first trial that future trials should compare only “*probably effective prophylactic regimes*”: the word he used was “*probably*” not “*possibly*”, and it is not easy to see the basis for probability here.

929 Aronstam et al *Twice weekly prophylactic therapy in haemophilia* A Journal of Clinical Pathology 24 May 1976 RLIT0000084

930 The report says that over the two years 15 boys altogether were involved: it must follow that there was an overlap between the two groups identified: Aronstam et al *Transfusion requirements of adolescents with severe haemophilia* A Journal of Clinical Pathology 1979 p1 RLIT0000093. The results – probably of this trial, though see the following footnote for an unpublished study also described as the third study, if that is the case – were reported to UKHCDO directors: Minutes of Haemophilia Centre Directors meeting 13 January 1977 pp9-10 PRSE0002268. It is to be noted that two boys (as it happens those most advantaged by the treatment regime in the eyes of Dr Kirk) both wanted to stop being part of the trial. The inference from what was reported to this meeting is that they were nonetheless kept on it.

931 Protocol for the third prophylaxis study carried out at Lord Mayor Treloar College OXUH0003758\_004. Interestingly, this ends with thanks to “*Immuno and Travenol for their support.*” Protocol for the third prophylaxis study carried out at Lord Mayor Treloar College p5 OXUH0003758\_004. Presumably the concentrates were supplied by those firms. This is another reason for thinking this study is distinct from that referred to in the preceding paragraph, which acknowledges help from the Sir William Coxen Trust Fund.

aimed to see if prophylaxis would improve the radiological appearance of joints and “*more particularly have any influence on haemophilic cysts.*” It concerned six boys. Two were given Hemofil, three were placed on Kryobulin and one was on cryoprecipitate. It aimed at giving them enough to raise levels to 30%, every other day (so in this respect was similar to the “three times a week” referred to in the preceding paragraph). However, in the event each had a different concentration.<sup>932</sup> Two of the boys showed a significant improvement in the radiological appearance of their knees, but none who had cysts showed any change. In one of the cases, the prophylactic regime simply failed.

Andrew Quinn told the Inquiry: “*I was one of six boys at Treloar’s who were selected to receive Factor VIII, prophylactically, for a year ... I was never advised that there were any risks attached to receiving Factor VIII. This was sold to me as a new treatment, which I could have as a ‘home treatment’ and which would change my life; it did but not in the way in which the medical profession had envisaged.*”<sup>933</sup> Andrew was infected with HIV, Hepatitis C and Hepatitis B.

## 2. Hepatitis

From 1970 to 1973, Dr Rainsford studied the **incidence** of hepatitis, which he called “serum hepatitis”.<sup>934</sup> The aim was to see if there was any pattern to the way in which antibodies and antigens to serum hepatitis correlated with clinical illness, the frequency of transfusion and the presence of antigens in the blood products with which they were being treated.

In 1975 there followed a **prospective study of hepatitis associated with the use of Factor 8 concentrates**. The protocol for this acknowledged that recent research had shown that viruses other than Hepatitis A and B might well be causing a significant amount of post-transfusion hepatitis.<sup>935</sup> The study looked to see if commercial concentrates had a higher attack rate than domestic ones: it sought to answer the question: “*Does the administration of factor VIII concentrates to haemophiliacs on regular replacement therapy significantly increase the incidence of transfusion hepatitis?*”<sup>936</sup> To test whether it did, it was arranged that pupils should receive injections drawn from only one batch of product over a three-month period. (This would have the result of limiting their exposure to donors, by contrast, as it will be seen, with the way most other pupils were exposed to a whole range of products, without any apparent concern about their exposure. The purpose of the restriction was not,

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932 Ranging from 19% to 37%.

933 Written Statement of Andrew Quinn paras 4-7 WITN1482001

934 Incidence of Hepatitis Associated Antigen Antibody amongst boys suffering from Coagulation Disorders (Interim Report) HHFT0000332. Strangely, given the discovery of Hepatitis B and the use generally of that nomenclature in the medical press, the term “serum hepatitis” remained in use at Treloar’s into the 1980s.

935 Hepatitis in Haemophilia Associated with the Use of Factor VIII Concentrates: A Prospective Study 1975 pp1-2 CBLA0000312

936 Hepatitis in Haemophilia Associated with the Use of Factor VII Concentrates: A Prospective Study p1 CBLA0000312

however, to protect the patient: it was to make it clearer whether one particular product caused more hepatitis than another.)<sup>937</sup>

The protocol said there would be 20 boys on cryoprecipitate, 10 on Kryobulin and 5 on BPL product.<sup>938</sup> However, a report on the study records that Hemofil was given to one child as part of the study. This boy in fact did not bleed frequently and so needed only limited treatment. It was administered despite the fact that it was already practice at the Oxford Haemophilia Centre<sup>939</sup> not to give “large pool material” to patients who had received relatively little previous treatment or to small children (that very point was known to Dr Rainsford and Dr Kirk at the time since it had been mentioned at a meeting considering the prospective study in advance).<sup>940</sup> The boy went on to develop acute hepatitis.<sup>941</sup> There was no consultation with parents about the research.<sup>942</sup> Dr Kirk reported the results of the study to the National Institute of Biological Standards in April 1977:

*“We have been conducting the Hepatitis Survey for some 19 months and are almost in a position to have a significant result. All the cases of clinical hepatitis and almost all the cases of asymptomatic hepatitis were confined to the patients restricted to commercial concentrates. There were no significant differences between the cases restricted to Hemofil and Kryobulin. In the next stage of the Study, I am proposing to restrict patients to either commercial concentrates as a group or Cryoprecipitate or Lister Concentrate as I understand that all commercial Factor VIII concentrates are being made from North American plasma including Kryobulin.”*<sup>943</sup>

Dr John Craske from the Public Health Laboratory Service encouraged further study.<sup>944</sup>

Ethically, the best interests of a patient should prevail. It is difficult to see how this principle could be applied to the next stage of the study as Dr Kirk proposed to conduct it: for he had concluded (i) asymptomatic hepatitis was much more likely to be suffered by those

937 Minutes of meeting to discuss the incidence of hepatitis in haemophilic patients 22 May 1975 pp2-3 OXUH0001103\_004

938 ie NHS concentrate manufactured in England at BPL.

939 Oxford was the reference centre for Treloar’s, so it might be expected that Treloar’s would follow its protocols.

940 Minutes of meeting to discuss the incidence of hepatitis in haemophilic patients 22 May 1975 p2 OXUH0001103\_004

941 Kirk et al *Prevention of contractures after bleeding into the calf muscles* 20 April 1976 p6 SWCX0000003\_002

942 There is considerable evidence to prove the absence of consultation, and hence the absence of informed consent. Two examples only need be given here: Nick Sainsbury gave evidence that his parents were told of what was a fait accompli: “*Your son has been selected to receive only Kryobulin when he requires transfusing.*” Draft Letter from Dr Kirk to parents of Treloar’s students December 1975 TREL0000022\_008. Further, there is a letter about another pupil written to his home clinician, showing that there had been no advance discussion about the research on him: “*As [Anon] would appear to receive only cryoprecipitate at your hospital I have selected him for this group and during this term he has received only this material.*” Letter from Dr Kirk to Dr Williams 8 December 1975 TREL0000147\_061

943 Letter from Dr Kirk to Dr David McGrath 1 April 1977 CBLA0000590

944 Letter from Dr Craske to Dr Aronstam 7 October 1977 HHFT0000925\_001



receiving commercial concentrates; but was proposing (ii) that a group of patients should receive nothing else, in order to study the effects – inferentially to see if, as already thought probable, they also succumbed to it.

Dr Craske applied for a grant to conduct further research at Oxford. When explaining his project, he referenced the hepatitis study, and provided a summary of the results that Dr Kirk had presented at the meeting on 14 December 1977. These showed that 15 out of 45 boys from Treloar’s had consistently elevated serum enzyme levels for over six months or more, associated with the use of freeze-dried Factor 8 concentrate. 10 out of 13 boys examined had evidence of enlarged livers and spleens<sup>945</sup> and 2 had evidence of chronic active hepatitis.<sup>946</sup>

### 3. Appropriate dosage regimes for particular joints

Third, there was a trial to see which of three dosage regimes addressed bleeds into knee, elbow and ankle joints most effectively. This involved pupils being given doses of 7, 14, or 28 units (per kilogram of their bodyweight), and was written up in *The Lancet* in January 1980.<sup>947</sup> This necessarily involved some pupils being given lower doses than would otherwise have been thought appropriate for their treatment. This risked those doses being ineffective. Indeed, one of the former pupils who gave evidence to the Inquiry recorded what the result was like for him. Mr BA<sup>948</sup> said:

*“I remember getting – I had a series of knee bleeds, and Dr Aronstam used to say to another doctor ‘Trial’, and I’d say oh – I’d think inwardly: hell, that means I get a tiny dose and I’m going to be back here in another three days. So my – say 10%, so you get a 10% dose. That was my recollection. And which I felt I hated, because I knew it wasn’t enough, and I saw in my notes actually another doctor wrote, ‘This boy’s had 10% doses for this knee and it isn’t enough’ ... these small doses are not working.”*<sup>949</sup>

What might have been regarded as unethical was that a pupil such as he was could not be given more factor concentrate, especially if it appeared more was needed, without depriving the study of a valid comparison between those who had “sufficient” treatment and those who did not. The rationale for conducting this trial is, however, revealing. It was to identify what might be the lowest effective dose of Factor 8. This was thought desirable for three reasons. First, the cost of Factor 8 threatened its continued provision; second, a supposed

945 Hepatosplenomegaly.

946 He applied for a research grant in April 1978 for “*Studies of the epidemiology and chronic sequelae of Factor VIII and IX associated transfusion hepatitis in the United Kingdom*”. Letter from R Buxton to Dr William d’A Maycock 19 April 1978 CBLA0000756

947 Aronstam et al *Double-Blind Controlled Trial of Three Dosage Regimens in Treatment of Haemarthroses in Haemophilia A* *The Lancet* 26 January 1980 RLIT0000198

948 Mr BA Transcript 21 June 2021 p151 INQY1000131. The probability is that he is referring to his memory of this trial, though it is not absolutely clear this is so.

949 He also said that no one had explained anything about it: which raises further ethical concerns. The 10% is a reference to an amount calculated by applying the percentage to the individual’s body weight by reference to a chart showing the level of dose indicated as a result.

“shortfall in human sources” threatened its continued supply; but third, and possibly most significant to the Inquiry, was that there was “growing evidence that *chronic hepatitis was a not-uncommon consequence of transfusion*”,<sup>950</sup> related to the total number of donors to whose blood a patient had been exposed.

## Consultation about research

The few surviving former pupils who had been among the research subjects in the trials just described told their memories to the Inquiry. They gave a consistent account that there had been no meaningful consultation with their parents, or with them.

One example was Gary Bennett who, together with his brother Tony, went to Treloar’s in 1980. He was then aged 10 or 11. He had had nothing but cryoprecipitate before he left home to become a boarder. Despite his home physician (Dr Morag Chisholm) saying to Dr Aronstam that she started all her home therapy patients off on NHS concentrate, at Treloar’s he was put on “long-term prophylaxis” for which three different types of concentrate were used.<sup>951</sup> He protested to the doctor “many times” that he did not want it, but was told he needed it.<sup>952</sup> He was also one of seven pupils put on a trial of DDAVP in May 1982.<sup>953</sup> His parents were not told of this.<sup>954</sup> His liver enzymes were tested regularly, and were persistently elevated, but he was never told by the school that he had hepatitis.

A parent, John Peach, recounted a similar story in relation to his two sons Leigh and Jason. Leigh first went to Treloar’s in 1978 aged 11. He had been under the care of Dr Charles Rizza at the Oxford Haemophilia Centre, who told Dr Aronstam that he would prefer Leigh to use NHS concentrate when self-administering his therapy.<sup>955</sup> What Leigh got at Treloar’s was very different – some NHS, indeed, but mainly Koate, Hemofil, and Factorate.<sup>956</sup> John was never told that his son was being given commercial concentrate.<sup>957</sup> Although there is some evidence that on one occasion Leigh’s mother was asked for consent for him to take part in an unspecified trial,<sup>958</sup> John had no idea of this. He was not told about prophylaxis being

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950 Emphasis added. Aronstam et al *Double-Blind Controlled Trial of Three Dosage Regimens in Treatment of Haemarthroses in Haemophilia A* The Lancet 26 January 1980 p1 RLIT0000198. The references for chronic hepatitis, and the implied and problematic consequences of this, are to papers from 1977 (Hasiba) and 1978 (the Preston paper, which features heavily in this Report).

