

1

Monday, 24th February 2020

1
2 **(10.32 am)**
3 **SIR BRIAN LANGSTAFF:** Ladies and gentlemen, let me
4 tell you what this week has in store for us.
5 First, let me put it in context. At the start
6 of this Inquiry, I promised that I would hear
7 from those infected and affected both first and
8 last. I've almost, but not yet quite, honoured
9 that promise so far as putting you first is
10 concerned.
11 This week is something of a stepping stone,
12 a transition between listening to the testimony
13 of those who have suffered, and then from June
14 onwards this year, taking the evidence of those
15 who are in positions of responsibility, as
16 clinicians, administrators, politicians,
17 suppliers, and others, when choices were made
18 which are said to have led to that suffering, or
19 which failed to deal with that suffering,
20 properly.
21 Within this week of transition, today marks
22 a stepping stone of its own. I said I'd not
23 quite honoured my promise so far as hearing
24 first from people who have been infected or
25 affected, I have heard oral evidence from

3

1 heard. 85 people have taken advantage of this
2 so far.
3 After the intermediaries have presented
4 their findings, then my promise will have been
5 fulfilled as far as those from whom I said
6 I would hear first is concerned. The evidence
7 of the intermediaries leads on neatly, later
8 today, to the evidence of experts -- there are
9 seven in all, counting both today and
10 tomorrow -- who have spent their professional
11 lives at the highest levels of psychology and
12 sociology, studying how people react to disease,
13 particularly disease which is life shortening or
14 life threatening, and affects every aspect of
15 a person's life, their relationships with their
16 partners, family and friends; their schooling;
17 the work they can do; their housing; their
18 finances; their ability or desire to bring
19 children into the world; their need for care;
20 their trust of those to whom they may still have
21 to turn if they seek treatment.
22 Although they have different roles, the
23 intermediaries report what is being said to them
24 without analysis or comment and the psychosocial
25 experts provide analysis of and commentary on

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1 189 witnesses. I have personally read over
2 a thousand statements, and that's an ongoing
3 process. I undertook to read every single
4 statement no matter how many there were, and
5 are, or will be, and I am doing. But it was
6 obvious from the start that there were many who
7 wanted their voices to be heard but did not wish
8 or did not dare either to give evidence orally,
9 or to make a written statement knowing that it
10 would be disclosed, even though their identity
11 could be anonymised.
12 So this Inquiry did what I believe no other
13 Inquiry has yet done: it found a way of giving
14 a voice and providing a public platform for this
15 group of people in a way that can be taken into
16 account. It asked trained experienced
17 interviewers to speak to anyone who wished it,
18 and to present a report which drew on all the
19 accounts given to them, so that it presented
20 a comprehensive overall picture of what they had
21 been told. The Inquiry calls them
22 intermediaries because that's what they are.
23 They provide another way, in addition to written
24 statements and oral testimony, by which the
25 voices of people and their families can be

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1 what has been said. The link between the
2 evidence of the intermediaries and the panel of
3 psychosocial experts is a close one. For
4 instance, one expert conducted research projects
5 focusing upon recording the life histories of
6 those with both haemophilia and HIV, and their
7 families. In doing so, she helped capture the
8 experience of roughly the same number of people
9 again as did the intermediaries. You can see
10 how the evidence follows on naturally.
11 But the evidence may achieve more than
12 simply telling you people's stories. Many of
13 those who have suffered tell me they want to
14 help to avoid anything like what happened to
15 them happening to others in the future. And
16 these experts will explain how the accounts of
17 those from whom we have heard fit with the
18 learning derived from the experiences of others,
19 reflected in expert journals and in their own
20 extensive studies, and what is known about the
21 best ways to reduce the risk of any repeat in
22 the future. That's something I want to consider
23 closely.
24 The evidence of the psychosocial experts
25 will finish tomorrow. It forms a natural bridge

<p style="text-align: right;">5</p> <p>1 between the lived experience of those who 2 provided evidence in any of the three ways 3 I have mentioned and the clinical experience, 4 research, knowledge and expertise to be given by 5 the clinical experts from whom we shall hear on 6 Wednesday about hepatitis, Thursday about HIV, 7 and Friday about bleeding disorders.</p> <p>8 I promised that this Inquiry will be open 9 and transparent. And what the Inquiry has asked 10 the experts has been disclosed. How they have 11 answered it has been disclosed. And further 12 supplementary questions prompted by core 13 participants through their representatives are 14 all open to view.</p> <p>15 Why do we need to hear this expert evidence 16 now? Well, the answer is threefold. First, to 17 provide a solidly based medical understanding 18 that will inform both the questioning of other 19 witnesses later this year and the report of the 20 Inquiry.</p> <p>21 Second, to let you know what the latest 22 state of knowledge is about conditions; many of 23 you will know only too well by experience.</p> <p>24 Third, so the wider public can hear, and as 25 they hear, that ignorance about HIV infection</p>	<p style="text-align: right;">6</p> <p>1 and hepatitis can be reduced.</p> <p>2 Let me be very clear about what the clinical 3 experts have not been asked to deal with. They 4 will not say what they think was right or wrong 5 about what happened historically. They will not 6 say what happened and when back then, except 7 only by way of background to explaining today's 8 medicine. What happened and when are matters of 9 fact, upon which the Inquiry will draw its own 10 conclusions of fact. So please, don't expect 11 any questions to be asked about that at this 12 stage of the Inquiry.</p> <p>13 Now, counsel to the Inquiry will explain the 14 mechanics of what is proposed for today and for 15 the rest of the week. Before we start this 16 morning's evidence from our three 17 intermediaries, Jackie Wilson, Kay Durrant and 18 Pam Allen, who wish to be known as Jackie, Kay 19 and Pam.</p> <p>20 Ms Richards.</p> <p>21 MS RICHARDS: Sir, as you've indicated, we will be 22 starting this morning with the intermediaries 23 and Ms Scott will be taking them through their 24 evidence.</p> <p>25 This afternoon we will start to hear from</p>
<p style="text-align: right;">7</p> <p>1 the evidence of the psychosocial group. There 2 will be five members of the group giving 3 evidence this afternoon, Professor John Weinman, 4 Professor Myfanwy Morgan, Dr Nicky Thomas, 5 Dame Lesley Fallowfield and Ms Sian Edwards. 6 Professor Deborah Christie is unable to attend 7 today but will be attending tomorrow morning, 8 and Dame Theresa Marteau will also be unable to 9 attend today but will be available tomorrow 10 afternoon.</p> <p>11 Sir, as you've indicated, one member of the 12 psychosocial group, Ms Sian Edwards, was closely 13 involved with the HIV and haemophilia life 14 history project, and we will be taking advantage 15 of her presence here to ask her to tell us about 16 that, in the course of either this afternoon or 17 tomorrow morning.</p> <p>18 The psychosocial evidence will continue into 19 tomorrow and then Wednesday's focus will be 20 hepatitis and we will be hearing from 21 Professor Graham Cooke, Professor John Dillon, 22 Dr Kate Jeffery, Dr Scott Jamieson and Dr Aileen 23 Marshall.</p> <p>24 On Thursday the evidence will focus on HIV, 25 and we will hear from Professor Jane Anderson,</p>	<p style="text-align: right;">8</p> <p>1 Dr Ian Williams, Dr David Johnston, 2 Professor Graham Cooke and Ms Sian Edwards. 3 Dr Gareth Tudor-Williams is probably going to be 4 unable to join us on Thursday.</p> <p>5 Then finally, on Friday, we will hear about 6 bleeding and blood disorders from 7 Dr Oliver Tunstall, Dr Richard Gooding, 8 Dr Sara Marshall, Dr Mallika Sekhar, 9 Professor John David Edgar and 10 Professor Jürgen Rockstroh. Professor Rockstroh 11 will be joining by video link in the morning 12 only.</p> <p>13 Sir, core participants have already, through 14 their recognised legal representatives or 15 otherwise, put forward suggested questions for 16 the expert groups arising out of their reports. 17 Ms Scott and I will not be necessarily be asking 18 every one of those questions, some of them later 19 in the inquiry, some are perhaps more 20 appropriately directed to other expert groups, 21 such as the ethicists, and other questions that 22 were suggested ask experts to address matters of 23 fact which are, for the reasons you've 24 explained, sir, ultimately for your decision.</p> <p>25 But we will break towards the end of the</p>

