

Witness name: Pam Allen  
Kay Durrant  
Jackie Wilson

Statement No: WITN4000002  
Exhibits: N/A

Dated: 02 June 2023

## **INFECTED BLOOD INQUIRY**

---

### **INTERMEDIARIES' REPORT: SUPPLEMENTARY**

---

We are providing this supplementary report in response to a request under Rule 9 of the Inquiry Rules 2006 dated 11 January 2019.

#### **Section 1. Introduction**

We were appointed in 2019 to act as intermediaries because some people had told the Inquiry that the stigma attached to their experiences means they would have difficulty in providing witness statements or oral testimony in the traditional way associated with public inquiries.

We interviewed 85 people during 2019, and our report was published on the Inquiry website. We gave oral evidence to the Inquiry on 24 February 2020. Since that time, 12 families have requested the services of an intermediary. This report covers their experiences without identifying them individually to protect their anonymity.

Our professional backgrounds are as follows:

Pam Allen: a qualified social worker with 43 years of experience in local authorities, the courts and the independent sector. I have worked directly with adults and children who have suffered trauma, including bereaved parents.

Kay Durrant: a qualified senior investigating officer with over 25 years of experience in the police service. I have extensive experience dealing with people who are vulnerable and have provided training nationally with the College of Policing on vulnerability and investigation. I am also a qualified and practising counsellor.

Jackie Wilson: a qualified social worker with 42 years of experience in local authorities, hospitals, family courts and the independent sector. I have worked extensively with families who have experienced trauma. I am also a qualified and practising therapeutic counsellor.

We offered a range of approaches to people for the interviews, including face to face conversations in their home or at a neutral venue nearby, telephone discussions or interviews by video link. During the interview the intermediary took notes, and then provided a draft report for the family member or members to review. This was to ensure accuracy and to reflect the authentic voice of those taking part. As with the participants in our first report, this process often surfaced long-held thoughts and feelings, and many people reflected that although distressing, it was also a relief to say things out loud and to have them formally recorded.

Where this report uses italicised quotes, these are words directly used by participants, and are included with their permission.

As we noted in our earlier report, we were humbled by the courage and dignity of the people we interviewed. Their compassion for others affected was clearly evident, as was their concern about those who could be affected by a similar circumstance in the future. A consistent view that ‘this must never happen again’ was strongly expressed throughout the group.

There were very strong echoes in this group of the experiences shared by the original group.

In this report more detail is provided on aspects which were not touched upon in the earlier set of interviews. These participants all experienced the pandemic and its personal, financial and societal challenges, and they have also had more opportunity to learn from other Inquiry participants and witnesses about individual or group experiences, and wider organisational, policy and research issues.

## **Section 2. How Infected**

In these 12 families we met with five people who were infected and 12 people who are affected, and their experiences included HIV and hepatitis C. The people affected had all been bereaved, whether as parents, children, spouses or partners. Families described infections arising from receiving infected blood products for haemophilia, or in transfusions during surgery, pregnancy, childbirth or dialysis.

### **Infection and diagnosis with HIV**

We heard about people being tested for HIV without their consent or even knowledge, and of not being told that they had the infection.

Some people spoke of being informed “*out of the blue*” by letter about the possibility of being infected as a result of ‘look back’ enquiries, and then waiting – sometimes for months – to hear the results. These were agonising waits, especially when they related to children needing to be tested.

One woman who was infected following a transfusion after childbirth still has a photograph of herself with her new baby, shortly after the birth, where the blood transfusion line is clearly visible. When she looks at this, she finds herself thinking, “*Is that it? Is that the moment?*”.

People talked of a lack of knowledge and information about HIV, and hepatitis C and their implications. Most were not offered therapeutic support at diagnosis or as the illness progressed, though one person was offered counselling in 2016 by their GP. Another was signposted to local NHS provision or the Terence Higgins Trust, being told *“there’s no stigma now”* – but neither of these were tailored to her particular needs and circumstances. Several people made the point that support services and information for HIV were frequently focused on the needs of gay men, and little was understood about the needs of people infected by blood and blood products – and the needs of their families.