951 Patient medical record of transfusion requirements for Gary Bennett p4 TREL0000110\_080

952 Gary Bennett Transcript 22 June 2021 p107 INQY1000132

953 Notes on DDAVP trial May 1982 HHFT0001430, Gary Bennett Transcript 22 June 2021 p103 INQY1000132

954 Gary Bennett Transcript 22 June 2021 p104 INQY1000132

955 Letter from Dr Rizza to Dr Aronstam 11 September 1980 TREL0000242\_012

956 Patient medical record of bleeding episodes for Leigh Peach TREL0000242\_041

957 John Peach Transcript 22 June 2021 pp71-72 INQY1000132. This is despite the fact that Dr Aronstam wrote a thesis in 1981 in which he described the contemporaneous medical literature as showing that commercial concentrate carried a significantly higher risk of causing hepatitis than did NHS concentrate, and cryoprecipitate carried even less risk. Aronstam *Bleeding Episodes in Severely Affected Adolescent Haemophiliacs and Their Management with Replacement Therapy* p72 TREL0000517

958 There is a signed form agreeing to Leigh “taking part in a trial as explained by Dr Aronstam.” Lord Mayor Treloar Hospital Trial Consent Form for Leigh Peach p2 TREL0000242\_034. There is no

trialled on his son.<sup>959</sup> Nor was he told about his having hepatitis when he developed it.<sup>960</sup> Jason too was treated with commercial concentrate without his parents' knowledge and without them being given any information about any risks of treatment; they knew only that there was the possibility of going "yellow" with "a bit of jaundice", which they understood to be both mild and unavoidable.<sup>961</sup>

Nicholas (Nick) Sainsbury, born in 1963, was treated with plasma at first, and then with cryoprecipitate (then regarded as "a wonder drug"). He went on receiving only that, until he went to Treloar's and was given concentrate for the first time. His parents were never sent any letters from Treloar's telling them about his treatment, save one which was written by Dr Kirk, and is the sole such letter in his records: "*Your son has been selected to receive only Kryobulin when he requires transfusing. By limiting him to this type of factor VIII containing material it will be easier to trace the source should he contract hepatitis.*"<sup>962</sup> Nothing in the letter sought his parents' consent for this; it was telling not asking. Nick told the Inquiry that they were never requested to consent to any part of his treatment. In contrast to the lack of information provided to his parents, Dr Kirk did write to a Dr C G L Raper (the consultant under whose care Nick was when at home) speaking of his (the doctor's) co-operation in "*the Hepatitis Study*" by making Kryobulin available for Nick's routine treatment.<sup>963</sup> This was a "*Study*" which had never been discussed with Nick's parents.<sup>964</sup>

Lee Stay, who went to Treloar's from 1980, reported that he frequently received concentrate. Nothing was said to him or to his parents about the risks: there was very little interaction between Treloar's and them. Though his parents had been closely involved with his treatment when he had been at home, they were not involved at all with that at the school.<sup>965</sup> What Lee was given was a complete mix of makes of concentrate, and batches were mixed as well. His case is an exception to the general absence of evidence of consent in that there is a document on file recording his father's agreement "*to Lee Stay taking part in a trial as explained by Dr Aronstam.*"<sup>966</sup> He says he was himself unaware of this trial; and, perhaps critically, and as with Leigh Peach, there is no information about the terms in which any explanation was couched, or even what the trial was.

A similar form was completed by Peter Baker's mother, recording agreement to her son "*taking part in a trial as explained by Dr Aronstam*"<sup>967</sup> but there is no explanation whatsoever

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material showing what this explanation was, nor how detailed it was if actually given. On balance, if there had been any sufficient explanation of what was involved it is likely that John Peach would have known of this. He plainly did not believe he ever had. John Peach Transcript 22 June 2021 pp72-73 INQY1000132

959 John Peach Transcript 22 June 2021 p73 INQY1000132

960 John Peach Transcript 22 June 2021 pp74-75 INQY1000132

961 John Peach Transcript 22 June 2021 pp79-81 INQY1000132

962 Draft Letter from Dr Kirk to parents of Treloar's students December 1975 TREL0000022\_008

963 Letter from Dr Kirk to Dr C Raper 27 February 1976 TREL0000074\_021

964 Nick Sainsbury Transcript 22 June 2021 p2, pp11-17 INQY1000132. Nick died in May 2023.

965 Lee Stay Transcript 23 June 2021 pp67-72 INQY1000133

966 Lord Mayor Treloar Hospital Trial Consent Form for Lee Stay p2 WITN1541009

967 Trial Consent Form TREL0000034\_096

as to what she was being asked to agree with. Peter’s recollection is that his mother was “*sent my school reports and that was it.*” He confirms that “*no advice or warning about the risk of infection from FVIII treatment was given to me or my parents beforehand.*”<sup>968</sup>

Though there were isolated reports of consent for participation in a study having been sought from parents, in general they were not consulted and, when they were, information was severely limited. On occasion, this prompted some parents to withdraw their “consent”.<sup>969</sup> The risks of hepatitis from treatment, and the increased risks of this from the use of commercial concentrates, were rarely mentioned, if at all.

Such early letters as have been retrieved were uninformative – one, from the headmaster describing the appointment of Dr Rainsford to the staff simply told the parents receiving it that during his work Dr Rainsford would “*collect information regarding the incidence of joint and muscle haemorrhage*” and implied that this was a “*study*” which would involve one group of boys receiving “*somewhat different treatment*” from that given to another. It immediately then said that “*equal care will naturally be given to every boy*” though, on reflection, this seems improbable. Why else would different treatment be given if not to see whether the effects were different as between the differently treated groups, and if the outcomes were different how could this care truly be “*equal care*”? The headmaster went on to say that he was “*sure that the new medical arrangements are very much in your son’s interest*” but did not give any reason why this was.<sup>970</sup>

A letter was written to a father, by Dr Arblaster, inviting his “*co-operation*” in the improvement of haemophilia treatment by agreeing to giving his son regular weekly injections of concentrated material (ie prophylaxis, though perhaps understandably that label was not used). The risks involved in this treatment were not mentioned.<sup>971</sup>

It emerges from another letter<sup>972</sup> that the introduction of a new form of treatment in 1973 was not thought to be a matter requiring the parent’s consent at all: it simply told the parents that their son “*has this term had a new form of treatment and it may well be that there are some aspects you would like to discuss.*”<sup>973</sup> On another occasion it appears that Dr Rainsford

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968 Unsurprisingly he felt “*betrayed by the doctors at Treloars College. They were supposed to be there to care for us. They took the Hippocratic Oath to do no harm. The moment they knew there was any possibility of causing harm to us they should have put us straight back on cryoprecipitate.*” Written Statement of Peter Baker para 6, para 15, para 16 WITN6413001

969 Letter from Anon to Dr Arblaster 10 July 1975 TREL0000065\_015, Letter from Dr Arblaster to Anon 12 July 1973 TREL0000065\_014. Over the next two years the boy would be treated with cryoprecipitate, Hemofil, NHS concentrate and Kryobulin. Treloar Haemophilia Centre treatment summary September 1970 to February 1975 TREL0000065\_007, Treloar Haemophilia Centre treatment summary February to June 1975 TREL0000065\_002

970 Letter from P Johnston-Smith to Anon 19 April 1974 p1 TREL0000020\_023

971 Letter from Dr Arblaster to Anon 21 March 1973 TREL0000277\_010. Though risks were not hinted at in the letter, discussion of the proposed treatment was offered if the parent wished it. It is thus possible that some risks might have been raised if there was any such discussion, though there is no actual evidence of this having happened.

972 Letter from Drs Arblaster, Rainsford and Aronstam to parents 13 July 1973 TREL0000027\_038

973 In other words, it was a question of acting first, and allowing for the asking of questions later: ethically, the wrong way round.

wrote to a parent asking for their consent to a “*special test*” on their son, without giving any reason for wanting to do it.<sup>974</sup>

Such letters seeking consent as the Inquiry has seen, remained generally uninformative about what was proposed, why it was proposed, its risks and benefits to the boy concerned, and what the alternatives were for that boy. A letter from Dr Painter seeking permission to study pupils to see whether the usage of DDAVP together with factor concentrate to treat a person with severe haemophilia might ensure a more long-lasting effect from the concentrate spoke of giving a boy both a higher dosage of concentrate and an “*other substance*”. One mother receiving this replied: “*Before agreeing to anything like this I would like to know a lot more about this ‘other substance’*”;<sup>975</sup> another receiving a similar letter asked: “*if you would let us know the nature of the ‘other substance’ and the results you would hope to obtain.*”<sup>976</sup>

## Treatment policies and product usage

A number of sources confirm a picture of a deliberately heavy use of concentrates, in which a range of concentrates – mainly commercial – was used indiscriminately (except when it was thought necessary for some research study to focus upon a particular type).

The particular sources on which the Inquiry has relied for this conclusion are the testimonies of the few remaining survivors, annual returns to the UKHCDO, publications by those who worked at the centre, statements from those who are still in a position to provide them, contemporary documentary evidence and correspondence. All paint broadly the same picture.

This picture is all the more vivid for the absence of any written statement of policy. By contrast with some other centres, there was no written policy as such – and the occasional articulations by Dr Aronstam of his “*approach*” do not always fit with what actually happened in practice.

When boys with bleeding disorders first came to Treloar’s, neither cryoprecipitate nor concentrate were available to use. In the late 1960s, fresh frozen plasma was the mainstay of therapy, and then, from the late 1960s to 1971, cryoprecipitate. Concentrates were probably first used after March 1969.<sup>977</sup> The general picture in the years that followed is that concentrates were used without any meaningful distinction between their sources, or brands. This usage brought with it risks of infection of which doctors at Treloar’s were aware (see what is said under the heading *Knowledge* above).

Where a real risk is identified, steps should be taken where possible to avoid or reduce it. Here, avoiding risk would dictate the use of lesser rather than greater quantities of product

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974 Letter from Anon to Dr Rainsford 16 May 1972 TREL0000186\_025

975 Letter from Anon to Dr Aronstam and Dr Painter 23 May 1978 TREL0000105\_040

976 Letter from Anon to Dr Painter 23 May 1978 TREL0000147\_018. Again, 1978. Both this and the previous response to Dr Painter refer to “*other substance*”, so it is to be inferred that this expression is in Dr Painter’s original letter, of which no copy now survives.

977 Letter from Dr Rainsford to Dr Maycock 18 March 1969 DHSC0100025\_098

so far as adequate treatment permitted. It would suggest a consistent use of the same product, and wherever possible the same batch of that product, for repeated infusions.

That the risk was not avoided as it could have been by these means<sup>978</sup> emerges from returns which were made annually to the UKHCDO based at Oxford, recording how much treatment material, of what type, had been used in the previous year. In 1976, the first year for which returns are available, just over 600,000 units of cryoprecipitate were used, just over 150,000 units of NHS Factor 8 and over 1,000,000 units of three different commercial concentrates.<sup>979</sup> Haemophilia B patients received NHS Factor 9. The handful of von Willebrand patients received mainly cryoprecipitate with some NHS Factor 9.

The following year, 1977, cryoprecipitate and NHS factor concentrates were both in active usage, but now four commercial products were used.<sup>980</sup> These were principally Hemofil, then Kryobulin, but also Factorate (Armour)<sup>981</sup> and Koate (Cutter).<sup>982</sup>

It is plain from contemporaneous records that most individual patients received multiple types of concentrate, as well as cryoprecipitate. It was common for pupils to have all four of the commercial concentrates supplied; it was a minority which only received one type. In addition, the majority, from time to time, had some NHS concentrate from Elstree; some also received concentrate from Liberton in Scotland.

By 1978 cryoprecipitate use had declined almost to nil: the usage of that, of NHS, and of commercial concentrates in the following years is set out in the figure below.

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978 Rather, it was amplified by what in fact happened.

979 Annual Returns for Lord Mayor Treloar Haemophilia Centre 1976 HCDO0000045\_003. Just over half was Kryobulin (from Immuno Ltd) and the balance was Hemofil (Hyland Laboratories) with a comparatively small contribution of 13,000 units of Koate (Cutter Pharmaceutical). As the text goes on to mention, the relative quantities of each of these varied. Until 1976 only Hemofil and Kryobulin were licensed for distribution and sale to centres; they were joined in 1976 first by Factorate (25 March 1976) and then Koate (Speywood Laboratories/Cutter) from 27 August 1976. The 1976 licensing of Factorate and Koate may explain the usage of those materials from then onwards, as well as Hemofil and Kryobulin.

980 Annual Returns for Lord Mayor Treloar Haemophilia Centre 1977 HCDO0001131

981 86,370 units.

982 57,680 units.

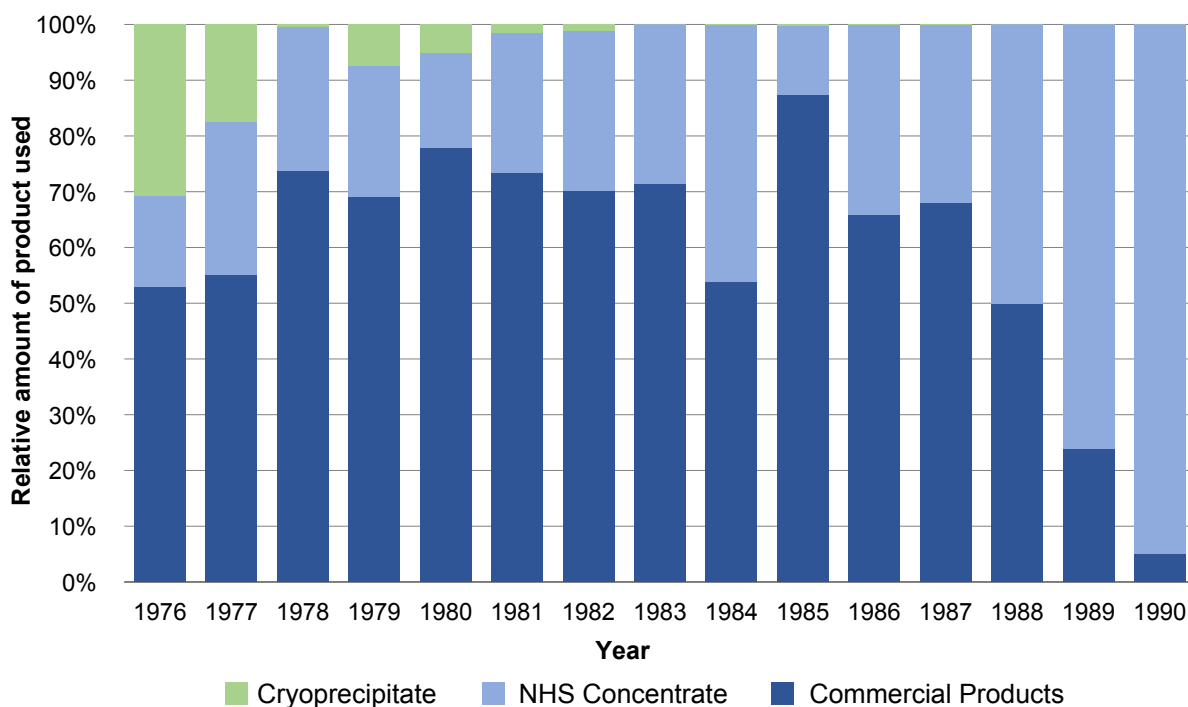


Figure 1: Treloar’s: All Patients 1976-1990<sup>983</sup>

### Quantity of product

Despite the knowledge referred to above, Dr Rainsford thought in early 1969 that boys had been undertreated before he came. He plainly took the view that more was better.<sup>984</sup> From the time he came, and throughout the 1970s and 1980s, usage of product at Treloar’s remained deliberately high. The object of treatment was to avoid joint pain and damage as far as possible; but there is no record showing that the gains treatment brought in the late 1960s were balanced against the risks, and measures that might have been taken even then to reduce them.