<p style="text-align: right;">9</p> <p>1 evidence of each expert group, so that core 2 participants can have the opportunity to raise 3 with Ms Scott and myself further questions that 4 they would like to be asked. 5 Sir, finally in relation to the mechanics of 6 this week, the Inquiry has asked those 7 responsible for the NHS in the four parts of the 8 United Kingdom, Northern Ireland, Wales, 9 Scotland and England, for information about the 10 availability of psychological support and the 11 arrangements made for the commissioning and 12 funding of psychological support, and for 13 information about current Hepatitis C care and 14 treatment and in particular, issues about scans, 15 blood tests, checks and monitoring. 16 The Inquiry has now received witness 17 statements that address those issues. They will 18 be disclosed or should be disclosed, I hope, to 19 core participants in the course of today, and in 20 the course of this week, I will explain and 21 summarise what those statements say at an 22 appropriate stage on one of the days. 23 Sir, that's all I needed to explain by way 24 of mechanics, and we're ready now for the 25 evidence of the intermediaries.</p>	<p style="text-align: right;">10</p> <p>1 SIR BRIAN LANGSTAFF: Thank you very much. May we 2 then have Jackie, Pam and Kay, please. 3 KAY DURRANT, sworn 4 JACKIE WILSON, affirmed 5 PAM ALLEN, affirmed 6 Examined by MS SCOTT 7 MS SCOTT: Can we start by each of you giving an 8 introduction to your professional background and 9 explaining the skills that you brought to the 10 intermediary role. 11 Pam, do you want to start us? 12 PAM: Yes, I'm happy to start, thank you. 13 A qualified social worker since 1979, which 14 clearly put me in a position of dealing with 15 people who've experienced trauma via their own 16 abusive situations or their experiences, 17 together with lots of experience of people with 18 bereavement and loss in various aspects of their 19 life. I also worked for the court during that 20 time preparing reports in a formal setting. 21 MS SCOTT: Kay, do you want to go next? 22 KAY: I'm a former senior detective, having served 23 for 25 years in the police service, and done 24 lots of work around trauma in the public 25 protection arena, in particular around family</p>
<p style="text-align: right;">11</p> <p>1 liaison officer roles in the homicide 2 investigations. I then latterly, in 2012, 3 commenced training as a psychotherapist, and I'm 4 involved in private practice, and again, that 5 has enhanced my knowledge with regards to 6 dealing with those with trauma. 7 MS SCOTT: And Jackie, do you want to? 8 JACKIE: Yes, I'm also a social worker, I've been 9 qualified for 38 years and, like Pam, I've 10 worked across a number of sectors in the family 11 courts in local authorities, but also in 12 hospitals as well, in paediatrics. And I'm also 13 just coming to the end of 4 years of training as 14 a therapeutic counsellor as well. 15 MS SCOTT: Before you talk about the substance of 16 the report, and what you were told by those you 17 spoke to, can we just establish your method of 18 working? 19 Can I start with you, Kay. Approximately 20 how many visits were carried out between the 21 three of you? 22 KAY: We visited between 50 and 60 homes or places 23 to meet with individuals and family members, and 24 the age range was meeting people between the 25 ages of 30 and up to the age of around 80.</p>	<p style="text-align: right;">12</p> <p>1 MS SCOTT: The chair in his introduction said that 2 you'd spoken to around about 85 people; is that 3 right? 4 KAY: Yes, yes. 5 MS SCOTT: Jackie, can I ask you, when did you carry 6 out these interviews and over what time period? 7 JACKIE: Over around a 12-week period last year, 8 largely between the end of January and the 9 beginning of April 2019. 10 MS SCOTT: What was the geographical spread of those 11 that you spoke to? 12 JACKIE: We saw people in England, Wales and 13 Scotland, and Northern Ireland. 14 MS SCOTT: In page 3 of your report, you say this 15 about the range of experience of those that you 16 interviewed. Six had been infected with HIV, 17 50 had been infected with hepatitis C, 11 had 18 haemophilia, three had thalassaemia, nine were 19 infected through routine surgery, 12 were 20 infected through emergency surgery, eight were 21 infected in connection with childbirth, and one 22 person had been infected by their partner. 23 Does that summarise that range of 24 experience? 25 KAY: (Witness nodded)</p>

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1 **MS SCOTT:** Jackie, can I ask you then about the
 2 interviews themselves. Where was it that you
 3 saw people?
 4 **JACKIE:** We saw people mainly in their own homes.
 5 We gave people the choice of where they would
 6 like to be seen. Most people chose to be seen
 7 in their own homes. Some people, for reasons of
 8 confidentiality, didn't want to be seen at home,
 9 because of other family members being aware of
 10 our visit, and so sometimes we saw people in
 11 conference centres, booked rooms, etc. Some
 12 people actually wanted to be seen quite some way
 13 away from their own home town as well. So we
 14 saw a small number of people in those
 15 circumstances as well.
 16 **MS SCOTT:** And did you do the visits alone, did you
 17 divide them up between you?
 18 **JACKIE:** We did -- we largely went alone, except
 19 that Kay and Pam did the Northern Ireland visits
 20 together.
 21 **MS SCOTT:** How long would a visit take on average?
 22 **JACKIE:** There was a range of visits. We weren't
 23 time limited at all. Our remit was we're here
 24 to listen to whatever people wanted to say to
 25 us. None of the visits were less than 2 hours,

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1 which we sent to our person. They added,
 2 subtracted, changed, got to a point where we
 3 both comfortable. So they were jointly authored
 4 reports, to the point that we put both our names
 5 at the bottom of the reports. So it's an agreed
 6 report of our conversation, which, as I say,
 7 then parts of that are included in our
 8 collective report.
 9 **MS SCOTT:** So the agreement was that the note of the
 10 interview was confidential?
 11 **PAM:** Yes.
 12 **MS SCOTT:** Then parts of that interview made its way
 13 into the final report?
 14 **PAM:** Absolutely. And the reason people had
 15 decided they wanted to discuss with an
 16 intermediary is that they felt they wanted to
 17 stay away from a legal framework, to ensure
 18 their confidentiality was primary, and that the
 19 people who saw their individual reports were
 20 actually very, very small set of people, ie,
 21 ourselves and people involved in the
 22 Blood Inquiry.
 23 **MS SCOTT:** So the reasons people used the
 24 intermediary service, if I can put it like that,
 25 were for reasons of confidentiality to keep

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1 and some of our longer ones were over 5 hours.
 2 So we think probably an average of three, three
 3 and a half hours.
 4 **MS SCOTT:** Pam, can I ask you then about the report
 5 writing. In terms of communication that you had
 6 with those you interviewed after the visit, what
 7 kind of communication did you have with them?
 8 **PAM:** I suppose I would start by saying that all
 9 our interviews were very emotionally charged and
 10 were -- could be quite traumatic in some
 11 circumstances, because this was the -- often the
 12 first time that the people we were interviewing
 13 had told their story.
 14 We established that -- the groundwork there,
 15 that we would produce a report, which would be
 16 a joint report, which was confidential, and we
 17 would also agree on which elements of that
 18 report people were then happy that were included
 19 in this report that we produced, for the
 20 Inquiry.
 21 So the methods that we used, we invited
 22 people to tell us their story. It was their
 23 time to tell us their story, and walk through
 24 their story. We took detailed notes at that
 25 point. We then went away, developed the report,