### **Infection and diagnosis with hepatitis C**

One woman finally and belatedly diagnosed with hepatitis C described having to wait five months for the results: she chased up doctors for test results and sometimes received curt and even rude responses, including from the Blood Transfusion Service. This woman was also told that the delay in receiving tests results was due to a funding ‘debate’ regarding which healthcare body should fund the tests. One woman who has been diagnosed within the past ten years described how responsive and helpful her GP has been, but had also experienced rudeness from other doctors who *“seemed aggrieved with the questions I wanted answers to”*.

Another woman described how, when she was tested for hepatitis C, she was asked to give additional samples ‘for research’, but it was never explained to her what this research was looking into.

In our discussions about late diagnosis, families raised the issue of how the underlying condition of hepatitis C may have influenced their vulnerability to developing other serious conditions, for example one had developed bowel cancer prior to the hepatitis C being recognised. They also queried whether the presence of hepatitis C may have reduced the effectiveness of treatment for other conditions. There was a shared sense of incredulity that there has not been a programme of general screening for hepatitis C, even though the authorities knew about infected blood and its implications. One woman who was diagnosed 34 years after being infected said: *“I was livid and it’s crazy not to find out that I had been given a potentially lethal infection.... thirty four years of not knowing and all the dentists I have seen could have meant I infected others”*.

One man described how his wife had been infected with hepatitis C during a period of dialysis, though this was not diagnosed at the time. She then had a kidney transplant which gave her a new lease of life but after a few years it began to fail. When she asked if she could go back on the transplant list, she was told she was not suitable because she had hepatitis C. This was the first time she was told about the infection which was only now diagnosed. Being denied another transplant was *“tantamount to a death sentence”*.

Some of those who were diagnosed experienced being asked about lifestyle issues and they reported how distressing and offensive this felt. This group also spoke of shame and stigma, which led to many choosing not to tell people about the infections.

## **Section 3. Impact**

### **Living with infection**

Families told us about their loved ones becoming isolated, losing confidence and “*their zest for life*”. People spoke of feeling that they had “*a death sentence*”, and one family spoke of the impact of learned paranoia, fatalism, and anticipation of danger as their father constantly tried to “*plan against disaster*”, even packing a 30-foot rope ladder for their holiday in case they needed to escape from the hotel.

With both HIV and hepatitis C, people spoke about the devastating mental health impacts on those infected, and on those caring for them. Depression, anxiety and loss of confidence were common, and the impact of this included becoming self-isolated, “*shrivelling away from life*” and shutting out loved ones. People shared experiences of how study and work were disrupted, and the long-term impact of this on financial and emotional wellbeing. One family described how their father withdrew from a lucrative proposal for his business to be merged with another because he could not cope with the larger groups of people in the new business. They said he “*shrank back into his small life*”. Another man who cared for his wife for many years before her death in hospital at the age of 47 said: “*I have been haunted by my failure to look after her at home. This is compounded by the fact that she died suddenly and unexpectedly and I wasn't at the hospital to be with her. I arrived 30 minutes after she passed. I found the months after her death very difficult. I hadn't realised how much her illness determined my very being.*”

### **Impact on family and other relationships: experiences of children**

With this group, we learned much more about the impact of infected blood on children. We spoke to affected people who were still children themselves when their parent became ill or when they lost siblings or a parent, and in one case, both parents. Infected parents also spoke to us about the impact on their children both during their childhood and as they entered adulthood.

In one family, an older child had strong memories of happy times when their father was active and vibrant: playing football, going swimming and having fun. The younger child was only three when her father became ill and reflected that she does not recall seeing her father happy.

One woman spoke of how family life was disrupted by her hepatitis C and its treatment, making an active lifestyle impossible as she frequently succumbed to lying in bed or on the sofa. Leisure activities with her children became almost non-existent, and she could no longer take part in family fun. In their adult life, her children have confirmed how uncomfortable they were about seeing her inject herself, and having the yellow sharps bin around. They said they felt they were existing, not living, because of her illness.