Recognition that Treloar’s was an outlier on the high side when it came to product usage is dotted throughout available documents. An early example is from May 1973, when a consultant pathologist wrote to the centre: *“One point which interests me is the amount of Cryoprecipitate which I administered is rather less than that given by yourselves. I have*

983 Lord Mayor Treloar Haemophilia Centre annual return 1976 HCDO0000045\_003, Lord Mayor Treloar Haemophilia Centre annual return 1977 HCDO0001131, Lord Mayor Treloar Haemophilia Centre annual return 1978 HCDO0001224, Lord Mayor Treloar Haemophilia Centre annual return 1979 HCDO0001294, Lord Mayor Treloar Haemophilia Centre annual return 1980 HCDO0001388, Lord Mayor Treloar Haemophilia Centre annual return 1981 HCDO0001487, Lord Mayor Treloar Haemophilia Centre annual return 1982 HCDO0001590, Lord Mayor Treloar Haemophilia Centre annual return 1983 HCDO0001686, Lord Mayor Treloar Haemophilia Centre annual return 1984 HCDO0001782, Lord Mayor Treloar Haemophilia Centre annual return 1985 HCDO0001875, Lord Mayor Treloar Haemophilia Centre annual return 1986 HCDO0001971, Lord Mayor Treloar Haemophilia Centre annual return 1987 HCDO0002064, Lord Mayor Treloar Haemophilia Centre annual return 1988 HCDO0002153, Lord Mayor Treloar Haemophilia Centre annual return 1989 HCDO0002247, Lord Mayor Treloar Haemophilia Centre annual return 1990 HCDO0002338

984 Letter from Dr Rainsford to Dr Maycock 18 March 1969 DHSC0100025\_098

*found that with the admittedly relatively minor bleeds which [he] has had here, a total of eight units given over two days seems to control the haemorrhage adequately. If you feel that it would be better to give larger doses however, I will bring my treatment into line with yours.*<sup>985</sup>

Dr Aronstam recognised that the usage at Treloar’s was high: in 1978 he referred to their routine use of prophylaxis “*in many clinical situations*” and described having secured “*all the material we need for our admittedly enthusiastic programme*”;<sup>986</sup> later he said expressly in his thesis that his policy was that bleeds should be “*treated vigorously*” where they involved adolescents.<sup>987</sup>

Richard Warwick, who attended Treloar’s between 1976 and 1982, recalled that: “*They were crazy about prophylaxis at Treloars. It was like every day. In many cases it would be come in after breakfast and go in to the sick bay out and either something would be laid out for us or we’d mix our own but generally it would all be pre-prepared and it would just be every morning, you know*”.<sup>988</sup> Stephen Nicholls, who joined Treloar’s in 1976, similarly recollected that the school:

*“really started to push the use of prophylaxis treatment. They encouraged most to be treated regularly with factor (in my case Factor IX) and if they could have you taking prophylaxis every other day then they would ... they remained very insistent and if you hadn’t been in for your treatment by 4pm a nurse would come and find you and take you to the treatment room ... at no stage was there ever any mention of the risks or danger involved in having this treatment”*.<sup>989</sup>

The available returns show a very significant rise in total usage of product during the second half of the 1970s. The probable reasons for this are a matter of interpretation. Though an increase in the number of pupils with severe haemophilia at the school is unlikely to be the reason since the school concentrated on admitting such pupils, it may have been that children admitted to the school were increasingly those who bled more frequently.<sup>990</sup> There was also, however, an increase in the individual amounts given per bleed. In a publication studying the years 1973 to 1977 the average amounts were shown to have

985 Letter from Dr Iain Frew to Dr Aronstam 2 May 1973 TREL0000059\_008

986 Letter from Dr Aronstam to Dr John Stafford 14 March 1978 CBLA0000745

987 Aronstam *Bleeding Episodes in Severely Affected Adolescent Haemophiliacs and Their Management with Replacement Therapy* p168 TREL0000517

988 Richard Warwick Transcript 20 June 2019 pp67-68 INQY1000023

989 Written Statement of Stephen Nicholls para 12 WITN1432001. See also: Stephen Nicholls Transcript 1 May 2019 p39 INQY1000002

990 This was at least part of the reason given by Dr Aronstam in an article in *The British Medical Journal* reviewing patterns of bleeding between 1973 and 1977. “*Over the five years of the survey [1973-77] the number of bleeding episodes more than doubled. Treatment policy remained the same, and so we presume that the haemophiliacs entering the college towards the end of the period were more severely affected. Facilities for home management have improved over the past few years and so fewer haemophiliacs have to travel long distances, which was previously a major reason for residence at a special school. The schools are probably now seeing only the worst cases, which cannot be managed at home. In support of this only one of the boys present at the college in 1977 had any detectable factor VIII compared with seven in 1973.*” Aronstam et al *Patterns of bleeding in adolescents with severe haemophilia* A British Medical Journal 17 February 1979 p2 RLIT0000092



risen by approximately 15%. This study however excluded those receiving prophylaxis.<sup>991</sup> When including the amounts given by way of prophylaxis and taking the 1970s as a whole, the average amount of concentrate received per pupil rose very considerably.<sup>992</sup> It seems probable that this was due in part to the use from the mid 1970s onwards of prophylaxis as “*routine*”<sup>993</sup> in a number of cases.<sup>994</sup> In summary, there were probably a number of reasons. Dr Aronstam, in another article in 1979, explained it thus: “*The increased usage of factor VIII in the years 1976 and 1977 was thus due mainly to [1] increased numbers of transfusions given per bleed and [2] to the use of prophylaxis but also [3] to a slight increase in the units of factor VIII given in each dose.*”<sup>995</sup>

### A variety of different products

Though the use of factor concentrates at an intensive level was a consistent theme, the treatment regimes applied did not appear consistent in other respects. Despite Dr Aronstam asserting that he tried “*to have a consistent approach to treatment here*” this is belied by what happened. Indeed, the quote continues: “*which means that I occasionally use a different approach to that of the Home Centre.*”<sup>996</sup> In short, he knew what treatment a pupil’s home centre thought best for that individual, but often<sup>997</sup> did not adopt it. This approach regarded consistency as something to be measured across the centre as a whole, rather than it meaning consistency for the pupil as an individual person. It was a wrongful approach to take. As a matter of principle, a pupil should have been regarded as an individual and not someone to whom a “one-size-fits-all” policy was to be applied. As a matter of principle, treatment should aim to fit the patient rather than the treatment centre.<sup>998</sup>

In the result, in place of whatever had been the home centre’s chosen regime, there was neither consistency as to the source/brand of the concentrate used, nor the adoption of any approach which sought to minimise the exposure of the pupil to the risk of receiving

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991 Aronstam et al *Patterns of bleeding in adolescents with severe haemophilia A* British Medical Journal 17 February 1979 RLIT0000092

992 The study dealt only with the years 1973-77. For the years 1976-80, the Inquiry can rely more reliably on the sources set out in the text, especially the returns to the UKHCDO.

993 Dr Aronstam’s description – see: Letter from Dr Aronstam to Dr John Stafford 14 March 1978 CBLA0000745

994 He said as much in: Aronstam et al *Transfusion requirements of adolescents with severe haemophilia A* Journal of Clinical Pathology 1979 p4 RLIT0000093. “*The use of prophylaxis resulted in an overall increase of about one-quarter in the factor VIII used during 1976 and 1977.*”

995 The numbers in brackets have been added for the sake of clarity of presentation, and do not appear in the original. For completeness, the text of the article continues: “*Twice weekly prophylaxis ... resulted in an increase of about 12% in usage of factor VIII. Prophylaxis given three times weekly reduced the bleeding frequency by about 60% at the cost of an increase of 77% in therapeutic materials.*” Aronstam et al *Transfusion requirements of adolescents with severe haemophilia A* Journal of Clinical Pathology 1979 p1 RLIT0000093

996 Letter from Dr Aronstam to Professor H Lee 14 Nov 1978 p1 TREL0000332\_068

997 The word “*occasionally*” may be an understatement of the frequency with which this happened. It is difficult to tell, save to say that no example of his honouring a request for specific treatment made by a “home” clinician stands out.

998 This is baldly stated: in practice, much may depend on the resources (of equipment, materials, and expertise) available to the treatment centre – but if there is a limitation in any of these respects, the decision as to what is best to be done must place the patient’s interests as paramount.

an infected dose. An example of this in practice is shown when Dr Layinka Swinburne, of the Leeds Haemophilia Centre, wrote suggesting that it was wise that her patient, Richard Warwick, be kept on Hemofil.<sup>999</sup> He had, plainly, been receiving that from his home centre. Dr Aronstam replied to say that the pupil had already had five different concentrates and that he would prefer not to “*confine [him] to a single Concentrate.*”<sup>1000</sup> Another came when Dr Rizza suggested in November 1978 that a number of boys should, if possible, all receive NHS material.<sup>1001</sup> This was effectively ignored: they were very largely given commercial material. Many accounts tell the same story.<sup>1002</sup>

In mid 1978, Dr Aronstam wrote that prophylaxis was “*much more effective given on alternate days than twice weekly.*”<sup>1003</sup> Such an approach would come close to double the prophylactic dose previously used. Yet by late 1978 Dr Aronstam suggested he did not believe in prophylaxis except in four cases: for those with 20-30 bleeds per 100 days, to cover a “bad patch”, to cover an extended course of physiotherapy, or for invasive procedures. He said that unless combined with an active course of physiotherapy, prophylaxis neither improved joint function nor reduced the underlying frequency of bleeding. He wrote:

*“I am well aware of [the] potential [of prophylaxis] for reducing the frequency of bleeding episodes, having published two controlled trials from this Centre. What I am also becoming increasingly aware of, is the potential danger to our haemophiliac population of hyper-transfusion with blood products. Over the past year only 12 of our 55 boys have had liver function tests which remained normal. Several authorities have recently reported increased incidences of chronic aggressive hepatitis. There is also accumulating evidence that the haemophiliac population has a higher blood pressure than the normal population and our observations here suggest that this may also be related to frequency of transfusions ... I am, therefore, increasingly wary of the indiscriminate<sup>1004</sup> use of blood products in our boys. This does not mean that I do not use prophylaxis in certain situations.”<sup>1005</sup>*

A preponderance of evidence suggests that this express concern about using too much (“hyper-transfusion”), injecting it too often (“frequency of transfusions”), and being

999 Letter from Dr Swinburne to Dr J Whitehead copied to Dr Aronstam 11 April 1979 TREL0000328\_077

1000 Letter from Dr Aronstam to Dr Swinburne 23 April 1979 WITN1592011. “Confining” him in this way would also have confined the risk, if it was thought that there was a risk that some products might be infected with virus: and this was, indeed, Dr Aronstam’s view as shown by the contents of his thesis (referenced elsewhere).

1001 Letter from Dr Rizza to Dr Aronstam 21 November 1978 TREL0000175\_090

1002 Dr Rizza wrote a similar letter to Dr Aronstam regarding another pupil in November 1978. Letter from Dr Rizza to Dr Aronstam 21 November 1978 WITN3195003. Instead he was treated with a range of different products including Hemofil, Kryobulin and Koate. Written Statement of ANON para 5 WITN3195001

1003 Letter from Dr Aronstam to Dr Ian Hann 25 July 1978 TREL0000075\_100. The letter itself sets out a reasoned approach to Dr Ian Hann’s patient, in treating what was a problematic elbow joint which had become a “target joint”, but the observation appears to be a general one.

1004 The use of the word “indiscriminate” to describe the regime which had been operating at Treloar’s supports the description the Inquiry gives at the start of this section of the report.

1005 Letter from Dr Aronstam to Professor H Lee 14 November 1978 pp1-2 TREL0000332\_068

indiscriminate in the use of concentrates did not lead to any noticeable shift in therapy. Indeed, some six months or so later Dr Aronstam was writing to express his doubts that using lower doses of Factor 8 had real virtue. Thus, to Professor Ilsley Ingram of St Thomas's, he said in May 1979 that: *"I am aware that there are many publications around at the moment extolling the virtues of lower doses of Factor VIII. All I can say is that I have yet to see anything that could be called hard data and the results must be classed as anecdotal."*<sup>1006</sup> This reads like a justification for continuing to use heavy doses of factor concentrate despite the concerns he had been expressing in late 1978. Shortly after that, though, he was saying:<sup>1007</sup> *"We only give prophylaxis in short courses here and only when a particular joint is being threatened. I am afraid we do not have the resources to give any of our 55 severe haemophiliac boys a long course of prophylaxis just because of bleeding frequency."* But, despite this, records of the total volume of concentrate used show no objective sign of it dropping; and it was inconsistent with what he had recently said about when the use of prophylaxis was indicated. In the course of the presentation to the Inquiry on Treloar's, the inconsistency was highlighted in an exchange between counsel and Inquiry chair.<sup>1008</sup>

It was not until after 1984 (when it had just become clear that many people with haemophilia had been infected with HIV, and potentially with AIDS, in consequence of repeated treatment with blood products) that the amount of Factor 8 given per transfusion reduced *"significantly"*.<sup>1009</sup> At the time, Dr Aronstam attributed this change to better joint health having been secured in the first place, as a consequence of the prophylactic approach adopted beforehand, such that by then less product was required to treat each bleed as it threatened to occur. This claim seems somewhat dubious and convenient, given (a) its timing, (b) Dr Aronstam's previous enthusiasm for more rather than less treatment, (c) the increasing doubt he had expressed about the proper use of prophylaxis, (d) the absence of any earlier indication<sup>1010</sup> that joint health was progressively being secured so that treatment could be reduced, and (e) the curiosity (if true) that joint health seemed to have improved in every pupil to the necessary extent across the board at more or less the same time.