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1 their identity private?
 2 **PAM:** Absolutely, and that of their families,
 3 obviously, which is still around stigma and the
 4 fear of that stigma. And also confidence.
 5 I think they felt that having an interview in
 6 their own homes generally, as Jackie explained,
 7 kept it, if you like, much more informal and an
 8 ability to have some control over that setting.
 9 **MS SCOTT:** So not having to write a formal statement
 10 was something that was attractive to some of the
 11 people you interviewed?
 12 **PAM:** Absolutely, yes.
 13 **MS SCOTT:** So you have provided a report which all
 14 three of you have signed. You all contributed
 15 to that, writing of that report, did you?
 16 **KAY:** Yes.
 17 **PAM:** Yes.
 18 **JACKIE:** Yes.
 19 **MS SCOTT:** The report is divided into themes, and
 20 you've grouped, under each theme, some of the
 21 experiences of those that you interviewed. I am
 22 going to take you through those themes and ask
 23 you questions about what you were told. But
 24 clearly, in the time that we've got available,
 25 we're not going to be able to cover the

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1 experiences of all of the 80 people that you
 2 spoke to, but am I right in understanding that
 3 you have taken into account everything that
 4 you've been told in your report --
 5 **KAY:** Yes.
 6 **MS SCOTT:** -- writing and your preparation for
 7 giving evidence today?
 8 **PAM:** Yes.
 9 **JACKIE:** Yes.
 10 **MS SCOTT:** Can we start, then, by -- you set out
 11 both at the beginning and the end of your report
 12 that you were all humbled by the experience of
 13 speaking to these 85 or so people. Is there
 14 anything you would like to say about the impact
 15 on you of having undertaken this exercise?
 16 **KAY:** I mean just to expand on that a little bit,
 17 I think all of us felt completely humbled and
 18 privileged that families were telling us some of
 19 the most painful experiences in their lives.
 20 And whilst we are professionals, you can't not,
 21 on a personal level, feel sad yourself, but
 22 obviously our professional hats were really
 23 important but it was also really important to
 24 show that kind of level of impact of hearing
 25 that, and families were telling us some of the

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1 lives, automatically humbled us. Most of the
 2 interviews had tears, and that was the tears of
 3 those people who were interviewing, and our own.
 4 It was a very consolidating experience having
 5 interviewing these people. We made an
 6 attachment within those hours that we spent with
 7 them, which is probably quite different to other
 8 things that we've done in our careers.
 9 **JACKIE:** Mm, mm.
 10 **MS SCOTT:** Okay, so moving on through the themes of
 11 the report, then, the first theme you pick up is
 12 infection and diagnosis with HIV.
 13 Pam, you spoke to two young men who had been
 14 told they were infected with HIV when they were
 15 in their teens. Do you want to tell us about
 16 what they told you?
 17 **PAM:** Yeah, these were two young men with
 18 haemophilia, young men at the time of the
 19 diagnosis, now in their fifties, mid-fifties.
 20 Very struck by the first man, who told me that
 21 he was a child when he was given the news. He
 22 was about 16 or 17, and I say "about" because he
 23 doesn't know exactly when he was told, but he
 24 was at college. And he'd -- he was at college
 25 and would regularly be called down to see the

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1 most traumatic times of their life, and some of
 2 that, many of the families, it's still continues
 3 with infections today, and those that have lost
 4 loved ones, and what was definitely needed was
 5 that ethic of care in terms of how we obtained
 6 that information. And I think we all agree it's
 7 one of the most significant things in our
 8 professional careers that we've contributed to,
 9 and we're honoured to do that and want to do the
 10 best that we can today to represent all our
 11 families.
 12 **MS SCOTT:** Is there anything anyone wants to add to
 13 that?
 14 **JACKIE:** I think we were really struck by people's
 15 dignity. The dignity that people showed, and
 16 their strength in managing these situations over
 17 years and decades in some instances. And we
 18 felt that -- as Kay said, it was a privilege --
 19 we felt that we saw the best of humanity.
 20 **PAM:** I think what I'd add to that is what we've
 21 stated in our report, that the people we met all
 22 said, "We're the lucky ones, we're the lucky
 23 ones, because we're still here." And that, to
 24 hear that from people who have experienced such
 25 trauma and such massive difficulties in their

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1 consultant. And this was in close proximity,
 2 the hospital and the college he was at. And he
 3 had a phone call that morning to say can he go
 4 down to see his consultant, go down to the
 5 hospital, which he did, without talking to his
 6 parents or anyone else in his family.
 7 He went down to see his consultant to be
 8 told that he was HIV positive and that the
 9 incubation period was probably 5 years, he'd had
 10 that for 3 years, so he possibly had 2 years to
 11 live.
 12 He was clearly shocked, he had no support.
 13 He was told then that he mustn't have sex with
 14 anyone or to exchange any bodily fluids. What
 15 he did tell me, which had a massive impact and
 16 certainly I'll never forget, the consultant said
 17 to him "But tears don't count." They wouldn't
 18 create an infection. He wouldn't be able to
 19 pass on the infection with his tears.
 20 He returned to college, he didn't tell
 21 anyone. He went home, he still didn't tell his
 22 parents until a few days later.
 23 To this day, no one outside his family and
 24 the medical profession have heard his story. No
 25 one understands his HIV now and hepatitis C