A group of siblings who lost their mother when they were aged between 3 and 17 said: “*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. The separation from our older brother was particularly affecting for us. 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, being helped to buy homes, to get jobs and to progress in areas where they have talent and could excel. None of this happened for us, we are just stuck."*

They reflected that the housing issue has deeply affected their stability. All of the siblings rent their homes and have experienced the instability of frequent moves. Unlike other people, they do not have the safety net of a parent's family home – "a secure home base" - to fall back on, even for temporary periods in between tenancies, and this is profoundly unsettling.

One man who was orphaned when still under 5, when both of his parents died from HIV, described himself as "*just so lost*" throughout his childhood and well into adulthood. He was placed with a carer over 200 miles from his home community and extended family. He remembers standing in a field and thinking "*Where's Mum, where's Dad, what am I doing here?*". He said: "*I felt jealous of all my friends growing up as they had the stability of having a mother and father, when I missed my parents dearly*".

One man who lost his mother when he was a teenager said that he became homeless after his mother died and he "*went off the rails*" for a period of over five years. He felt he had nothing to lose and that he didn't care about what he did, or the consequences. He describes himself then as "*rushing around headless*". He got into trouble with the law and eventually served a prison sentence. It took him a further ten years to get his life on an even keel.

We heard some different experiences of how young people had dealt with the loss of a sibling: for example, one young person felt a sense of relief that their brother's suffering had ended, whereas another described impacts on their own emotional wellbeing and self-confidence.

There were several comments from people who had lost their parent or parents during childhood about the impact on their own parenting capacity. One man explained how he would have valued the practical support of his mother as he was getting to grips with being a new parent, but the biggest loss was that "*I miss the warmth of someone to say to you it's going to be alright*."

Another said that they felt they had no model for how to parent their own children, especially as they entered adolescence. This woman felt her children had missed out on having a loving grandparent who can offer support and advice and be a living link to family culture and traditions.

### **Stigma and shame**

These families went through very distressing experiences relating to stigma and ignorance about the disease. One person commented on how this was fuelled by the press. People spoke of experiencing verbal abuse in their communities and having to

move house because of the stigma. One woman described coming home from school aged 9 and finding her mother tearfully scrubbing off the word 'AIDS' which had been daubed across the house in red paint. Years later, when visiting her mother's grave, she was horrified to see that it had been desecrated. This family also experienced bricks being thrown at the house and eventually had to move after burning rags were pushed through their letterbox. Another family spoke of their children having to change school because of being shunned by former schoolfriends.

One family kept their children at the same school after they had to move house because the staff there had been so supportive, but the children's walk to school was now longer and they described having to "*keep their heads down*" because they were more exposed to verbal abuse from their community. Several affected people have chosen not to tell people about their family's experience of HIV, even decades later. Some have not told their current partners or children, either because of a continuing sense of misplaced shame, or because they don't want to expose their loved ones to the same anxieties and prejudice that they have experienced. They describe the emotional toll of maintaining these secrets over so many years as exhausting.

On the morning of the day their son died from HIV, one family had to endure a statement being released to the press by the local coroner stating that a local boy with haemophilia had died and was HIV positive. Although not named, everyone knew who he was. They said that their life in the community then became intolerable.

Some people spoke about how shame was exacerbated for people who belonged to a faith community. One woman spoke of the intense shame her aunt felt about having hepatitis C, as she was devout in her faith which rejected the use of alcohol. She feared that people would assume the hepatitis was caused by alcohol misuse. Her husband was a minister in this religion and she had a very visible role in the local community, which included welcoming visitors into their home, often to stay the night. This caused huge stress as she felt great anguish about the possibility of infecting them, and would undertake extensive deep-cleaning and infection control measures before anyone came, balancing this with her need to keep the hepatitis C private.

Another family spoke extensively about how as a black Caribbean family, the stigma of HIV robbed them of the cultural traditions associated with their culture. They were unable to have their traditional Nine-Night for family mourning or a large well-attended funeral. Their mother's body was immediately taken from the home after death and the coffin was sealed straight away: no-one had the opportunity to see her body in the funeral home. No-one in their community was prepared to look after the children after her death, and they were separated, with some going to live with a white carer in a rural area where they experienced racism in the community and the carer struggled to bring them up in their cultural traditions.