## Why did Dr Aronstam adopt the practices he did?

The reasons for adopting a regime in which pupils were given a wide range of different products and different batches of the same product, and such unusually large amounts were used as a matter of course, and the desire of "home" clinicians for the use of particular products was overridden, may be explained by Dr Aronstam's responding to what he considered his research indicated. Dr Aronstam claimed it was for *"a consistent approach"*;<sup>1011</sup>

1006 Letter from Dr Aronstam to Professor Ingram 18 May 1979 p1 TREL0000072\_029

1007 Letter from Dr Aronstam to Anon 16 January 1980 TREL0000108\_016

1008 Counsel Presentation on Lord Mayor Treloar School and College Transcript 23 June 2021 pp177-179 INQY1000133

1009 Treloar Haemophilia Centre: Report to the Region p4 HHFT0001073

1010 So far as the Inquiry is aware.

1011 The claim comes in response to a criticism that in an individual case he was not providing prophylaxis, and his use of "consistency" was thus used to defend that approach in this individual's case. Letter from Dr Aronstam to Professor H Lee 14 November 1978 p1 TREL0000332\_068

the approach in similar situations does not seem to have been consistent (though that in itself is not a reason for adopting it in any individual case, and “consistency with what?” is not answered). However, his thesis indicates that he sought what he described as a “*rational*” basis for choosing a dose of Factor 8.<sup>1012</sup> This was a narrow view of what was “*rational*”, based on what he thought worked in reducing bleeding, as shown by the studies conducted at Treloar’s into prophylaxis,<sup>1013</sup> and into the use of different treatment regimes for target joints. A wider approach could have built on and valued the experience of parents and home clinicians about what worked for an individual pupil, but the narrow approach did not do this. And to live up to the description of “*rational*” it should have taken into account the known risk of infection.

Another possible reason is one he gave when talking to the chief executive of Speywood Laboratories in August 1978.<sup>1014</sup> The latter’s file note describes how Dr Aronstam’s “*first requirement is convenience of administration*”. There was a logistical reason for this – because of the concentration of young pupils with severe haemophilia, who were told to attend the sick bay if and when they needed therapy, and who had lessons to return to, the time taken to deal with each individually could be significant. Dr Aronstam is recorded as saying: “*they can often have 15 infusions to give at a time*”. Other sources support the reason being “*convenience of administration*” by speaking of Dr Aronstam’s preference for Hemofil because it was easier, and hence quicker, to dissolve, allowing for less time to be spent by staff treating boys.<sup>1015</sup>

Another possible reason might be a desire to use large amounts of product in order to research the effects of doing so, rather than its usage depending on a direct appreciation of clinical need. There is little doubt that research was a central interest for clinicians at Treloar’s, from the appointment of Dr Rainsford as a research fellow, to various published papers and a 186-page thesis for a doctorate authored by Dr Aronstam. There are signs that a desire to conduct research might have involved discounting risks which should not have been downplayed. Thus in October 1982 Dr Aronstam was prepared to be listed as the sole investigator for a clinical trial exemption certificate to permit him to administer Mono-V3:C, a product of Speywood Laboratories, to up to 50 pupils over an 8-month period.<sup>1016</sup> This was in order to see how effective it was in the treatment of bleeds into their knees, elbows and ankles. This product was to be made from bulk cryoprecipitate manufactured by

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1012 He entitles the final section of this thesis “*Summary of original observations and their contribution to the rational use of Factor VIII*” in: Aronstam *Bleeding Episodes in Severely Affected Adolescent Haemophiliacs and Their Management with Replacement Therapy* p168 TREL0000517

1013 Described above.

1014 Note of Meeting with Dr Aronstam Director Lord Mayor Treloar Hospital and Consultant Basingstoke District Hospital 25 August 1978 IPSN0000331\_008

1015 Written Statement of Dr Michael Painter para 17 WITN5277001. This would be consistent with his approach to record-keeping – Letter from Dr Aronstam to Peggy Britten 3 November 1982 TREL0000116\_139. He described how he proposed to cease recording **all** batch numbers of products supplied to every boy because of the work it involved: the numbers of boys and the demands which treating them brought plainly weighed on him.

1016 Speywood Laboratories Ltd application for Mono-VIII: C clinical trial certificate March 1983 pp1-2 DHSC0003949\_102, in particular Part 1A Particulars of Product and Trial DHSC0003949\_104 and Part 1B Clinical Trial Protocols DHSC0003949\_105

Alpha Therapeutic Corporation in Los Angeles. This was risky, since it involved products of uncertain effect derived from pooled plasma, originating from an area where hepatitis was prevalent, at a time when haematology had woken up to the idea that blood products might transmit the cause of AIDS, and with little obvious benefit which the individual pupils would gain from it.<sup>1017</sup>

A further indication of a link between a keenness to perform research and the use of unusually large amounts of product emerges from a letter written in 1978 from a clinician in Plymouth to Dr William d'A Maycock seeking his help.<sup>1018</sup> The clinician could not give the boy more than half the amount of (as it happens, safer, NHS) concentrate in his centre that the boy was receiving (in his case, of commercial concentrate) at school. His letter complains how Treloar's "*had a large research grant and were able to give the boy 740 units of Hemofil every alternate day*" as prophylaxis; Treloar's were spending over £20,000 annually on his therapy whereas Plymouth by contrast required a specific grant to cover even just half the therapy the clinician thought necessary.<sup>1019</sup>

An indiscriminate choice of product persisted from the start of Dr Aronstam's directorship. The use of cryoprecipitate was dwarfed by the use of concentrate. In 1982 and 1983, at a time of growing concern being expressed about concentrates manufactured in the US from large pools, which led some clinicians to use more cryoprecipitate in order to reduce overall risk, none was used.<sup>1020</sup>

Of concentrates, comparatively little NHS concentrate was used compared to an extensive usage of commercial.<sup>1021</sup> Almost symbolically, a small fridge was used for housing NHS material; a large fridge for commercial. And although a number of pupils recollect Dr Wassef as having said that Scottish product was the best (it being remembered by one witness that he had indicated a space on the top shelf of the small fridge when he said this),<sup>1022</sup> none of this is shown in the annual returns as having been used in any year between 1980 and 1983, inclusive.<sup>1023</sup>

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1017 Alpha Therapeutic UK Ltd application for Antihaemophilic Factor (Human) Wet-Paste (Bulk Cryoprecipitate) product licence 24 March 1983 p1 DHSC0003946\_060. The request was declined in March 1983. What happened nonetheless illustrates Treloar's approach to risk and research.

1018 Letter from Dr John Stafford to Dr Maycock 21 March 1978 p1 CBLA0003023

1019 Letter from Dr John Stafford to Dr Maycock 21 March 1978 p1 CBLA0003023

1020 See the annual returns at: Annual Returns for Lord Mayor Treloar Haemophilia Centre 1982 HCDO0001590, Annual Returns for Lord Mayor Treloar Haemophilia Centre 1983 HCDO0001686

1021 See Figure 1. NHS product approached 50% of total usage in 1984. Otherwise Treloar's used approximately two and a half times as much commercial concentrate as NHS.

1022 Adrian Goodyear Transcript 5 June 2019 pp69-70 INQY1000014. Joseph Peaty remembers Dr Wassef saying: "*This is good clean Scottish product you're getting today Mr. Peaty.*" Joseph recalls: "*I was in a lot of pain at the time so didn't question it, but the word 'clean' struck me as odd. I remember thinking 'does that mean the other products I get aren't clean then?' The comment made no sense to me. I trusted the doctors would not give me anything 'unclean' so I dismissed it.*" Written Statement of Joseph Peaty para 310 WITN4607001

1023 Lord Mayor Treloar Haemophilia Centre annual return 1980 HCDO0001388, Lord Mayor Treloar Haemophilia Centre annual return 1981 HCDO0001487, Lord Mayor Treloar Haemophilia Centre annual return 1982 HCDO0001590, Lord Mayor Treloar Haemophilia Centre annual return 1983 HCDO0001686

In 1977-78, most patients received multiple different products (usually three or four different types of commercial concentrate). In 1979, only one patient received solely one type. The returns for the centre include adults who were treated there as well as school pupils: but they show that it was the younger patients who tended to receive the greater variety of product. Yet there is evidence that it was entirely possible for Treloar's to arrange to keep a pupil on one type of treatment only, since this very thing was arranged for the hepatitis study of 1975.<sup>1024</sup>

In 1984, a year in which generally the risks of AIDS being transmitted by blood became clear beyond doubt, some cryoprecipitate was used again, and an increasing amount of NHS concentrate. However, although this might have indicated a response to these risks, concentrate usage at Treloar's was recorded at its highest level yet during that year.<sup>1025</sup>

## Knowledge of risks

Was it known at the time that this enthusiastically intensive and largely indiscriminate use of comparatively large amounts of different commercial concentrates was unsafe? The short answer to this question is "Yes".

There is no doubt that the risks of viruses being transmitted through blood or blood products were well known to Treloar clinicians. Not only was it a prerequisite for research, a fundamental aspect of Treloar's, but knowledge of the risks is displayed in what the clinicians there wrote at the time. A useful summary, for instance, of the risks of hepatitis is provided by Dr Aronstam's thesis of 1981.<sup>1026</sup> He said that: "*Hepatitis has always been a risk for the patient with haemophilia who required therapy with plasma or plasma products ... but the risk increased markedly with the introduction of pooled concentrated preparations of factor VIII.*"<sup>1027</sup> He acknowledged a risk that the hepatitis might be Hepatitis B, even though screening had improved, since RIA testing<sup>1028</sup> as it then stood still left 20-40% of Hepatitis B

1024 Trial of Factor VIII Concentrates at Lord Mayor Treloar College meeting 9 March 1973 p3 MRCO000065\_011. A further example is the trial of prophylactic therapy from 1973-75, by arrangement through the MRC: Dr Ethel Bidwell said she could provide product for the first prophylaxis trial provided there were never more than ten boys participating.

1025 Lord Mayor Treloar Haemophilia Centre annual return 1984 HCDO0001782

1026 In his thesis he set out in the abstract that: "*The work presented in this thesis attempts to rationalise the use of factor VIII*". In his introduction he sets out how the coming of replacement therapy transformed the outlook, treatment brought new problems, and repeated that it was important to rationalise the use of factor VIII therapy. However, he does not in the event do this, for the closing words of his thesis are: "*a project developing from this thesis may finally bring about the elimination of haemophilic arthropathy and allow the home therapy programme to achieve its highest potential – the true normalisation of haemophiliac life.*" Aronstam *Bleeding Episodes in Severely Affected Adolescent Haemophiliacs and Their Management with Replacement Therapy* p5, p170 TREL0000517

1027 Aronstam *Bleeding Episodes in Severely Affected Adolescent Haemophiliacs and Their Management with Replacement Therapy* p72 TREL0000517. For this proposition he cited Bryan et al (1969), and Kasper and Kipnis (1972), adding that: "*Many of the earlier reports of transfusion-related hepatitis concerned patients who had received concentrates derived from large plasma pools*", citing papers from 1949 and 1963 (Davidson, Cronberg, Belfrage and Nilsson).

1028 Radioimmunoassay, begun in 1975: previously counter electro-osmophoresis ("CEOP") was the first to be used as a screening test, succeeded by reverse passive haemoagglutination ("RPHA"). The Australia antigen was first discovered using an agarose gel immunodiffusion ("ID") system, which was not suitable for bulk screening, though it continued to play a part in uncovering non-A non-B

infections in the pool, and outbreaks of it had been reported from time to time. The conditions this might lead to included cirrhosis and (“probably”) primary liver cancer.<sup>1029</sup> It might also be hepatitis which was neither Hepatitis A nor B.<sup>1030</sup> So far as this form was concerned, Dr Aronstam went back to Dr Harvey Alter’s seminal work in 1972,<sup>1031</sup> and described how the introduction of freeze-dried concentrates had led to outbreaks of this form of hepatitis too. Of particular significance, given the recollection of a number of witnesses that non-A non-B Hepatitis was thought by many at the time to be a mild disease, of little long-term consequence, is his observation<sup>1032</sup> that: “*this form of hepatitis is as likely to progress to chronic hepatitis as the hepatitis B variety*<sup>1033</sup> ... *and is therefore at least as important.*” He went on to observe that:

*“It appears therefore that at present about half of all severely affected haemophiliacs have persistently abnormal liver function tests<sup>1034</sup> and more than half of these will have histological evidence of serious chronic liver disease. This bleak picture has developed in spite of the use of increasingly sophisticated screening tests for HBsAg [Hepatitis B surface antigen] and donor blood ... We also know that even if HBsAg could be eliminated non-A, non-B hepatitis would still be capable of inducing chronic liver damage ... The addition of a further chronic disabling disease to the lot of patients already suffering from severe haemophilia is a therapeutic catastrophe and will be a major concern to those concerned with the transfusion therapy of haemophiliacs for some time to come.”<sup>1035</sup>*

The association between pooled plasma and its products and the risk of hepatitis had been recognised long before Dr Aronstam wrote those chilling words.