<p style="text-align: right;">21</p> <p>1 status. Certainly a story I will never forget.</p> <p>2 The next young man was 19. He, similarly</p> <p>3 haemophiliac, was told he was HIV positive and</p> <p>4 had been for 3 years. Again, the incubation</p> <p>5 period, and he do thought that he'd got</p> <p>6 approximately 2 years to live.</p> <p>7 He described being in a state of denial, and</p> <p>8 just taking himself off. He couldn't actually</p> <p>9 remember where he'd lived for a few years after</p> <p>10 that. He'd wandered and not been part of his</p> <p>11 family, got odd jobs, and it took him a good few</p> <p>12 years to actually come to terms with what had</p> <p>13 been said and to seek out treatment. He, again,</p> <p>14 is in his fifties now.</p> <p>15 MS SCOTT: Kay, you spoke to a family who were given</p> <p>16 diagnosis by letter. Can you tell us what you</p> <p>17 were told by them?</p> <p>18 KAY: Yeah, both this case and another case that</p> <p>19 I'm going to talk about were two families where</p> <p>20 I met the parents of children who had HIV. The</p> <p>21 first one was a young boy who was 11 years old,</p> <p>22 and the devastating news was not delivered in</p> <p>23 person but a letter that they received one day</p> <p>24 and just went to the front door and opened this</p> <p>25 letter and in this letter it said, "Your 11-year</p>	<p style="text-align: right;">22</p> <p>1 old son has HIV".</p> <p>2 Desperate for more information, the parents</p> <p>3 contacted the hospital; this young man was</p> <p>4 haemophiliac and they had specialist</p> <p>5 professionals that they dealt with. And the</p> <p>6 consultant was on holiday for another two weeks,</p> <p>7 and this time for them was just horrendous in</p> <p>8 terms of getting that in the manner that they'd</p> <p>9 had that information delivered, and then having</p> <p>10 to wait for a further two weeks to have any</p> <p>11 conversation with a consultant.</p> <p>12 And this family later found out that the son</p> <p>13 had been infected some years earlier, this was</p> <p>14 backed up by medical notes, but in particular,</p> <p>15 there was a big thing for them because they were</p> <p>16 hearing at the time that if you could survive</p> <p>17 HIV for more than 2 years, then you were likely</p> <p>18 to live longer, and for desperate parents, they</p> <p>19 were really trying to get information and that</p> <p>20 was very difficult for them.</p> <p>21 The second family was a couple's again young</p> <p>22 son who was wrongly diagnosed with haemophilia</p> <p>23 and later in years he was found to not be</p> <p>24 haemophiliac. He was 3 years old, and later in</p> <p>25 his life, when he was about seven, they found</p>
<p style="text-align: right;">23</p> <p>1 out that he was HIV positive. And again, it</p> <p>2 took his parents two months to get the results,</p> <p>3 and again, that pain and agony of waiting and</p> <p>4 then obviously receiving the news at the end</p> <p>5 that their son had HIV. The commonality again</p> <p>6 between the two families is when their children</p> <p>7 were informed that they were HIV, which for both</p> <p>8 families were around the age of 13 or 14, where</p> <p>9 they'd started to form relationships and both of</p> <p>10 the young boys were getting girlfriends and the</p> <p>11 parents had to then share the information with</p> <p>12 their sons, and, you know, responses such as "Am</p> <p>13 I going to die", and having to deal with that</p> <p>14 with a teenager, were extremely traumatic for</p> <p>15 both families.</p> <p>16 And to this day, both of those boys are</p> <p>17 still alive, living with HIV, and one of the</p> <p>18 parents says every time a telephone rings,</p> <p>19 "That's my life", in terms of "Am I going to</p> <p>20 find out that he's died?" And it's just that</p> <p>21 constant fear of their child dying, even though</p> <p>22 we're a number of years ahead, is still as</p> <p>23 powerful today as it was then.</p> <p>24 MS SCOTT: Jackie, can I ask you then to start us</p> <p>25 off on the next theme in your report, which is</p>	<p style="text-align: right;">24</p> <p>1 infection and diagnosis with hepatitis C.</p> <p>2 JACKIE: We saw a large group of people in</p> <p>3 respect of this issue and we've been able to</p> <p>4 find three key themes that we want to speak</p> <p>5 about today.</p> <p>6 The first one was when people presented with</p> <p>7 symptoms, there was a reluctance and</p> <p>8 a significant delay in professionals</p> <p>9 acknowledging that these might be as a result of</p> <p>10 hepatitis C, so a lack of investigation, and an</p> <p>11 explaining away, really, of symptoms,</p> <p>12 particularly when people presented with the very</p> <p>13 significant fatigue that goes with it so people</p> <p>14 were describing -- they said it was because of</p> <p>15 their stage in life, so if they were young</p> <p>16 children, women who had just had had babies, if</p> <p>17 they had demanding work roles, et cetera, there</p> <p>18 was a almost a default mechanism of kind of</p> <p>19 explaining it away, and sometimes that went on</p> <p>20 for years into more than a decade, and people</p> <p>21 spoke about all that time, the disease was</p> <p>22 silently progressing within them. Obviously</p> <p>23 they had concerns about infecting others and</p> <p>24 we'll come on to speak about that later.</p> <p>25 The second theme was about some real</p>

<p style="text-align: right;">25</p> <p>1 insensitivity in the way that people were 2 informed about their hepatitis C status.</p> <p>3 Then the third area was once the hepatitis C 4 was recognised and confirmed, a real reluctance 5 to acknowledge that it might have come from 6 infected blood or blood products. So, for 7 example, one chap who was -- had a transfusion 8 as a result of an injury, late in his life, in 9 his sixties, and then developed the hepatitis C. 10 He'd been in the army during the war and the 11 doctor asked him if he'd been a drug user or 12 shared to needles in the army in the 1940s and 13 he was horrified by this. It felt a real slur 14 on him.</p> <p>15 Lots of people described being told they 16 must have caught it abroad. One woman told me 17 that her late husband was told by his specialist 18 that he was imagining the symptoms, and when she 19 accessed his records after he'd died, the record 20 said, "This is a miserable man, always 21 complaining", and this man had cirrhosis by the 22 time he was diagnosed.</p> <p>23 One woman was told by a doctor who didn't 24 examine her physically, and didn't do any tests, 25 that she had ME rather than hepatitis C.</p>	<p style="text-align: right;">26</p> <p>1 Very few people were given detailed 2 information about hepatitis C, we found, when 3 they were first diagnosed. And many people 4 described having to do that research for 5 themselves, particularly if they had any 6 specialist issues. And some of their GPs 7 actually acknowledged that and saw them as 8 experts by experience, and were grateful for the 9 help that they were given. But it was 10 unsettling for people to think that their 11 clinicians didn't have the level of experience 12 that they wanted them to have.</p> <p>13 Lots of people described themselves being 14 asked about their lifestyle, particularly in 15 relation to alcohol use. Many were asked 16 whether they'd used drugs and whether they'd had 17 contact with sex workers, which was terribly 18 demeaning for them.</p> <p>19 In terms of how people were told, one man 20 told me he had haemophilia, and he went to his 21 regular haemophilia clinic with his wife and two 22 small children and was told in the room without 23 any warning that he had hepatitis C and that he 24 had 3 years to live, and he had his children on 25 his knee, a three-year-old, and his wife had a 1</p>
<p style="text-align: right;">27</p> <p>1 year old baby.</p> <p>2 Another man who was 23 at the time had 3 thalassaemia, he was told by his consultant that 4 he had tested positive for hepatitis C and this 5 conversation took place in a corridor in the 6 hospital. He'd not been asked whether he'd 7 consented to the testing being carried out and 8 there was no discussion about treatment, as with 9 Pam's description, the only advice he was given 10 was that he shouldn't have unprotected sex.</p> <p>11 And again, this was discussed in the 12 corridor. There was no other description at 13 that time of the implications of hepatitis C.</p> <p>14 Pam's got some more examples.</p> <p>15 PAM: Yes, I met a lady who was infected at the 16 point that she had needed to have an emergency 17 caesarean. Child was at 25 weeks, and placenta 18 was ruptured. Her husband had made the decision 19 about needing the caesarean and following that, 20 obviously she needed blood. She was 21 haemorrhaging, and this was the point that she 22 became infected. She didn't know that for 23 20 years, and 20 years on.</p> <p>24 The point of this here is twofold, that 25 talking about how she became infected clearly</p>	<p style="text-align: right;">28</p> <p>1 brings to the fore the trauma of losing her 2 baby, losing her child, and that she didn't give 3 consent to any of the treatment at that time.</p> <p>4 Her husband clearly felt that he needed to 5 make that decision because her life and the life 6 of the baby were both hanging at that point and 7 he needed to make a decision, so the trauma of 8 having to talk about how she became infected and 9 the loss of a child is clearly something which 10 is unimaginable.</p> <p>11 Moving on from that, this lady then 12 experienced some of what Jackie has just 13 referred to for years, the foginess, the 14 depression, the weight loss, the fatigue, and 15 didn't know until another 20 years on that she 16 actually had hepatitis C, and how that had been 17 contracted.</p> <p>18 She also -- and we go on to talk about it 19 later on in the report -- was a blood donor, 20 because she was grateful that she'd actually 21 been given blood, which had kept her alive. She 22 went on to be a blood donor, and we'll talk 23 about that later on and the impact there of the 24 guilt of that instance as well.</p> <p>25 And the late diagnosis that I met, like</p>