One woman commented that the impact of shame on black communities is severe, and coupled with the lack of tailored information for people from ethnic minorities, might be the reason for apparently low numbers as Inquiry participants. In recent years she describes herself as sitting on the edges of support groups for people affected, never feeling that they met her family's needs. She has never found any useful information about the experience of black families in relation to infected blood.

#### **Section 4. Impact on education and work**

One family spoke of the significant impact on career progression for the infected person and the premature retirement of their spouse in order to become their carer. Others spoke about infected young people who were clearly high achievers, until their infection and illness robbed them of the energy to complete their studies or otherwise meet their potential.

One woman who was very well educated and qualified in her field spoke of having to step down from a highly paid role because of the impact of the hepatitis C symptoms and how this curtailed her career progression. Similarly, others spoke of having to work part time, or to take less taxing jobs which were well below their earning potential. The lifelong earnings loss in these cases was considerable.

Another woman had to ask for time off work for treatment, and explained to her manager that she might have hepatitis C: he physically recoiled and said “Oh, you have AIDS?”. Following this exchange, she immediately experienced intolerance and avoidance from her colleagues. She felt that she had been cast out, and from that point on she stopped telling people about her illness.

#### **Section 5. Treatment, care and support**

We heard two very different experiences of support from MPs. In one case, where the mother had HIV, the family were actively supported by their local MP throughout the period of the illness and following her death. The children recall this MP taking them to the zoo, and to her own home, and playing with them at their home. Unlike other people who came to the home, who were clearly afraid to sit down or touch anything, the MP came straight in and would get on the floor and play with them. The MP also raised the family’s situation in Parliament. She attended the funeral, and the family recall her “*getting rid*” of the press who were “*hanging around the cemetery*”.

In contrast, one woman who was infected spoke of repeatedly approaching her MP recently to seek support with a range of issues being discussed in the Inquiry, and asking him to raise some specific financial issues in parliament. She was disappointed to achieve no response to her requests, except in one instance a ‘cut and paste’ email response which did not address the questions posed.

#### **Attitude of healthcare professionals to infection**

These families had mixed experiences with professionals. Some described being treated with respect and compassion by staff: one family described how a family support worker never shrank from physical contact when playing with the children, and how important this was as so many people were withdrawing and they were feeling so isolated.

The experience of symptoms being dismissed by health professionals was common, with people enduring symptoms - sometimes over decades – which were not picked up as indicators of hepatitis C. One family said “*Illness hung over Dad all his life*”.

Another family spoke positively about a specialist social worker post being established at a local hospital to support parents and carers of children with HIV. A number of mothers were helped to form a peer support group, many of whom remain in contact. However, fathers were not included in this group, nor was there a fathers' group, which contributed to couples adjusting to this difficult reality at different paces.

The point was made that now, following the pandemic, everyone is very familiar with personal protective equipment (PPE) but that these families have for decades associated PPE with tyranny and stigma. Vivid memories were shared of how stigmatising the PPE used in barrier nursing was for their loved one and for them. One person spoke of professionals coming into their home *"who didn't hide the fact that they were uncomfortable in that situation"*. One man said a major cause of his mother's distress when ill with HIV was that she was made to feel dirty and *"felt like a leper"* because staff made a show of using double protection. Another person recounted a nurse shouting across a clinic *"don't forget to double glove for that one"*.

### **Treatment for hepatitis C**

We were told about the impact of hepatitis C, and the earlier treatments. People spoke of crushing fatigue, nausea, pain, 'brain fog', weight loss and flu-like symptoms. They gave examples of once proud and vibrant people becoming diminished, both physically and emotionally. There were harrowing descriptions of end-of-life experiences: loved ones being described as *"painfully thin"*, *"completely yellow"* and in dreadful pain. One family spoke of their father saying: *"God must be cruel to keep me this way"*.