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Hepatitis. See: Gocke et al *Correlation of Australia Antigen with Posttransfusion Hepatitis* Journal of the American Medical Association 1970 RLIT0002023, Gocke A *Prospective Study of Posttransfusion Hepatitis: The Role of Australia Antigen* Journal of the American Medical Association 1972 NHBT0000118\_020

1029 Aronstam *Bleeding Episodes in Severely Affected Adolescent Haemophiliacs and Their Management with Replacement Therapy* p75 TREL0000517. For the latter proposition he cited: London *Hepatitis B Virus and Antigen-Antibody Complex Diseases* New England Journal of Medicine 1977 RLIT0002025

1030 Aronstam *Bleeding Episodes in Severely Affected Adolescent Haemophiliacs and Their Management with Replacement Therapy* p77 TREL0000517

1031 Alter et al *Posttransfusion Hepatitis After Exclusion of Commercial and Hepatitis-B Antigen-Positive Donors* Annals of Internal Medicine 1972 PRSE0001521. Dr Alter and others showed that after excluding commercial and Hepatitis B antigen positive donors, post-transfusion hepatitis remained. This was cited by the Nobel Prize committee in awarding Dr Alter the Nobel Prize in 2020.

1032 Aronstam *Bleeding Episodes in Severely Affected Adolescent Haemophiliacs and Their Management with Replacement Therapy* p77 TREL0000517

1033 He cited Seef and others 1975 and Spero and others 1978 for this proposition.

1034 Aronstam *Bleeding Episodes in Severely Affected Adolescent Haemophiliacs and Their Management with Replacement Therapy* pp79-80 TREL0000517. Earlier, in the 1970s, Dr Aronstam had described how 43 out of 55 (78%) of his boys at Treloar’s had elevated liver enzymes on testing. He is not on record as recognising that if what he said in his thesis is accurate, then the rate of attack at Treloar’s which those number indicate was more than one and a half times as many as the “*about half*” that he was quoting; nor that it indicated that around 40% of the pupils with haemophilia (all of whom were severe) would develop serious chronic liver disease.

1035 Aronstam *Bleeding Episodes in Severely Affected Adolescent Haemophiliacs and Their Management with Replacement Therapy* p79 TREL0000517

In May 1969 Dr Rainsford identified that the hepatitis of a boy under his care at Treloar's was almost certainly caused by plasma – it was homologous serum jaundice rather than infectious jaundice.<sup>1036</sup> The risks were brought home by continued experience of administering large doses of concentrated therapy: in autumn 1974, there was an outbreak at the school in which ten boys were affected following use of a batch of Hemofil.<sup>1037</sup> It may have been that there was a subsequent outbreak in 1975.<sup>1038</sup>

Non-A non-B Hepatitis was specifically identified at Treloar's in association with the taking of Kryobulin: "*He<sup>1039</sup> is not our only case of non-B hepatitis of short incubation after receiving concentrates*" was what was said about it at the time.<sup>1040</sup>

Former pupils recollect that a number of their fellow pupils turned yellow in around 1975. It is likely that it was about this time that the headmaster Alexander Macpherson knew that the treatment given might result in hepatitis. It might have been earlier still: though he thought, looking back, that the nursing sister at the time may have been "*the first one to tell me that she'd concerns about it, that this was in the air, and that they were beginning to wonder about it.*"<sup>1041</sup> This was a long time ago, and he could not be sure. But he certainly knew by 1974/75 when there were outbreaks of hepatitis: "*this was concerning, very worrying, worrying for the parents. And worrying for the care staff, who had to look after them. Because none of us really knew how infectious this was, and that certainly caused a lot of anxiety.*"<sup>1042</sup> Nick Sainsbury remembered him standing up at meal time, and saying that "*I understand that some of you are worried about this hepatitis that's been going round ... We've been told to ask you not to worry, there are two types of hepatitis, the fatal kind, serious, and the non-fatal, mild type, and you've got the mild type so there's nothing to worry about.*"<sup>1043</sup> Alexander Macpherson confirmed he was sure he did tell the school about the two different types of hepatitis: he said this information came from the doctors.<sup>1044</sup> The information is inconsistent with what Dr Aronstam wrote in his thesis: the latter understood (at least by then, and there is nothing to show any revelation that caused him to change his mind between 1975 and 1981) that the "*two types*"<sup>1045</sup> were equally serious.<sup>1046</sup>

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1036 Letter from Dr Rainsford to Dr G Kelley 5 May 1969 p1 TREL0000382

1037 Haemophilia and Other Coagulation Defects Amongst Boys Resident at Lord Mayor Treloar College 14 March 1975 NHBT0107241

1038 Counsel Presentation on Lord Mayor Treloar School and College Transcript 24 June 2021 INQY1000134, Letter from Dr Maycock to Dr Vaughan 7 April 1975 pp1-2 DHSC0100018\_174

1039 Referring to a pupil at the school.

1040 Form on Anti-Mitochondrial Antibodies from Dr T Hamblin to Dr Kirk 20 January 1976 TREL0000070\_056

1041 Alexander Macpherson Transcript 24 June 2021 p24 INQY1000134

1042 Alexander Macpherson Transcript 24 June 2021 pp24-25 INQY1000134

1043 Nick Sainsbury Transcript 22 June 2021 p5 INQY1000132

1044 Alexander Macpherson Transcript 24 June 2021 pp25-26 INQY1000134

1045 Presumably Hepatitis B and non-A non-B Hepatitis. Given the link to treatment acknowledged at the time, Alexander Macpherson could not have been given to understand by clinical staff that one was Hepatitis B and the second Hepatitis A, for the latter is only rarely transmitted by blood and this was known at the time. Alexander Macpherson Transcript 24 June 2021 p25 INQY1000134

1046 "*Whatever the nomenclature, this form of hepatitis is as likely to progress to chronic hepatitis as the hepatitis B variety (Spero et al 1978, Seef et al 1975) and is therefore at least as important.*" Aronstam



Dr Kirk reported in April 1977 that the cause of hepatitis was believed to be commercial concentrate: “*almost all*” the cases were confined to those who had used them.<sup>1047</sup> Dr Painter recorded speaking to some parents in early 1978, appearing to regard Hepatitis B which had become chronic as potentially leading to a grim future, and a matter of significant concern.<sup>1048</sup> This tends to suggest that he shared the view of its seriousness which Dr Aronstam expressed in his thesis.

The risk that mixing the products of different manufacturers might increase the risks of hepatitis was drawn to the attention of Treloar’s in October 1979 by Dr Craske, discussing an individual case of non-A non-B Hepatitis at Treloar’s:

*“This is another example of a phenomenon we have observed for the past two years. It appears that one type of N/A, N/B [non-A non-B] hepatitis is associated with Hemofil and possibly other American concentrates. The second type of short incubation of N/A, N/B [non-A non-B] hepatitis [sic] appears to be associated with transfusions of NHS concentrate or Kryobulin, manufactured by Immuno Limited. Since we know that Immuno acquires much of this plasma from one of the American drug companies, it appears unlikely that the association of the two types of N/A, N/B [non-A non-B] hepatitis with different products can be related to different sources of donor plasma. It appears much more likely that it is due to different methods used in the preparation of American and European concentrate. It follows from this that it might be wise to try to maintain patients who have received only Kryobulin and, or, NHS material in the past on one or other of these products during their stay at the Lord Mayor Treloar School.”*<sup>1049</sup>

This fell on deaf ears. It should nonetheless be acknowledged that when Dr Craske asked for people with mild haemophilia to be given NHS Factor 8 for non-urgent operations such as tooth extraction, saying “*We have found from observations at Oxford that this is the best way of finding out whether the material is associated with cases of hepatitis*”,<sup>1050</sup> Dr Aronstam replied: “*I totally disagree with this concept. I do not wish any of my mild haemophiliacs to develop hepatitis in any form and therefore adopt the policy of either using D.D.A.V.P. or Cryoprecipitate.*”<sup>1051</sup> Dr Craske backtracked: “*What I meant to say, and on rereading my letter is not made clear, is that I would suggest a trial of NHS concentrate be made to cover such operations, where other concentrates such as commercial material would be indicated.*”<sup>1052</sup>

As to knowing the risks of infection with the causative agent of AIDS, over and above the risks of hepatitis, Dr Aronstam can be taken to have been familiar with the reports emerging

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*Bleeding Episodes in Severely Affected Adolescent Haemophiliacs and Their Management with Replacement Therapy* p77 TREL0000517

1047 Letter from Dr Kirk to Dr D McGrath 1 April 1977 p1 CBLA0000590

1048 Letter from Dr Painter to Dr David Winfield 7 March 1978 p1 TREL0000257\_044

1049 Letter from Dr Craske to Dr Aronstam 5 October 1979 HHFT0000909

1050 Letter from Dr Craske to Dr Aronstam 10 May 1979 HHFT0000916\_003

1051 Letter from Dr Aronstam to Dr Craske 14 May 1979 HHFT0000916\_002

1052 Letter from Dr Craske to Dr Aronstam 16 May 1979 HHFT0000916\_001

in the medical literature and elsewhere; he certainly should have been, responsible as he was for the treatment of children. He was a regular attendee at meetings of the haemophilia reference centre directors after 1981<sup>1053</sup> and would have been privy to the information available at each. He was present when AIDS was discussed in September 1982, at the “Heathrow meeting” of 24 January 1983, the 14 February 1983 meeting which followed it, and the meeting of September 1983, at which discussion about an increased use of cryoprecipitate occurred in the light of the first known death of a person with haemophilia in the UK from AIDS.<sup>1054</sup>

Practice at Treloar’s shows that the clinical staff were well aware that their heavy use of commercial concentrate risked causing AIDS. From as early as February 1983, individual records show that pupils were examined for any signs of the “stigmata of AIDS”. The signs looked for included weight loss, difficulties swallowing, lymph nodes, signs of oral thrush. Earlier still, from some date in January, many pupils’ T-cell ratios were recorded. There is no contemporaneous record showing why this was done. However, the obvious reason was to monitor a risk of AIDS, for the T-cell ratio is directly related to the efficiency of the immune system, and AIDS was known to be a malfunction of that system. No other reason is apparent.

## What was said and done to reduce the risks of AIDS before 1985?

Except that in November 1984 Dr Aronstam switched from using unheated commercial product to using heat-treated commercial product (though he continued to use unheated NHS concentrate)<sup>1055</sup> he did little of which the Inquiry is aware.<sup>1056</sup>

He did not even tell others about the risk until it became inescapable. Though the clinical staff were almost certainly aware in late 1982 to early 1983 that treatment with commercial concentrate risked AIDS, the headmaster was not told until much later. Alexander Macpherson recalls that AIDS was first discussed properly by the Governing Body in 1985, so it must have been only a short time before then that Dr Aronstam told him. He had not known of pupils being tested for the stigmata of AIDS; and no letters were sent to parents to tell them of the risks to their children before that.<sup>1057</sup>

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1053 Having attended the haemophilia centre directors meetings since 1971.

1054 Minutes of UK Haemophilia Centre Directors meeting 13 September 1982 CBLA0001619, Notes of meeting with Immuno 24 January 1983 PRSE0002647, Minutes of Haemophilia Reference Centre Directors meeting 9 May 1983 HCDO0000411, Minutes of Haemophilia Reference Centre Directors meeting 19 September 1983 HCDO0000413

1055 Letter from Dr Aronstam to Dr P Barbour 18 December 1980 TREL0000247\_047

1056 Joseph Peaty told the Inquiry that Dr Aronstam had been considering treating him with the Bonn Protocol using high doses of commercial concentrate to try to eradicate his inhibitor since 1980 and initiated the protocol in February 1983. Dr Aronstam had corresponded with his home clinician in 1980 and Joseph asks: “*Shouldn’t a reassessment of the ‘immediate risks’ have been made in 1983 that should have indicated avoidance of my unnecessary exposure to potentially high viral titre commercial concentrates that would potentially infect and go on compounding the viral load with repeated exposure of further viral load and virus variants?*” Written Statement of Joseph Peaty para 260 WITN4607001

1057 Alexander Macpherson Transcript 24 June 2021 pp27-28 INQY1000134

Dr Aronstam showed what he understood about the risk when he wrote to a GP on 14 June 1983,<sup>1058</sup> talking of “*the current hysteria*” about AIDS, and recording that he had advised the patient<sup>1059</sup> of “*the very small risk numerically*”<sup>1060</sup> of him acquiring the disease, though the letter goes on to record loss of weight, “*a few lymph nodes*” and that his T-cell count was showing the “*same sort of inverted ratio that characterises the illness*”. In fact the patient in question was infected with HIV and died from AIDS-related illnesses in 1988.<sup>1061</sup>

In short, the only response to an acknowledged risk of AIDS from commercial concentrates was to monitor pupils closely. Their records showed results thought possibly significant in relation to AIDS. Yet neither this, nor the recommendations of the UKHCDO following a meeting of reference centre directors in May 1983, nor the knowledge in later 1983 that people who had had commercial concentrate had contracted AIDS and at least one had died, led to any change in treatment, or approach. A manifestation of what remained his approach appears from a letter in March 1984. It concerned a relatively young child.<sup>1062</sup> Dr Aronstam advised “*a course of effective prophylaxis*”. He added: “*I note your comment about factor VIII preparations affecting ‘T’ cells. This is a very worrying problem for all of us in haemophilia care. At present the general view is that while the disease is horrific, the numerical risk of it is nevertheless very small and should not deflect us from the appropriate treatment. Naturally we are all reviewing the situation constantly.*”<sup>1063</sup>

He did seek some information which might have led to a change of policy. Thus he did write to BPL in March 1984 about a specially accredited pool of donors being used at Oxford for people with new and mild haemophilia and asking whether the material was available generally.<sup>1064</sup>

There does not appear to have been any change of policy despite the “constant review” referred to.<sup>1065</sup> Moreover, there is evidence that though he appreciated the risks to which

1058 Letter from Dr Aronstam to Dr Ahmed 14 June 1983 TREL0000143\_058

1059 Who was not a pupil.

1060 This can only be a reference to the number of cases amongst people with haemophilia which had thus far emerged.

1061 It is a matter of concern that at a time when the Communicable Disease Surveillance Centre had asked for reports of AIDS cases to be sent to it, this case was not notified at least as a suspected case. This on its own may reveal something of the quality of the surveillance overall, which depended critically upon clinicians making reports. Not all did – as the example of the “Bristol case” (the patient whose death was reported in the autumn of 1983) also shows.