<p style="text-align: right;">29</p> <p>1 Jackie and Kay, a number of women who all 2 experienced these symptoms of fatigue, poor 3 memory, severe aches and pains, confusion and 4 saw GPs over many years who talked about their 5 busy lives and that there were women who were 6 working, sometimes had children, and weren't 7 dealing with the stress of their lives very 8 well, and it was often into 20, 30 years before 9 they were diagnosed. 10 So during that period of time their 11 confidence, their lack of self-esteem, their 12 feeling of vulnerability, had been layered upon 13 layered during that period pre-diagnosis. 14 I think Kay has got more examples there, 15 too. 16 KAY: I just wanted to continue the theme around 17 the late diagnosis of hepatitis C. One of the 18 families I met a lady who was infected with 19 hepatitis C and her two daughters. Sadly the 20 lady passed away last year so isn't here to 21 obviously hear this evidence being given today. 22 I think it's really important that I reflect 23 something she said that day as well to me. But 24 one of the issues for her was that her family 25 had requested the medical records and found out</p>	<p style="text-align: right;">30</p> <p>1 that she'd been diagnosed 14 years previously, 2 and it was actually in the notes, and the GP had 3 taken the decision not to inform her or the 4 family of the diagnosis based on the patient's 5 mental health. 6 This lady did have depression, which is no 7 shame at all, and she had capacity and she had 8 that choice taken from her for 13 years; and she 9 felt very, very strongly that this wasn't 10 a decision for a professional to take away from 11 her. That should have been hers. And she said 12 to me, "I should have been told, because I could 13 have infected by family." 14 The impact that had on her psychologically, 15 finding that out, 13 years later, I can't 16 describe, you know, how she reflected that day. 17 She was a lady then in her eighties and it had 18 had such a profound impact on her life, knowing 19 that these 13 years she could have been 20 responsible for hurting somebody else. 21 Her actual daughter said to me, "You know, 22 it's disgusting and it makes me angry that they 23 didn't tell her. It was irresponsible and it 24 put my mum, the family and the health 25 professionals at risk".</p>
<p style="text-align: right;">31</p> <p>1 Just to touch on two other cases as well, 2 family cases that I heard of, was where families 3 had pre-existing conditions, and yet didn't find 4 out until 2004 and 2009 and yet they'd been 5 being having all these blood tests being taken 6 for years and years and years and one of the 7 ladies found out, because she was progressing 8 through to IVF procedures and found out in 9 a private process that she had hepatitis C, not 10 through any other procedures, and likewise, for 11 the other gentleman as well. He had 12 a pre-existing condition that meant that he 13 regularly had to have blood tests but again, 14 didn't find out until 2004, and they have real 15 questions around, you know, even if it was in 16 the early nineties, where hepatitis C was, you 17 know, there was a test available, why did it 18 take so long for us to find out, and the 19 implications of us having that for so many years 20 was so important for us to know, and both very 21 angry about that. 22 JACKIE: I met with the family of one infected 23 woman, who, when she was eventually diagnosed 24 after her diagnosis, she went to an appointment 25 with consultant hepatologist, and the way the</p>	<p style="text-align: right;">32</p> <p>1 progress of the illness was described to her, 2 she was given a flow diagram which had been 3 produced by the British Liver Trust and she kept 4 it and I saw that. It looked to be part of 5 a Powerpoint presentation that has been prepared 6 for professionals, and the diagram showed the 7 progression of hepatitis C and its implications 8 and it showed a life expectancy of 30 years. 9 There was an arrow that went across with 10 "Diagnosis" with 30 years and "Death" being at 11 the end of it and it showed the progression, 12 from potential infection to cirrhosis and liver 13 cancer to the end stage. 14 At this point it was 26 years since the 15 woman had been infected, and she said that she 16 was left to make the calculation herself. She 17 said, "I had to do the maths", which was that 18 she had got less than 4 years to live, and she 19 did unfortunately pass away within that period. 20 MS SCOTT: Pam, I think you also spoke to a number 21 of people who were angry that there hadn't been 22 a re-call programme that could have identified 23 them earlier. 24 PAM: Yes. 25 MS SCOTT: Do you want to speak about that in a bit</p>

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1 more detail?

2 **PAM:** Yes.

3 **JACKIE:** Yes, we will speak about that later. Do

4 you want to talk about that now?

5 **PAM:** Yes, I will give a couple of examples here.

6 The first person I visited was a woman who had

7 had blood transfusions in 1973. But only been

8 diagnosed with hepatitis C 3 years previously,

9 and she started to tell me her symptoms and what

10 life had been like during those intervening

11 years by way of her health. It was the first

12 time I'd heard this, and took my notes, and she

13 was a very, very brave lady, because she was

14 very unsure about contributing to the Inquiry,

15 I'd had telephone conversations with her before

16 I met her, and indeed, once she started talking,

17 it was like the floodgates had opened.

18 She, as I say, gave me a perfect account of

19 the physical symptoms and emotional symptoms and

20 how her life had changed.

21 The next lady I saw, I knew what she was

22 going to say when she started to talk to me

23 about her symptoms. I knew what was coming and

24 throughout my interviews, I certainly understood

25 that these women who had all experienced these

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1 alcohol, whether her partner had been involved

2 with sex workers. She asked if he could look at

3 his notes to check that he was seeing the right

4 person, had he got the right name, she was so,

5 so confused about the line of questioning, and

6 highly distressed at the line of questioning.

7 At some point, then, she was trying to think

8 about what possibly could have happened. It was

9 actually the same hospital that she was getting

10 these results, where she'd had a blood

11 transfusion some 30 years since with an ectopic

12 pregnancy and it was only at that point that the

13 consultant was able to change their approach to

14 her. She'd gone on this visit for her results

15 alone because she expect the results of

16 a standard blood test, so was entirely and

17 deeply traumatised.

18 Throughout this period when she had felt

19 very vulnerable and weak because her health had

20 been so poor at least having an explanation

21 about why her health had been so poor and her

22 emotional wellbeing had been so poor, had at

23 least explained to her that it wasn't about her

24 difficulties but actually it was a physical

25 illness, but the way that this was delivered was

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1 same symptoms didn't know about each other, and

2 they saw that HIV and hepatitis C was something

3 that was generally about people who'd led

4 a different type of life, or who indeed had

5 illnesses such as haemophilia. They did not

6 understand that there were women out there with

7 hepatitis C in similar circumstances. That in

8 itself, I started to say to these women, "There

9 are other women with your experiences", and that

10 brought some comfort.

11 The second lady I saw, who'd had blood

12 transfusions in 1985, the way she found out

13 about her hepatitis was again, very traumatic.

14 She'd spent, as I say, 30 years, this lady,

15 experiencing these dreadful symptoms that were

16 very debilitating for her. Then she had what

17 she saw as routine blood tests as she was

18 entering menopause, possibly, went to the

19 hospital for her results, and the consultant's

20 line of enquiry entirely confused her, asked if

21 she was or had been a sex worker, asked if she'd

22 ever taken any intravenous drugs or snorted, and

23 she said she didn't even understand what

24 "snorted" meant.

25 Then asked her if she'd been involved in

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1 clearly something that she could never recovery

2 from.

3 **JACKIE:** The lady that I spoke about earlier who had

4 seen the Powerpoint slide, she was a woman who

5 kept -- left a written testimony of her

6 experience of the infection, and in this she

7 wrote, and I want to quote this, she said:

8 "I feel that my country knew where they were

9 sourcing blood from, and when they had the

10 opportunity to correct this terrible disaster by

11 completing a re-call programme, they failed to

12 carry it through. This was proposed in 1985.

13 If I had been traced and tested in 1985, then

14 the virus would have been more treatable, maybe

15 even clearable, and today I would not be left

16 with the cirrhosis of the liver which could lead

17 to liver cancer. I'm left with a possible death

18 sentence. It's destroyed all of my plans for

19 the future, and I've lost my ability to dream."

20 This lady did unfortunately pass away

21 relatively soon after that.

22 **MS SCOTT:** That anger at there being no recall

23 program, is that something you heard from other

24 people that you see.

25 **KAY:** It is.

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1 **JACKIE:** It was a really strong issue.

2 **MS SCOTT:** Before we move on to the next theme, is

3 there anything anyone wants to say about

4 infection and diagnosis of hepatitis C?

5 **PAM:** No.

6 **JACKIE:** No.

7 **KAY:** No.

8 **MS SCOTT:** The next theme you pick up, and you've

9 already referenced this, is infection of blood

10 donors, Kay, do you want to start us off on that

11 theme?