People's experiences with interferon and ribavirin treatment were described as *"brutal"* and *"punishing"*. Others felt they were not taken seriously, such as one woman whose consultant's response to her description of the effects of her treatment was *"That's not possible, nobody else has reported that"*. There were also examples of having to travel some distance for fibroscans as the equipment was only available in certain regional centres.

One woman was initially handed her home treatments in the hospital clinic. After five or six visits she was instructed to collect the medication from the hospital pharmacy. She was surprised to then be handed a bill. She queried this, and in a room full of other patients she was told loudly, and with contempt, that everyone had to pay for their drugs and she was in fact receiving £240 worth of drugs. She felt humiliated and embarrassed as the room fell silent to listen to the conversation.

Other examples showed a lack of understanding of the difference between HIV and hepatitis C. One person recounted being told by a nurse on an open ward that their parent had HIV, then another staff member coming over and saying no, it's not HIV it's hepatitis C – this was as recently as 2015.

### **Section 6. Financial support**

The timing of our work with this group meant that most of them were aware of the interim payments made in autumn 2022 to infected people and infected or bereaved spouses. All were very pleased about this as a *"good starting point"* of



acknowledgement and validation. There were also strong feelings about the financial needs of bereaved parents and bereaved children, and many discussions about the very long-term financial losses associated with infected blood.

In one family, the widow of an infected man was now in nursing care, and the family were very unclear about the status of the interim award and the previous Skipton Fund payments in terms of inheritance tax and care cost assessments. Further enquiries to the English Infected Blood Support Scheme (EIBSS) proved helpful, but it became clear that some local authorities are not yet fully aware of these exemptions. Given the age demographics of many infected and affected people, the family feel that expert advice should be readily available to families for complex financial situations along with more clarification in local authority guidance so that families do not feel they have to “*fight their case*” for exemptions.

Several people commented that the waivers required from people involved in litigation were unfair, with one saying “*it felt like bribery*”. Others said that the prospect of impending death influenced how people viewed financial matters. One family described how their father was preoccupied for twenty years with providing for his wife and children, working up to the age of 70 even though he was very ill. They spoke of watching him trying to do his work while lying on the sofa, determined to carry on. He was aware from the Skipton Fund that an ex-gratia payment would be made to his wife on his death and he “*became obsessed*” with ensuring that his death certificate should include the infection with hepatitis C. On his death, his family faced “*a battle*” in trying to carry out his wishes to secure this. Although they found individual Skipton Fund staff kind and compassionate, the process of receiving the payment for their mother was bureaucratic and distressing. The Skipton Fund insisted on a report from the oncologist and the process took six months.

Another woman was disadvantaged by trying to plan ahead and make arrangements for a pre-paid funeral plan as soon as she learned of the infection with hepatitis C. She has now been advised by EIBSS that she is unable to claim this money back as applications are only accepted for funding a pre-payment plan in advance of it being taken out. She has challenged the Department of Health and Social Care about this, who responded in 2022 by saying: “*The department has noted your comments and suggestions and it will consider these alongside the findings and recommendations from the Inquiry when it reports, in due course.*”

We heard examples of people being refused Personal Independence Payment (PIP) in relation to the impact of hepatitis C, and having to go through a draining and distressing process of appeal. One woman was denied three times, eventually being awarded PIP on appeal, but the process was extremely stressful, and she found the doctors to be very rude and dismissive of her condition. This further exacerbated the depression and loss of confidence arising from her illness. The point was made in this and other examples of the inherent unfairness in the illness being caused by a failure of the state and infected people feeling further punished when seeking state support.

One woman who had received infected blood had self-cleared by the time she was tested, thus only showing antibodies which indicated that the infection had been present. Nevertheless, despite never having had a positive test for HCV, she has had to pay higher premiums for mortgages, life assurance and holiday insurance in the

many years since. She feels this is very unfair. She described one very distressing episode when in a discussion with the mortgage adviser in a busy estate agent's she was loudly bombarded with searching and insensitive questions about her lifestyle.