1062 For whom, if the reference centre directors’ guidance was to be followed, cryoprecipitate should be used or NHC concentrate in preference to commercial. Letter from Dr Aronstam to Dr S Barnes 19 March 1984 TREL0000343\_044

1063 Letter from Dr Aronstam to Dr S Barnes 19 March 1984 TREL0000343\_044

1064 Letter from Dr Aronstam to Dr Terence Snape 6 March 1984 CBLA0001810. Dr Terence Snape recorded that they spoke and Dr Aronstam’s concern was for two babies in the area who as yet were untreated, but he also offered to enter suitable pupils for a prospective study of a “*hepatitis reduced*” product and Dr Snape referred the issue to Dr Richard Lane: Memo from Dr Snape to Dr Lane 12 March 1984 CBLA0001812. There is no record of a response. He also wrote to Professor Arthur Bloom about a boy: “*We put him on an accredited donor pool long before heat treated material became available and thankfully he now remains HTLV III antibody negative. We are, of course, also hopefully protecting him against Non A Non B.*” Letter from Dr Aronstam to Professor Bloom 30 September 1985 TREL0000126\_066

1065 Letter from Dr Aronstam to Dr S Barnes 19 March 1984 TREL0000343\_044

some of the pupils were exposed he did nothing to act on it.<sup>1066</sup> Similarly, when Professor Arthur Bloom informed him that one of the pupils had received some of the same batch as the Cardiff patient who had developed AIDS, he identified that the boy was one of fifteen boys<sup>1067</sup> who had reversed T-cell ratios<sup>1068</sup> but this knowledge does not seem to have caused him noticeably to adjust his treatment policies. Thus, the prophylaxis programme continued – indeed, as late as December 1984, Dr Wassef wrote<sup>1069</sup> to a fellow clinician at Nottingham describing how a pupil had been on prophylaxis “*almost the whole length of this term*”, using unheated concentrates until that November, and asking that during the Christmas holidays this intensive use of concentrate be continued.<sup>1070</sup>

There is evidence that prophylaxis continued until 1987, three years later, when it was discontinued because of the risks that immune-suppressive effects would follow,<sup>1071</sup> but none which shows that it was discontinued in 1983, 1984, or 1985 because of the increased risks that infection would follow.<sup>1072</sup>

## What was said to pupils about the risks of AIDS

Little truly informative was said to pupils. Typical of recollections are those of Gary Webster, Mr BA and Mr BC. Gary Webster records newspapers disappearing from the library at the time that they started to carry reports about AIDS. The boys did not remove them. It is likely that this was done by staff to shield them from the knowledge of what was being said. No one discussed with him whether it was wise to use prophylaxis in late 1984: the clinicians went on giving him “cover” despite all that was being reported. His sense was that the clinicians were being economical with what they said.<sup>1073</sup> Mr BA remembers Dr Aronstam calling everyone into the school hall. He told them in a calm manner, that “*there was this thing called AIDS but, you know, don’t worry. Only two people in the UK with haemophilia*

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1066 An example is: Letter from Dr Aronstam to Dr David Evans 7 July 1983 TREL0000248\_095. A pupil had been having intensive treatment. Dr Aronstam thought it was no longer having benefit, but did not himself take a decision to stop giving the pupil so much concentrate. He wrote to the home clinician, leaving the decision to him whether to continue with it – a contrast from occasions when the home clinician had written to him to ask for a particular course of treatment and he had ignored the request. What he said was: “*While we have supplied [Anon] with enough material to see him through the summer holidays, I have my own reservations as to whether it is ethically right in the current climate. I have no doubt that you will see him sometime during this vacation and would be quite happy to fall in with any decision you might make in this respect.*” Letter from Dr Aronstam to Dr David Evans 7 July 1983 p1 TREL0000248\_095

1067 Out of 43. Letter from Dr Aronstam to Professor Bloom 13 June 1983 TREL0000145\_066

1068 Where there are more CD8 (“killer”) cells than CD4 (“helper”) cells, rather than the common position which is more CD4 than CD8.

1069 Letter from Dr M Wassef to Dr Ernest French 14 December 1984 TREL0000247\_007

1070 Ian Greig was infected with HIV and died in 2001. His widow’s and brother’s statements are: Written Statement of Helen Dabbs WITN1180001, Written Statement of Alexander Greig WITN3375001

1071 Letter from Dr M Wassef to Dr Alistair Sawers 16 July 1987 TREL0000092\_132

1072 However, a report from 1 January 1986 suggests that the average amount of Factor 8 given per transfusion was significantly reduced after 1984, and there was from then on a focus on providing the dose which he identified from his earlier research as being the minimum. Treloar Haemophilia Centre: Report to the Region 1 January 1986 HHFT0001073

1073 Gary Webster Transcript 21 June 2021 p133 INQY1000131

*have it, so very small risk*".<sup>1074</sup> Nothing was said about how AIDS was spread, or how to avoid it. Mr BC came to know Dr Hasmukh Dasani when, as a training doctor, his rotation took him through Treloar's. Dr Dasani told him that he was shocked at the number of different batches that were being offered to those at Treloar's and he said "*that he mentioned that perhaps they should cut down the exposure and give only certain batches to certain, you know, students to minimise their risk ... I think the Armour product was generally considered as dirty. And he was quite surprised that they were still using that one [Armour]*".<sup>1075</sup> This was of particular relevance to Mr BC who had been receiving huge doses of high-potency Armour.

Dr Aronstam downplayed the risks, both publicly and to individual pupils, and both of hepatitis and AIDS. Publicly, he said to *The Guardian* in May 1983 that "*Our patients are hysterical ... Every report brings haemophiliacs crying to us*" and went on to suggest a similarity between that and reports of a hepatitis outbreak at the school (which he denied was the case, though it had sparked a Department of Health warning about the risk of hepatitis infection from imported Factor 8 and of the danger from contaminated US blood). He was saying that the 1981 outbreak had been overinterpreted,<sup>1076</sup> and by extension so had the risk of AIDS.

As to individual pupils – he wrote in June 1983 to the home clinician for an individual showing the stigmata of AIDS, to say that: "*He is realistic about AIDS and feels as I do that the benefits of treatment far outweigh the small risk of acquiring this condition*".<sup>1077</sup> Of another pupil, who was less accepting, he said the very next day:

*"I am sorry to report that he has lost movement in both elbows and [sic] both shoulders. This appears to be a direct result of his reluctance to treat himself adequately because of the current hysteria about AIDS. I have explained the very small risk numerically of him acquiring the disease, but he is adamant ... It is worrying in this respect as he has lost some weight, we have found a few lymph nodes and his T lymphocytes are showing the same sort of inverted ratio that characterizes the illness."*<sup>1078</sup>

None of the boys were told that they were being tested for HIV (when the tests became available) nor that before that they had been checked to see whether they had any signs that they were developing AIDS. When it emerged in late 1984 that there were infections, the Treloar's clinicians told the boys that it had been an unavoidable accident.<sup>1079</sup>

## How the boys found out

The individual accounts show no consistent practice in telling individuals that they had been infected with HIV. Sometimes the reason was the age of the boy concerned: some who

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1074 ANON Transcript 21 June 2021 p156 INQY1000131

1075 ANON Transcript 23 June 2021 p25 INQY1000133

1076 *The Guardian Warning against Aids 'panic'* MDIA0000022

1077 Letter from Dr Aronstam to Dr I Joiner 13 June 1983 TREL0000107\_173

1078 Letter from Dr Aronstam to Dr Ahmed 14 June 1983 TREL0000143\_058

1079 Gary Webster Transcript 21 June 2021 p137 INQY1000131

were infected at Treloar's had left the school by the time that tests were available. Others, however, were simply never told by the school, although still pupils. 37 pupils had tested positive for HTLV-3 (HIV) as recorded by Dr Aronstam in February 1985.<sup>1080</sup> John Peach's younger son, Jason, was one of the pupils recorded by Dr Aronstam in February 1985 as HIV positive. Jason was noted in July 1985 to have signs of AIDS: "*Lymphadenopathy ... thrush and difficulty in swallowing*". He left the school in May 1986, having never been told of his infection. John was never told by Treloar's of these infections: he learned, in the case of each of his children, from the Oxford Centre, which was their home centre.<sup>1081</sup>

Gary Bennett learnt from his home doctor too: Dr Chisholm told him in 1986 that he had tested positive.<sup>1082</sup>

Mr BC contracted HIV before 11 January 1984 (he had been having daily transfusions with Factor 8 from June 1983). He was told at school when he was about 16. He knew nothing of its effects beyond what he picked up from the papers or TV.<sup>1083</sup>

The mother of one boy was asked to come to the school and was told in a meeting about her son being infected with HIV; she was told to tell her son. "*There was no follow up. I was given no explanation about what it meant or what to do or not to do as a result. I did not know how to feel as I did not know what it was. I had to leave him in tears*".<sup>1084</sup> Another boy was told in a brief meeting with Dr Aronstam: "*He went on to tell me that the life expectancy for HIV positive patients was no more than 10 years. It was a death sentence ... it was like being punched in the face, I remember clearly rocking back in my chair.*"<sup>1085</sup>

Lee Stay was unaware that any test for HIV was being carried out. Indeed, the evidence which the Inquiry has considered suggests that none of the pupils were told that they were being tested. Though Lee's own doctor was told in March 1985 that he was positive, neither he nor his parents were told at that time. Lee himself did not learn of it until 1986. He remembers clearly this being when he was at sixth form college, and that it was at Easter time and he was told by Dr Aronstam.<sup>1086</sup>

Adrian Goodyear provided two particular insights into Dr Aronstam's thinking. In 1984 he recalls being invited with another boy to spend a day with Dr Aronstam at his house.

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1080 Letter from Dr Aronstam to Dr Snape 20 February 1985 CBLA0002054

1081 John Peach Transcript 22 June 2021 pp83-86 INQY1000132. John Peach's understanding was that his elder son Leigh had not been told by the school that he had been infected. However, in her statement to the Inquiry Leigh's widow Andrea said "*Leigh recounted to me his experience at Treloars College being told that he was HIV positive, and it was traumatic. A whole group of boys (including Leigh) were called into the gym or auditorium. They were told that they had **all** tested positive for HTLVIII, something none of them had previously heard of or understood ... The boys were then told that there was no cure and that they would probably die.*" Written Statement of Andrea Peach para 8 WITN7128001. Emphasis in original.

1082 Gary Bennett Transcript 22 June 2021 p116 INQY1000132

1083 ANON Transcript 23 June 2021 pp30-32 INQY1000133

1084 Written Statement of ANON paras 13-16 WITN1406002. Her son confirms that "*We were not provided with any information in relation to how to manage or understand the infection.*" Written Statement of ANON para 14 WITN1406001

1085 Written Statement of ANON para 10 WITN1512001

1086 Lee Stay Transcript 23 June 2021 pp81-82, p86 INQY1000133

Dr Aronstam was well liked by the boys. They had a pleasant time, enjoying what he recalls as a summer afternoon:

*“towards the end of the day [Anon] and I thought we would be helpful kids and we picked up the tray, the lemonade tray, to take it back to a small kitchen annex that was at the back of his house and we caught him, caught him welled full of tears, he had big bags under his eyes anyway and they were full and he was pushing his hands on the sink like this [indicated] rocking and we’d never seen that, just in pain I think, emotionally in pain”.*

His companion asked:

*“‘What’s wrong Dr A? What’s wrong?’ And he goes again, ‘We’ve fucked up ... We’ve messed up. It’s all gone wrong’, words to that effect, and he was not inconsolable because that would have been an exaggeration but we knew he wasn’t expecting us to go and be helpful. We weren’t supposed to catch him. So [my companion] asked ‘Are we going to be OK, Dr A? Are we alright? Are we okay?’ The reaction was unique, a worry, and he said ‘We’ll do our best. We’re going to do our absolute best for you’. He never said we were going to be okay.”<sup>1087</sup>*

From that day forward Adrian knew that something had gone wrong.

He was told he had HIV when he was one of five pupils called to see the medics over lunch. He recalls they beat about the bush for fifteen minutes, and then *“Dr Aronstam just came straight out with it and said, ‘You’ve been given HIV. Some of you here have been given HIV. You have it.’ He lifted his left hand and said, ‘You have, you haven’t, you have, you haven’t, you have.”*<sup>1088</sup> Adrian was the fifth to be told. He was told he had two to three years to live, just before ten to two: that was the time he had to go back to class. He was not even given the afternoon off.