12 **KAY:** Yeah, several people were concerned that

13 they'd been blood donors and that they'd

14 actually passed on the infection without their

15 knowledge, and we've kind of discussed this and

16 put this under this theme in of good people

17 doing good things.

18 You know, one gentleman that I met was

19 17 years old and had been involved in a road

20 traffic collision, and as a consequence of that,

21 has had life-saving treatment in the hospital,

22 and was so so grateful that that had been done,

23 that he went on, like others, to be blood

24 donors.

25 15 years later, he was waiting for his next

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1 he still has hepatitis C. So yeah. That's, you

2 know ... Pam?

3 **PAM:** A couple of examples from me ... we met

4 a woman who had blood transfusion when she was

5 14, and she started to be a blood donor when her

6 age permitted, and she then discovered in her

7 30s that she had hepatitis C. This lady was

8 pretty tremendous in so many ways. She now

9 worked in a factory with -- actually depot, with

10 lots of men. In fact, she's the only woman

11 working in the depot and very, very keen to keep

12 her cup separate and all her individual items

13 separate because of her fear of cross-infection.

14 But the blood donor van, as we call it, comes

15 round, the mobile van, to the factory to take

16 blood donor, and all the men go out to give

17 blood, and she can't and doesn't. They don't

18 know why she can't and doesn't, and they call

19 her names like scary cat, et cetera, because she

20 wouldn't give blood.

21 Clearly she can't share with them why she

22 can't give blood, and the -- listening to her

23 account, because she was such a good woman who

24 given blood for years, but then as Kay was

25 explaining, felt so so guilty about the number

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1 appointment to go and donate blood, which he did

2 every year, and the service contacted him to say

3 that wasn't possible, and he had to wait

4 a couple of weeks to find out why, and the why

5 was because he had hepatitis C. He was

6 absolutely devastated. This was a man who had

7 already, once he'd got diagnosed, as a result

8 significantly in terms of his relationship with

9 his children, because he was so scared of

10 infecting them, and then at the same time, his

11 mind was around the guilt, and, you know, it's

12 very easy to say well it's not his to have. He

13 felt guilty guilt. He still feels guilty that

14 other people, throughout that 15-year period,

15 would have been infected and he was doing a good

16 thing having had his life saved.

17 I think it brings up the issue that we talk

18 about later on, which is in the absence of any

19 psychological services, specialist psychological

20 services with people who can get the support to

21 work through that and feeling guilty, and to

22 kind of work through that that's not something

23 that they have to bear, he today lives with that

24 tremendous guilt, and it continues to impact on

25 all his relationships in the here and now, and

40

1 of people she may have infected during that

2 time.

3 Another example was a woman who had had an

4 ectopic pregnancy and she was a very rare blood

5 group so she was encouraged and obviously wanted

6 to give blood which she did, and continued to do

7 that for 20 years and during that time had

8 possibly infected people and lived with the

9 guilt of that also.

10 **(Off the record comments from Sir Brian)**

11 **(11.30 am)**

12 **(A short break)**

13 **(12.00 pm)**

14 **SIR BRIAN LANGSTAFF:** Yes.

15 **MS SCOTT:** So we were, Jackie, I was asking you just

16 before we broke, to move on to the next theme,

17 which was other infections.

18 **JACKIE:** Yes, we saw a small number of people who,

19 around about ten to 12 years ago, in their

20 memory, were advised that they might have been

21 exposed to variant CJD through their treatment.

22 And whilst they felt some reassurance that this

23 was being properly investigated, the manner in

24 which they had been informed of that was really

25 quite brutal.

41	<p>1 They all spoke about receiving a letter</p> <p>2 completely out of the blue, and that wasn't --</p> <p>3 there was no phone call, there was nothing via</p> <p>4 their GP. And the letter said, in a very formal</p> <p>5 manner:</p> <p>6 "We understand you have received blood or</p> <p>7 blood products from someone who has been</p> <p>8 diagnosed with variant CJD. Would you like</p> <p>9 a test?"</p> <p>10 And they, for some of them, this was the</p> <p>11 period when they were not only managing the</p> <p>12 symptoms of the disease but they were in that</p> <p>13 period where they were having interferon,</p> <p>14 ribavirin treatment as well, and it was just the</p> <p>15 last straw for some of them, and one of them</p> <p>16 said, you know, "What else? What else is going</p> <p>17 to be thrown at me?" in that respect.</p> <p>18 So that was a relatively small number of</p> <p>19 people but a big impact for them at that time.</p> <p>20 MS SCOTT: Kay, can I ask you, then, to move on to</p> <p>21 the next theme you pick up in the report which</p> <p>22 is consent.</p> <p>23 KAY: Okay, so very few people could recall being</p> <p>24 asked for consent about the use of blood</p> <p>25 products or a blood transfusion, and nobody</p>	42	<p>1 recalled any of the risks of transfusion being</p> <p>2 discussed with them by professionals at the</p> <p>3 time. And it was just accepted with those who</p> <p>4 had haemophilia and thalassaemia that they would</p> <p>5 receive these products, and almost like, "This</p> <p>6 is a wonder drug", and there was this kind of,</p> <p>7 you know, we're really grateful for this, but</p> <p>8 none of those risks and the issues around</p> <p>9 consent and any discussions were recalled or</p> <p>10 very few were recalled. Particularly, I wanted</p> <p>11 to make reference to a lady that I met who'd</p> <p>12 been informed by her consultant that she'd</p> <p>13 sought out herself a second opinion, because the</p> <p>14 treatment that she was being given in another</p> <p>15 hospital was interferon only, because she had</p> <p>16 genotype 1 hepatitis C, and as a consequence of</p> <p>17 that, she was being given the treatment, and she</p> <p>18 was really struggling with the side effects, and</p> <p>19 it was getting to the stage in terms of that it</p> <p>20 was impacting on every part of her life and her</p> <p>21 family's life, and she wanted to come off this</p> <p>22 or at least know some more information.</p> <p>23 And she felt real pressure from the first</p> <p>24 professional to continue, and this went on for</p> <p>25 quite a long time, until she eventually said no,</p>
43	<p>1 enough's enough, and she sought a second</p> <p>2 opinion. She went to a completely different</p> <p>3 hospital, and had a very different experience,</p> <p>4 but what she also learnt from the second</p> <p>5 consultant was "You are on a trial" and she had</p> <p>6 no idea that she'd been on a trial. She'd had</p> <p>7 no discussion about it, she'd not consented to</p> <p>8 it.</p> <p>9 And this is in contrast to another gentleman</p> <p>10 that I met in a different area of the country</p> <p>11 who also had genotype 1 hepatitis C, who'd had</p> <p>12 a really long conversation about interferon only</p> <p>13 treatment, and its success. And actually, he'd</p> <p>14 made a decision, because it was so low at the</p> <p>15 time in terms of, you know, what could happen,</p> <p>16 he'd not -- anyway, he'd waited until 2015,</p> <p>17 until the new drugs became available, and that's</p> <p>18 when he made a different decision. But it</p> <p>19 brings out this real issue of consent around</p> <p>20 risk, and consent around trials.</p> <p>21 And I was going to hand over to Jackie, then</p> <p>22 to talk about another issue relating to consent.</p> <p>23 JACKIE: Okay. When -- lots of people who had</p> <p>24 transfusions in an emergency said obviously that</p> <p>25 they weren't in a position themselves to</p>	44	<p>1 consider the implications, but none of them --</p> <p>2 it wasn't explained to them about the possible</p> <p>3 risks of having transfusions. One person's</p> <p>4 parents were telephoned in the middle of the</p> <p>5 night to give consent, the person was 16, and</p> <p>6 she'd had a haemorrhage after an operation. And</p> <p>7 but they were told they were asked to give</p> <p>8 consent verbally and they were told it was in</p> <p>9 the context of life-saving procedure.</p> <p>10 And they and other people reflected on the</p> <p>11 guilt that that brought for them, that they had</p> <p>12 consented for their child to have that</p> <p>13 transfusion.</p> <p>14 Lots of people said to us there was this</p> <p>15 terrible irony of having their life saved on the</p> <p>16 one hand, but being given something which would</p> <p>17 ultimately limit their life on the other hand,</p> <p>18 and that was very difficult to deal with.</p> <p>19 There was a specific issue that someone</p> <p>20 explained to me, and this was a person who, in</p> <p>21 a relatively new relationship, was informed by</p> <p>22 her partner that he had HIV infection, and it</p> <p>23 was agreed that she would go to his consultant</p> <p>24 to have some tests, which she did. But she was</p> <p>25 also tested for hepatitis C. She didn't know</p>