One family described their mother's deep distress that no financial support was available to her although she had been infected with HIV through a transfusion. At that time, financial support was being offered only to people with haemophilia. She was understandably embittered about this as she desperately wished to give her children some financial foundation for their future. She had no savings and was unable to work. Each of her children has had to overcome significant financial challenges in their lives.

After their mother's death, the younger children were awarded small lump sums of varying amounts from the Eileen Trust. The oldest was not given any financial support even though he was actually 17 and still a minor when his mother died. When the children reached 18, they had no further follow up from the Eileen Trust, and all feel that this support and advice should have continued at this sensitive time of transition in their lives.

They feel they were "accelerated" to independence at 16 and 17, and the lack of financial knowledge and support meant they were ill-equipped to manage their finances, all getting into significant debt. They describe feeling excluded seeing people receiving the monthly support payments when there is nothing for the children of infected parents. They make the point that their loss is lifelong, and if their mother had not been infected but had survived, they would have benefitted from her support - including financial support - well into adulthood. This family feel that they have been "out on our own".

### **Section 7. Messages to the Inquiry and points for the future**

In discussing this with the families, some frequent comments were:

*"I am angry and think it's wrong. I want my Mum's voice to be heard."*

*"MPs must act in the interests of the nation in accordance with the public trust placed in them. They should always behave with probity and integrity and are accountable for their decisions and actions to the public."*

*"If the reason for using infected blood was about cutting costs, then those responsible should be made aware that this has been the biggest cost that anyone could have endured."*

*"Someone made turnkey decisions that set this tragedy on its horrific course. Someone is liable and should be held to account for their actions."*

*"Someone needs to be accountable so that if I die from this my kids know what happened."*

*"Our free NHS makes people in rest of the world envious, but this status does not give doctors the right to treat people as they think they should be treated"*

*without asking the patient. Responsibility comes with that status and this was not shown when blood was not properly screened.”*

*“Accepting too many mistakes indicates that there was a level of casualness which is unacceptable.”*

*“I am angry for my husband. I didn’t know to what extent they knew and didn’t do anything.”*

*“The Inquiry should aim to bring truth and reconciliation.”*

Families wanted the Inquiry to achieve the following:

- Help should be offered as a matter of course, rather than expecting people to ask for it. This includes psychological and financial help
- The ripples of impact of infected blood on families sadly go beyond spouses and the Inquiry should make recommendations regarding wider financial redress for the impact of historic failures
- There should be more support for affected people, which considers the long-term impact on their lives. The impact on children of infected people, especially those who were still children when their parent or parents died should be considered in terms of compensatory financial support and lifelong access to psychological support
- The Inquiry should strongly advise UK Governments to create the opportunity for anonymous whistle blowing where an ‘insider’ may be concerned about practices or agreements that affect the wellbeing of UK residents
- The Inquiry outcomes should be tracked and managed to ensure the recommendations are applied and not just paid ‘lip service’. Time frames for the completion of the work should be set out
- The Inquiry should be mindful that a heightened sense of shame in minority communities and a lack of tailored support will have prevented many people of colour coming forward, therefore their numbers could be underestimated
- For the infected, monies awarded by the support schemes should be paid from the date of infection, if known, not from the date of application
- There should be parity for funeral costs. If an infected person can demonstrate they have paid for a funeral plan, it should be reimbursed, and the Inquiry should address the unfairness of this EIBSS rule
- When a person dies as a result of infected blood products, their death certificate should always cite this as a cause of death.

Although the aim of this process was to allow people to share their experience anonymously, two families asked for their loved ones to be named in this report:

Susan Chisholm	1947 – 2005
Philip Gray	1956 – 1994

**Statements of Truth**

I believe that the facts stated are as stated to me.

Name: Pam Allen

Signed: GRO-C

Dated: 02 June 2023

I believe that the facts stated are as stated to me.

Name: Kay Durrant

Signed: GRO-C

Dated: 02 June 2023

I believe that the facts stated are as stated to me.

Name: Jackie Wilson

Signed: GRO-C

Dated: 02 June 2023