After he left school, he still lived locally. In about 1991 he had a further conversation with Dr Aronstam, when he went to the centre for a bleed to be treated. It was a bit late. Only he was there in the centre. Picking the story up in Adrian’s own words:

*“I went ‘hello’ and he said, ‘Oh, come on in’ and I walked in to a man that was staring at his desk. I can only say in that moment, in that 15 – – it was very short, 15 minutes – – he was a broken man. Exactly that. That gets me. I was counselling him. ‘Don’t worry, you did your best’. ‘No, we messed up. AIDS didn’t need to happen. The PHLS [Public Health Laboratory Service] have let me down ... They let me down, they set me up’ and I kept trying to comfort him, saying, ‘You done your best, this is just an accident, you’ve done your best’ because we believed then that was the scenario. I couldn’t really comfort him but he actually poured me a brandy as well. We actually had a brandy.”<sup>1089</sup>*

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1087 Adrian Goodyear Transcript 5 June 2019 pp80-81 INQY1000014

1088 Adrian Goodyear Transcript 5 June 2019 p83 INQY1000014

1089 Adrian Goodyear Transcript 5 June 2019 pp75-76 INQY1000014

Others have given a similar account of being told of the outcome of HIV testing in groups. One pupil (Julian Gatrack) recalled that pupils were told that they were infected with HIV in the presence of other pupils who had tested negative; he was wrongly informed that he was positive.<sup>1090</sup> The widow of a pupil (Ian Greig) described her late husband's recollection of *"being seated in a big room, at Treloars with a lot of his friends while the staff went around the room saying 'YES, NO, YES, NO' to indicate whether they were HIV positive."*<sup>1091</sup>

Another boy, who had joined Treloar's aged seven and a half, recalled that *"We were all taken into a room, five at a time. Dr Aronstam and Dr Wassef, along with some nurses, were present in the room, and they went around pointing to each boy in turn saying, 'yes' or 'no', and that was how we found out if we were infected or not."* He was nine or ten years old – and this was how he learned that he had been infected with HIV.<sup>1092</sup>

## Communication and consent

There are very few records of conversations with parents being recorded, or referenced. It is more likely than not that there were very few such conversations. Alexander Macpherson, as headteacher, had written authorisation from parents to give consent for necessary medical treatment (though the expectation was that this would relate to emergency treatment rather than anything pre-planned). When forms were brought to Alexander Macpherson for him to sign to give consent, he gave it because he trusted the doctors.<sup>1093</sup> However, his evidence was *"I was certainly not asked to sign any consent forms for research, clinical studies or trials, or blood testing nor would I have agreed to do so."*<sup>1094</sup>

In his book, Dr Aronstam wrote: *"It is for the haemophiliac or his advisor to balance the severity of his bleed against the urgency of his commitments and his assessment of the long-term consequences of possible under-treatment"*.<sup>1095</sup> Note the words are *"the urgency of his commitments"*. There is no suggestion that the *"haemophiliac or his advisor"* should consider the risks of treatment: the long-term consequences mentioned are specifically those of non-treatment, not of treatment itself. However, the theme that it is for the patient to decide how he should be treated in his own case is further emphasised in the book, where Dr Aronstam wrote: *"My philosophy on the whole is that if it is important to a patient it warrants a prophylactic dose. I let him decide."*<sup>1096</sup> Though he went on to recognise that there were further arguments to consider as to whether prophylaxis was necessary: *"The risk of complications such as hepatitis and AIDS makes prophylaxis unacceptable to some doctors and some haemophiliacs ... Even if they [your own doctors] feel prophylaxis is*

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1090 Written Statement of Julian Gatrack para 21 WITN1231001

1091 Written Statement of Helen Dabbs para 6 WITN1180001

1092 Written Statement of ANON para 15 WITN5364001. His elder brother was also infected with HIV and Hepatitis C from his treatment at Treloar's, and died in 1999.

1093 Usually, he said, the forms were brought by Dr Wassef. Alexander Macpherson Transcript 24 June 2021 p38 INQY1000134

1094 Written Statement of Alexander Macpherson para 7 WITN5561004

1095 Aronstam *Haemophilic Bleeding: Early Management at Home* 1985 p11 RLIT0000666

1096 Aronstam *Haemophilic Bleeding: Early Management at Home* 1985 p107 RLIT0000666



*indicated, the ultimate decision is yours.*"<sup>1097</sup> Despite this expression of view, there are a number of examples of Dr Aronstam writing with information to GPs and other clinicians which he was not actually giving to parents, and there is little documentary or other evidence of information about treatment being provided to pupils or parents.<sup>1098</sup>

The risks of infection were simply downplayed from one infection to the next. A pupil who was infected with Hepatitis B whilst at Treloar's states that his mother was never told about the diagnosis, though a group of pupils were told collectively that they had tested positive – and that "*because we were haemophiliacs we would get over it unlike other people*".<sup>1099</sup> The evidence generally was that pupils were told that hepatitis was not something for them, as people with haemophilia, to worry about. When it came to AIDS, little if any information was provided; there is evidence that they were told that only two people in the UK with haemophilia had AIDS, and one recollected that they were given to understand that it related to people with haemophilia in the US rather than the UK. Perhaps consistent with the suggestion from the recollections of Adrian Goodyear that Dr Aronstam found it difficult to come to terms with the infection of the pupils from treatment he had been responsible for giving to them, is that for the most part parents were not told directly of their child's diagnosis that they were positive for HTLV-3/HIV infection. A few were. Most were not.

The evidence before the Inquiry suggests, overwhelmingly, that there was no general system or process for telling parents of the risks of viral infection. Nor were pupils told. Parents were not given details, nor even core information, about their children's treatment at Treloar's for haemophilia.<sup>1100</sup> They were not told, for instance, that despite their home clinicians' recommendations as to the treatment product, the pupils were being given a range of different concentrates. Parents were not told that AIDS-related investigations or tests were undertaken or that pupils were monitored for the stigmata of AIDS. When there was the 1974/75 outbreak(s) of hepatitis, the evidence suggests that parents were

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1097 Aronstam *Haemophilic Bleeding: Early Management at Home* 1985 p107 RLIT0000666. Most of the boys were of an age at which their participation in decisions about their treatment and future would have been appropriate, but if not this philosophy infers that their parents at least should have been given the information with which to make their own decisions about their child's treatment and future.

1098 One mother whose son attended Treloar's from the age of nine records that he reported a close relationship with the doctors and nurses at the centre, but that she "*was not provided with any information beforehand about the risks involved in using FVIII. I understood it to be a miracle drug to the haemophilia community.*" Written Statement of ANON paras 10-11 WITN1428001

1099 Written Statement of ANON para 9 WITN3224001. A boy who attended Treloar's between 1968 and 1977 states "*At no point in time, have my parents or I been provided with information or advice beforehand, surrounding the risk of being exposed to blood borne infections, as a result of receiving either whole blood, cryoprecipitate, plasma or Factor VIII.*" Written Statement of ANON para 31 WITN5343001

1100 Gary Webster told the Inquiry that his parents were not given any information about the products that he was receiving "*they didn't even know when I had a bleed. My mum's comment was that 'We only found out what had happened to you when' I told them ... Other than that, they wouldn't know if I was on Factor VIII, what I was on. I wouldn't even have thought they knew when I changed from cryo to concentrate.*" Gary Webster Transcript 21 June 2021 p109 INQY1000131. Sheila Squires, whose son Peter attended Treloar's from 1973-1978, was not told anything about his treatment: "*As far as we were concerned, he was still receiving cryoprecipitate and we were not told any different ... In the 5 years he attended Treloar's, we never had any consultation with a medic and no one ever provided an update on Peter's treatment and condition.*" Written Statement of Sheila Squires paras 24-25 WITN4641001

not systematically told that their sons were amongst those who had been infected. Nor is there evidence to suggest any systematic approach to informing parents about non-A non-B Hepatitis or of the significance of abnormal liver function tests. Neither pupils nor parents were told that children were being tested for HTLV-3/HIV and, not having been told, were obviously not in a position to consent to that process of testing. And then, parents were, for the most part, not told the outcomes of those tests.

Stephen Nicholls' father Robert stated that *"we were never consulted or asked for consent regarding any medical trials and or tests while Stephen was a minor at Treloars."* In 1979 Stephen started on a programme of prophylaxis: his parents were not consulted or briefed about this. They signed a loco parentis form in case he had an accident and needed immediate treatment, but *"We did not give permission for all of Stephen's haemophilia related treatment to be done without our consent. Neither were we consenting to non-emergency treatment, whereby our consent could have been sought within a reasonable time frame ... I cannot remember one incident when we were called in to consent to treatment."* Robert believed that *"this chance concentration of resident Haemophiliac Treloar boys under one centre was an irresistible, probably well-intentioned opportunity, for research, trials and analysis."*<sup>1101</sup>

There are some, few, exceptions to what is nonetheless a general picture. Thus, there is some evidence of a few parents responding to requests for consent – asking, for instance, for further details, and in one case complaining that the dose their child was already receiving was *"quite high"* at Treloar's and that they would not wish him to receive a higher dose except in exceptional circumstances.<sup>1102</sup>

Dr Aronstam did tell Alexander Macpherson, over a series of meetings, of pupils' HIV status. He did tell the governing body on 24 February 1986 that parents of children carrying the AIDS antibody were *"already aware of this fact"*.<sup>1103</sup> This was because the headmaster had been told that they had been informed, though he cannot remember by whom that was. On the evidence available to the Inquiry it was in fact untrue. Alexander Macpherson regarded it as the haemophilia centre's obligation to notify parents, and not his. The centre was concerned with the clinical care of pupils who were patients; his principal focus was the discipline and running of the school. As far as he, the headmaster, could remember there were very few pupils who did not have the HIV virus – he assumed, therefore, that they all did. There is no evidence from him, or otherwise, that Alexander Macpherson questioned Dr Aronstam as to how that had come about. The conclusion is inevitable that he did not ask, and was not told. He did however report to the Governing Body, on the same occasion, that *"the correct inference to draw from the Minute on this subject from the last Meeting was that although*

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1101 Robert also said *"When Stephen was 12, in 1979, he came home all excited saying that he had new stuff from America, and that everyone was having it. I remember reading the package and there were no warnings. However, I had grave concerns."* He was in the navy and had seen US commercial blood donations centres himself. Written Statement of Robert Nicholls para 3, paras 18-20, para 22, para 32 WITN6477001

1102 Letter from Anon to Dr Aronstam and Dr Painter 24 May 1978 p2 TREL0000070\_027

1103 Minutes of Lord Mayor Treloar College Governing Body meeting 24 February 1986 p2 TREL0000365

*‘very few’ of the haemophiliac boys carrying the AIDS antibodies would develop AIDS, this meant that at least one would do so at some stage*.<sup>1104</sup>

## Support and treatment

Neither the headmaster nor the housemaster (Ian Scott)<sup>1105</sup> was involved in telling any pupil of his infection. If and when pupils were first told at the school that they had tested positive, they had no supporting presence. Their parents were not present. Nor was there any structured facility for giving support after that, although there was a psychiatrist available, at least in principle, and a counsellor.<sup>1106</sup> The survivors do not recollect any such support being given, and Dr Aronstam appeared in later writing to acknowledge that he provided most of the “*counselling*” himself. In his report to the region in 1986, Dr Aronstam wrote: “*Antibody positive haemophiliac children enter adolescence with an increasing viral load. Nature has programmed them for sexual experimentation at a time of maximal infectiousness. The counselling involved in this situation must be expert, intense, patient and even more time consuming if breakout of the virus from this group is to be averted.*”<sup>1107</sup> Later he said “*Who should counsel?*” and answered his own question: “*in our centre I and a nursing sister have done it all up till now.*”<sup>1108</sup> Given the absence of any recollection by a surviving pupil of anyone else providing counselling, it is probably the case that the psychological and counselling services potentially available were not utilised as they might have been.

Dr Aronstam did also write about his concept of counselling for pupils with haemophilia. He said in an article:

*“My experience leads me to believe that the quality and intensity of counselling before the adolescent is told of his seropositivity will influence the acceptance of subsequent advice. An education programme about HIV disease is likely to precipitate inquiries from young people about their own HIV status. If the positive aspects of the disease have been emphasised a truthful answer can then be given more easily and the child should not be devastated ... The logistics of such a programme may be daunting but this matter is serious and those of us who care for haemophiliac children should be addressing it urgently.”*<sup>1109</sup>

1104 Minutes of Lord Mayor Treloar College Governing Body meeting 24 February 1986 p2 TREL0000365

1105 Written Statement of Ian Scott para 71 WITN5314001

1106 Though he did not recollect an additional counsellor when he gave evidence, after time to think Alexander Macpherson recalled that two child psychotherapists were taken on “*to help the boys cope with the emotional troubles after the infected blood epidemic hit.*” Written Statement of Alexander Macpherson para 50 WITN5561004

1107 Treloar Haemophilia Centre: Report to the Region 1 January 1986 p3 HHFT0001073

1108 Treloar Haemophilia Centre: Report to the Region 1 January 1986 p3 HHFT0001073

1109 Aronstam *Letter to the Editor on AIDS advice to haemophiliacs* The Lancet 10 October 1987 RLIT0000130. There are at least two problems in regarding this as an acceptable approach. First, he talks of AIDS having “*positive aspects*”. Second, he implies that the doctor giving counselling would first know that a child had been infected, then run an education programme about AIDS, in order to get the child to ask about his own status: he would know that the child had been infected but deliberately have kept that from him until the education programme was completed. This approach suggests that although he was knowledgeable about the children he would counsel and about their haemophilia,

The housemaster Ian Scott identified a lack of training which would have enabled staff to offer psychological support to infected pupils.<sup>1110</sup> He said that he found himself ill-equipped to address individuals' concerns when they were suddenly presented with an HIV diagnosis and confronted with questions as to what HIV/AIDS could mean for them: "*This ... was beyond anything which my past experience and training had prepared me for.*"<sup>1111</sup> He thought that the headmaster had not contacted any external organisation to ask for help as to how to assist the boys best, nor to his knowledge had the sister (Trish Turk), Dr Pat Tomlinson, or Dr Aronstam.

Though Alexander Macpherson thought that the way in which the boys who were told of their infections was handled badly, and he acknowledged the effect of knowing of their infection: "*they [pupils] had this rage inside them ... and, 'Why me? Why me?' ... they were rebelling ... there was actually nothing you could do about it*", he said that he did not think the school could have done any more. The staff probably did everything they could. "*They were infected and they were going to die and that was it.*"<sup>1112</sup>

## Outcome

Since a number of pupils left Treloar's without knowing that they had been infected when they left, and others may have died elsewhere, it is unclear precisely how many pupils contracted AIDS, and how many died. Secondary school covers only seven years of a pupil's life. The data therefore available from Treloar's will not tell the whole picture. However, the best overview is probably that provided by the surviving pupils themselves: they say that out of 87 infected, only around 30 are now left.<sup>1113</sup> More contemporaneous records are those of a report to the region by the Treloar's centre in 1986, which recorded that 43 of its patients were HIV antibody positive. Two had seroconverted in 1980, five in 1981, ten in 1982, eleven in 1983 and five in 1984. The remaining ten had all been "*seropositive for at least three years*".<sup>1114</sup>

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he was not properly qualified to be an effective counsellor for those grappling with the bombshell knowledge that they had probably been dealt a death sentence.