<p style="text-align: right;">45</p> <p>1 that the partner had hepatitis C, and so she 2 wasn't asked for consent or told that she was 3 being tested for hepatitis C. 4 When she took this up later with the 5 consultant, she was told that she couldn't be 6 told that she was being tested, because it would 7 have compromised the confidentiality of the 8 other person, and she felt really strongly that 9 her rights, her welfare, had been overridden by 10 the confidentiality of someone else. 11 So the next section is we want to talk about 12 people living with the infection, and we're very 13 much minded that this audience can tell us a lot 14 more than we could ever explain to you. I'm 15 going to speak to the accounts that were given 16 to us about impact on individuals of that. 17 People talked about the impact of 18 hepatitis C particularly in vivid detail, and 19 the really common issues were chronic 20 debilitating fatigue and how that impacted on 21 their lives, often lasting for years, as we've 22 said earlier, without diagnosis. 23 Other symptoms were severe aches, 24 gastrointestinal problems, skin changes and 25 sweating, these are physical issues. Cognitive</p>	<p style="text-align: right;">46</p> <p>1 impairment was often described as "brain fog" to 2 us, and that led to a debilitating level of 3 confusion and inability to focus that was 4 sometimes combined with associated anxiety and 5 depression, and quite a few people spoke to us 6 about losing their way on the way home, not 7 being able to remember journeys. Lots of people 8 were really anxious about driving, for example, 9 because of the impact of that upon them. 10 People have also experienced mental health 11 problems to a significant effect, which really 12 impacted on everyday life, their relationships 13 as well. People described the later stages of 14 the disease, again physical issues, where the 15 liver and organs were affected. Living with the 16 worry about varices and the possibility of those 17 bursting there -- obviously enlarged veins. 18 People having to go through really painful 19 and invasive tests, particularly in the early 20 days when liver biopsies were very invasive and 21 involved. Without going into too much detail, 22 long needles and breaking through the skin. 23 One witness said to me, "As a result of my 24 infection and the worry around it, I've suffered 25 mental strain and stress to the point of</p>
<p style="text-align: right;">47</p> <p>1 thoughts of suicide, out of my fear of having 2 a nasty death." 3 So it wasn't just about where people are at 4 the moment, or were at the moment, in the course 5 of their disease, but that kind of anticipation 6 about where this would lead to. And the point 7 we would want to make was, even though we've 8 seen -- the majority of people we've seen have 9 now been cleared of the illness, lots of them 10 are still experiencing some of the symptoms of 11 the illness itself, the impact of those, and of 12 the treatment which we will come to speak about 13 later as well. 14 PAM: I want to briefly speak about the impact on 15 the family and the relationships, and there's 16 a number of strands to this element. The strand 17 of the pressure in a family of keeping a secret, 18 the stigma, if the outside world was to realise 19 what was happening by way of the infections. 20 But also, the actual daily routines in families 21 which were creating lots of stress: the need or 22 perceived need to keep separate towels, to keep 23 separate crockery, to make sure that there was 24 no bodily fluids exchanged between the infected 25 person in the family, on the adult, and the</p>	<p style="text-align: right;">48</p> <p>1 children of that family. 2 So the different elements that were 3 happening there together with, within some 4 families, you've got more than one infected 5 person, particularly with families where there 6 was haemophilia and we got brothers, sons, 7 fathers, et cetera. So you'd got a number of 8 layers of different tensions and pressures for 9 those families. And the impact on keeping the 10 secret, and meeting a number of people who 11 actually didn't want to have discussions within 12 the family because they didn't want to burden 13 the rest of the family with what they felt was 14 their condition. So to have your children 15 having to understand that condition, they felt 16 was burdensome, so kept a lot of that to 17 themselves, which created stress, anxiety, and 18 often depression in the way that Jackie has 19 relayed it. 20 So we'd got families who certainly had a 21 feeling of secrecy and an underlying, almost 22 depression, but certainly an anxiety within the 23 families which was palpable often. 24 I think Kay was going to talk to us about 25 a specific case that she'd been in contact with.</p>

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1 **KAY:** One of the families who I met had a child
 2 who had been infected with HIV, and I think
 3 probably to explain the impact on family and
 4 relationships, the best way is to use her words,
 5 and what she says is "We have nothing else to
 6 compare this to. Our child was infected and it
 7 took the joy out of our lives. Psychologically
 8 we became different people. We're cut off from
 9 others, and the depression we carry has at times
 10 almost torn us apart. In the darkest days, I
 11 even chose the music for our son's funeral."
 12 And although this couple feel extremely
 13 lucky that their son is still alive, what we
 14 talked about was the impact this has had on them
 15 as couple, and within their family relationships
 16 outside of that, and with their other son. And
 17 one of the things that we commonly found was
 18 that we would sit in maybe the front room of
 19 somebody, we'd be talking to two people, and
 20 they'd be sharing their thoughts, feelings, and
 21 exactly what had been going on for number of
 22 years, and one part of the family member would
 23 say to the other, "I never knew you felt like
 24 that. I never knew that had gone on for you."
 25 And that was a common thing that came about,

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1 Going back to the issue about personal
 2 relationships, we did see a few people who sadly
 3 found that their closest personal relationships
 4 were affected. One man that I spoke to who had
 5 lost his brother to HIV, when he was -- when he
 6 was 20 and his brother was 23, "Growing up, he
 7 was my best friend. We were inseparable in the
 8 school holidays but his HIV diagnosis drove
 9 a wedge in our relationship. It was something
 10 that we never discussed properly and we were
 11 never close after that, and that's one of my
 12 biggest regrets and I feel guilt to this day".
 13 We saw people who made the decision, as Pam
 14 has alluded to earlier, about just not taking
 15 the risk of having an intimate relationship, of
 16 starting a relationship, with a partner.
 17 I have to say we met some wonderful people
 18 who would have made wonderful partners,
 19 wonderful parents, and they had had choice --
 20 they felt they had that choice taken away from
 21 them. And I think one man really summed that up
 22 for me and said, "It's hard to go on a date with
 23 a woman and tell her you've been infected, and
 24 that she and any children she had could have
 25 been infected too by having a relationship with

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1 that this holding the feelings down, sometimes
 2 even in the most close relationships because
 3 actually they were just surviving the moment,
 4 trying to put one foot in front of the other,
 5 day by day. So yeah, that's them and I'll just
 6 hand back to --
 7 **JACKIE:** To me.
 8 The business of keeping secrets was a real
 9 strain for people, we found. And a few people
 10 said to us they had to learn new techniques of
 11 when they were in company with people and to be
 12 able to manage the kinds of things that they
 13 talked about in case the conversation went down
 14 a particular route, and they found themselves
 15 saying something which they then had to
 16 extricate themselves from.
 17 So not at all expecting in their lives that
 18 they would have to do that. And one chap
 19 I spoke to said, "I'd never lied to anybody in
 20 my whole life before", and that was a really
 21 hard experience about not being able to tell the
 22 truth to his workmates about his condition, and
 23 quite a few people said that they had other
 24 chronic conditions when they were asked about
 25 their symptoms as well.