1110 Written Statement of Ian Scott para 41 WITN5314001. Amanda Beesley, whose late husband Andrew had been a pupil at Treloar's, and who worked between 1984 and 1988 as a unit leader at Treloar's, recalled that: "*What we didn't have was any help to know how to support the boys. So boys that had been diagnosed with infections and would come back to the house and talk to us about it, we had no training for how to talk with them about that, how to help them come to terms with it – – anything, really, how to support them.*" Amanda Beesley Transcript 16 October 2019 p167 INQY1000042

1111 Written Statement of Ian Scott 24 March 2021 para 43 WITN5314001

1112 Alexander Macpherson Transcript 24 June 2021 p73 INQY1000134. He had a reason for this. Dr Aronstam encapsulated it: "*The specialised nature of the haemophiliac condition makes it impossible to win the trust of the patient unless you are seen to have a thorough understanding of the primary illness. For this reason I do not see a role for the injection of specialised counsellors into our Unit.*" Treloar Haemophilia Centre: Report to the Region 1 January 1986 p3 HHFT0001073

1113 Collins submission 16 December 2022 p94 SUBS0000063

1114 Treloar Haemophilia Centre: Report to the Region 1 January 1986 p1 HHFT0001073. UKHCDO were not able to provide data for the number of pupils infected with HIV at Treloar's from the National Haemophilia Database. HIV positive patients were allocated to the centre which reported the first positive HIV result rather than the centre potentially responsible for issuing the treatment that caused the infection. Written Statement of Professor Pratima Chowdary p1 WITN3826036

Although the precise figures may not be determinable, it can be said with confidence: (a) a large percentage (probably about 70%) of those pupils with haemophilia who attended Treloar's School died in consequence of their infection; (b) of those who were pupils in the early 1980s, a great majority were infected with HIV; (c) very few, whether suffering from HIV or not, avoided being infected with hepatitis.

## Commentary

This chapter will have made grim reading.

Lord Mayor Treloar College had a laudable aim. By bringing together a large group of young people with severe haemophilia, it allowed them to avoid the isolation that could have followed in mainstream education. The experience of being educated there was potentially enjoyable, and there was a rapid response if and when they should have a bleed. But what might otherwise have been a valuable experience was irreparably damaged by their being given infected blood products. It turned what could have been uniquely rewarding into a nightmare of tragic proportion.

Not only were the treatments they were given infected. From the time that Dr Rainsford was appointed, if not before, the clinical staff were also well aware this might happen. The risk called for a response to reduce or eliminate it. And it demanded that those who were affected by it – children, to the level of their understanding, and their parents – should have been made aware.

Although the risks could not at that time have been avoided entirely, since there was then no means of eliminating all Hepatitis B, non-A non-B Hepatitis or HTLV-3/HIV from the blood supply because none of the causative viruses had yet been identified, there were several ways in which those risks could have been minimised. Instead they were amplified. Most probably with research in mind, the clinicians administered greater amounts of blood product than would generally have been given in other centres at the time. And they experimented extensively with prophylaxis even though that doubled or tripled the amount of concentrate given (and therefore most probably doubled or tripled the risks).<sup>1115</sup>

If the aim had been giving the boys treatment which carried the least risk of infection, a number of measures were available. They included providing the smallest doses that might be consistent with treatment, limiting pupils to one type of product (and so far as possible to a single batch), and using cryoprecipitate or NHS concentrate rather than commercial concentrates wherever available. Each and all of those measures would limit the number of different donors to whose blood an individual was being exposed. In practice, the regime of prophylaxis so enthusiastically adopted (by Dr Aronstam in particular) inevitably led to a need to purchase commercial concentrate – for there would, on any showing, have been insufficient NHS concentrate to supply that demand without depleting supplies of NHS concentrate to other centres which had an equal case for its receipt. Thus, the more

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1115 Subject to there being a threshold at which no additional risk would be significant.

prophylaxis was embraced, for trial or for routine treatment, the greater the proportion of commercial product was bound to be, compared to the proportion of NHS. When in some cases other clinicians, parents and pupils requested to have or to avoid particular forms of treatment, they were largely ignored, though the requests could have been honoured.

The probability is that convenience of administration led to pupils getting the appropriate amount of concentrate for their bleeds from a variety of different manufactures, and a mix of batches, without knowing the additional risks that this subjected them to. It also precluded any significant use of cryoprecipitate.

In short, the regime adopted was probably the most infective of any that might have been used to treat haemophilia at the time.

Pupils were given false reassurance about the significance of hepatitis, which was minimised in part by regarding it as an inevitable risk of treatment. As a general rule, neither pupils nor parents were told, except in the most limited of terms, of the fact that research was being conducted in which the pupils were participants. Nothing was said about the risks (except that which was falsely reassuring) and many pupils were never told that they had contracted an infection either with Hepatitis B, or HTLV-3/HIV (when those infections could be tested for) or that their liver function tests indicated that they probably suffered from non-A non-B Hepatitis. Nor were they warned what any such infection might mean for them. Nor were their parents, as a general rule. Those who were told of HTLV-3/HIV infection were told in a manner which on any view was unacceptable.

Increasing awareness that AIDS was probably caused by an infectious agent did not significantly change the regime, but it did lead to checks being made from January 1983 onward for any sign of AIDS developing in a patient (though nothing was said to the pupils or parents about the results or their possible significance). The risks of infection and its consequences were already high beforehand, but despite the added weight of AIDS no significant change in treatment was made. This was wrong: changes could have been made. They should have been. It is difficult to disagree with the summation of Alexander Macpherson who said: *“And if they [the haemophilia doctors] didn’t immediately take action when they knew that infected blood was being used, I’m very surprised, and I think that – I think that was remiss and that was a mistake which I would say was culpable.”*<sup>1116</sup> The doctors did not take immediate action. There is nothing to suggest they took on board a letter of 24 June 1983 from the UKHCDO in which Professor Bloom and Dr Rizza described the “general recommendations” of the reference centre directors which, in the case of children, was to the effect that *“many Directors already reserve supplies of NHS concentrates (cryoprecipitate or freeze-dried) and it would be circumspect to continue this policy.”*<sup>1117</sup> Nor, once they knew of infections, did they take action to ensure a system of proper counselling<sup>1118</sup> for adolescents at

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1116 Alexander Macpherson Transcript 24 June 2021 p77 INQY1000134

1117 Letter from Professor Bloom and Dr Rizza 24 June 1983 HCDO0000270\_004

1118 There was too much of the arrogance of the proud amateur about the reasons which Dr Aronstam had for thinking that he, and a nurse, were the best counsellors to deal with young men who

the time of their lives when, according to Dr Aronstam’s own writings, they might most have needed it. Those who were infected did not have the support they should have received.

This, of course, is said in retrospect. However, retrospectivity is **not** an explanation for what happened. What occurred was not an inevitable course of events. It was not a tragic accident, in the sense of something that was unavoidable. It was not the result of an unknown against which steps could not be taken effectively.

Whilst it cannot be ruled out that some infections with hepatitis or with HIV would have occurred even if a different treatment policy had been adopted, or that some infections would still have occurred if prophylaxis, product mixing, and batch mixing and the use of concentrate were kept to a minimum, the probability is there would have been many fewer.<sup>1119</sup>

It is more difficult to assess precisely why such a regime, with its tragic consequences, was adopted. The picture of Dr Aronstam as a remorseful and broken man painted by Adrian Goodyear suggests that he never had any intention of harming his pupils. It does not go so far as to suggest that in the light of the knowledge he had at the time he acted appropriately for the best of his pupils as individuals.

What might have been an overriding aim is revealed when considering evidence about research trials on prophylactic therapy. On 27 October 1972, at a meeting of the haemophilia centre directors, there was discussion about a protocol for a trial of prophylactic therapy. Dr Biggs thought it to be clear that no individual haemophilia centre could organise a trial of this type, for ethical reasons apart from anything else. Yet the Lord Mayor Treloar College appeared to be willing to do so. This is uncomfortable. In the event, half the cohort at any one time<sup>1120</sup> had a dose which was less than thought appropriate to provide prophylactic cover. They still had to have treatment for their bleeds as and when they occurred, but some would have received what was effectively a meaningless additional dose<sup>1121</sup> with all the risks that accompanied it. In 1975, Dr Aronstam recognised in a communication with the MRC (who funded the trial) that: “*We have now gone as far as we can with this trial in the face of, I may say, enormous difficulties which I feel were a direct result of using a placebo for this study.*”<sup>1122</sup> If, as seems to be the case, only a placebo was to be given to pupils who would need further treatment, then they would need to have been informed of that, and their parents asked to consent: otherwise, the unethical position is reached of providing treatment believed to be insufficient for one half of the patients treated whilst the others are getting at least as much as they needed and if not more. One of the central principles identified

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were struggling to cope with the bombshell knowledge that their life was likely to end within a couple of years.

1119 See the chapter on *Haemophilia Centres: Policies and Practice*.

1120 The whole of the cohort were affected for half the time because it was designed so that there was a switch from the high prophylactic dose to the low dose for each participant. Thus each had half the time on one dose and half on the other – the idea being that that provided each person as their own best reference point to assess whether and to what extent there had been benefit overall.

1121 Meaningless, that is, for them – it was of course potentially meaningful for research. It is considerations such as this that tend to an overall conclusion that research was favoured above the best interests of the individual patient.

1122 Letter from Dr Aronstam to Dr Bunje 22 July 1975 MRCO0000065\_005

by the group of medical ethics experts who reported to the Inquiry was that research and trials should not prejudice ongoing treatment, but be conducted where it is thought, on a reasonable basis, that they might add benefit to the individual patient.<sup>1123</sup> It is clear that this principle was not at play here. It should have been.

It is difficult to avoid a conclusion that the advancement of research was favoured above the immediate best interests of the patient.

Accordingly, though it seems almost certain that Dr Aronstam and the other clinicians in his team would not have wished their patients to suffer infection as they did, and were upset when it happened, this is not because they strove at all times to do the best for each individual patient. On the available evidence they did not.

In conclusion, the likeliest reason for the Treloar's treatments having the catastrophic results they did is that clinicians were seduced by wishing to believe, against available information, that intensive therapy might produce better overall results; by the desirability of convenience in administration rather than the safety of treatment; and by ignoring some of the treatment implications of the research projects they wished to pursue.

I acknowledge that these conclusions are reached in the absence of direct evidence from Dr Aronstam and Dr Rainsford in particular. Nonetheless, hard though they may be to read, I believe the conclusions are fully justified by the evidence available. I have been helped considerably by the range of evidence from a number of witnesses, both oral and written – those who were pupils at the school (not all of whom had haemophilia); parents of former pupils; the fiancée of one former pupil; the partners of others; and staff, as well as by the range of documentation. I have considered all of it.

### **Treloar's as an exemplar**

At the start of this chapter, I said that the tragedy that was Treloar's both illustrates and highlights the nature of, and many of the reasons for, the national treatment disaster which was infected blood.<sup>1124</sup>

In summary, as regards the treatment of pupils at Treloar's:

- (1) The pupils were often regarded as objects for research, rather than first and foremost as children whose treatment should be firmly focused on their individual best interests alone. This was unethical and wrong.

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1123 Medical Ethics Expert Panel Transcript 27 January 2021 pp58-100, 112-131 INQY1000091, Expert Report to the Infected Blood Inquiry: Medical Ethics April 2020 pp91-103 INQY0000241

1124 In saying this, I have not lost sight of the fact that the treatment regimes adopted at Treloar's were arguably more intense in the sheer quantities of concentrate administered than were regimes elsewhere. That the outcome for the pupils of Treloar's was demonstrably as dreadful as it was cannot be attributed solely to that: it was caused by the mix of factors described in the chapter.



- (2) There were multiple research projects during the 1970s to early 1980s where informed consent for participation was neither sought nor given. This was unethical and wrong. (There are echoes of this in relation to treatment at other centres).
- (3) The risks of treatment, including viral risks, were well known to the clinicians involved in decision-making regarding haemophilia treatment at Treloar's. (This was true generally across the UK).
- (4) Those risks were not explained to parents or to pupils, such that pupils were treated in the absence of informed consent. This was unethical and wrong. (This was true generally across the UK).
- (5) Those responsible for treatment adopted treatment policies and practices (including the widespread use of commercial concentrates, prophylaxis and treating individual boys with multiple different products and batches) which had the effect of increasing the risks of viral infection. This was wrong. (Though prophylaxis was not in widespread use elsewhere, home treatment was. Such treatment (not to the same extent as prophylaxis, but similarly favouring the use of commercial freeze-dried concentrates) could add to the risks a patient faced. The indiscriminate use of a wide mix of products was particularly pronounced at Treloar's – and it appears that the effects of this were particularly cruel – but it was also true to a varying extent across other treatment centres in the UK).
- (6) Those responsible for treatment failed to respond to the risk of AIDS by making any significant changes to the treatment regimes. This was wrong. (True in many other centres across the UK, though not in all).
- (7) Tests were undertaken on pupils, both in relation to liver function and, in 1984/85, in relation to HIV, without the knowledge or consent of pupils or parents. This was unethical and wrong. (There is evidence that testing without knowledge or consent was widespread in the UK).
- (8) Some pupils and parents were never informed by Treloar's that they had tested positive for HIV. This was unconscionable. (There were many delays in communicating diagnosis across the UK).
- (9) The way in which other pupils were informed of the fact that they had tested positive was unsupportive, insensitive and wrong.
- (10) Insufficient support was provided to pupils after diagnosis. This was wrong. (The need for dedicated psychological support was unanswerable in the 1980s.)

The outcome at Treloar's of this combination of events, for these reasons, demonstrates in microcosm much of what went wrong in the way in which many haemophilia clinicians treated their patients across the UK.

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