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1 me."
 2 And that was terribly, terribly sad for us
 3 to see that.
 4 **PAM:** I think probably people in this room will
 5 all remember the medical advice in the 1980s for
 6 men co-infected with HIV, and hepatitis C, which
 7 was to abstain from any sexual activity which
 8 involved exchange of bodily fluids. And at
 9 least two of the men interviewed remained
 10 celibate throughout their twenties after
 11 receiving this advice, and I say "at least"
 12 because clearly this was a sensitive and
 13 difficult subject for any of us to be talking
 14 about with the people we interviewed. So it was
 15 quite difficult to actually get the extent and
 16 understanding of how this had affected people in
 17 all kind of parts of their relationships.
 18 So the two men who talked about being
 19 celibate, one did marry later, but the other
 20 never felt able to have a relationship for fear
 21 of infecting a partner.
 22 Similarly, the advice on sexual activity was
 23 not clear for people infected with hepatitis C,
 24 and everyone who we interviewed described
 25 significant stress because of this, as we've

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1 said. Even when they were in very close, loving
 2 relationships, it was still an area that was
 3 very difficult, and probably one of the most
 4 difficult areas for us to explore and understand
 5 entirely, other than we knew that the amount of
 6 stress that this certainly brought with it.
 7 We'd met a number of couples who spoke with
 8 immense sadness about limiting their families
 9 because of hepatitis C ...
 10 Obviously on a number of occasions it meant
 11 that until they'd had their infection cleared,
 12 or noticed that the infection was cleared, some
 13 were older. Fertility had diminished in some
 14 cases. Others just felt they could not risk the
 15 infection returning if they had children. And
 16 emotionally being spent, in the sense of even
 17 beginning to think about the responsibility of
 18 children.
 19 We spoke with a number of women who had
 20 terrible, terrible sadness as their lives had
 21 been about having children at the appropriate
 22 point, and that had now been something that was
 23 lost to them.
 24 So we certainly -- I think those were some
 25 of the very, very sad interviews, that even

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1 because you have hepatitis C."
 2 And that was how she then found out about
 3 that. She did then conceive naturally, and she
 4 said that there was real trauma, then,
 5 surrounding her second child's birth, which was
 6 highly, highly medicalised. When he was born,
 7 he had to have his stomach emptied via suction
 8 to ensure that no blood had been ingested and
 9 she said the midwives took him to the other side
 10 of the room to do that so she wasn't able to
 11 hold him for quite some time. Eventually, they
 12 were both moved from the labour suite and placed
 13 her in a side room away from other patients, so
 14 that she couldn't mix with other mothers, and
 15 she said that was a highly traumatic period of
 16 the first hours and days with her second child,
 17 and that really impacted on her as a parent as
 18 she went forward.
 19 **MS SCOTT:** Jackie, I'm going to ask you now to turn
 20 to the next theme you pick up in your report
 21 which you've alluded to already, quite a lot,
 22 and that's stigma and shame.
 23 **JACKIE:** Mm-hm, this was a huge issue for absolutely
 24 everybody that we saw. And you'll have heard
 25 that it's mapped through the other things that

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1 though there'd been a recovery from hepatitis C,
 2 the future was limited in so many ways, with
 3 a terrible, terrible sadness ...
 4 **KAY:** I just wanted to follow that with looking at
 5 those that were -- the impact in communities.
 6 So one of the families that I met, and those
 7 with underlying conditions, with thalassaemia
 8 and haemophilia, developed friendships with
 9 others at some of the places that they were
 10 going to have their treatments and their
 11 transfusions, and one of the real impactful
 12 things was a gentleman who said to me "We were
 13 like a little family. We were in and out all
 14 the time. And it was hard seeing them die."
 15 And how that impacted on him, and his life, and
 16 still does, today.
 17 **JACKIE:** I spoke to one woman who, unbeknown to her,
 18 was infected during a transfusion after the
 19 birth of her first child, and then had some
 20 trouble conceiving later on, when they wanted to
 21 extend their family. And she was referred for
 22 IVF, and obviously part of the that service was
 23 that she had to have some blood tests, and she
 24 received a telephone call from the hospital
 25 which said, "You are no longer suitable for IVF

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1 we've said, people lived with an enduring sense
 2 of feeling blamed and feeling shamed about the
 3 infection. Which was really compounded by the
 4 national mood: lots of people said the whole
 5 thing was mixed up about the national mood in
 6 the eighties, in particularly around HIV and
 7 AIDS and the judgements that were placed on
 8 people in respect of that, and a sense of moral
 9 panic, really, that they felt very frightened
 10 about.
 11 More than a couple of people talked to us
 12 about being called junkies in the street and in
 13 other wider friendships. Some people didn't
 14 tell their children at all about their
 15 condition, as Pam was saying earlier, and that
 16 was because they didn't want their children to
 17 be bullied at school. They were really afraid
 18 of that ...
 19 I saw one woman who was really acutely
 20 anxious about anyone finding out that she was
 21 infected. And the receptionist at her
 22 child's -- at her GP surgery was also a parent
 23 at her child's school, and she went through such
 24 agonies every day wondering whether this
 25 receptionist might have shared, inadvertently or

<p style="text-align: right;">57</p> <p>1 in any other way, information about her 2 infection. And this led to a really crippling 3 anxiety. So the family felt obliged to move 4 house, and they moved 25 miles away, away from 5 all of their support networks. And then, 6 four years later, she had a new neighbour who 7 was a GP at a local surgery and again, this 8 triggered her anxiety, and the family had to 9 move again.</p> <p>10 And the issue there was that there were 11 additional burdens for people about dealing with 12 this situation about having to move themselves 13 away from the support networks which were 14 helping them through it.</p> <p>15 KAY: I just wanted to touch on the issue that 16 we've mentioned there about society's response 17 to the blood infection through the time, and 18 specifically in relation to prejudice and 19 discrimination, and one family I met talked 20 about in the eighties, having a sign in their 21 local area displaying a sign that said, "No 22 homosexuals or haemophiliacs", and what people 23 were doing with that led to another gentleman 24 who was haemophiliac having to have his own 25 glass in his local pub because people knew that</p>	<p style="text-align: right;">58</p> <p>1 he had haemophilia, therefore he might have HIV. 2 And society at that time and in the media, there 3 was some high profile kind of footage being 4 released about HIV that was creating this fear 5 and scaring the community, and that was leading 6 to a real lot of prejudice and discrimination in 7 society. So not only did we have these internal 8 issues of managing family relationships, 9 managing yourself, you've then got the societal 10 impact of the prejudice that was out there, the 11 fear that was out there, and how that was 12 handled and managed at the time, was adding to 13 the psychological stress of our families.</p> <p>14 MS SCOTT: Pam, did you want to add anything? 15 PAM: Just bringing us to present day, really, 16 that we know that people felt there was an 17 ignorance around hepatitis C, but a need to 18 share some of their status with others, as 19 a need to protect others. But what they were 20 hoping was, from the Blood Inquiry, that there 21 was much more of an understanding within our 22 communities about infected blood and how it was 23 caused, and that publicity from the Inquiry 24 would raise awareness and help to quash these 25 ill-informed myths that were around. So they</p>
<p style="text-align: right;">59</p> <p>1 brought us into present day as to what they 2 hoped from, from the Inquiry.</p> <p>3 MS SCOTT: Pam, can I ask you then to pick up on the 4 next theme in your report, which is an impact on 5 education and work.</p> <p>6 PAM: Yes, certainly. 7 We've heard that we've met with a number of 8 people with haemophilia, and we know that in the 9 seventies and eighties, it certainly wasn't 10 uncommon for children with haemophilia to be 11 educated at what we know as special schools 12 during that time for pupils with additional 13 health needs.</p> <p>14 And I interviewed two men educated in one of 15 these schools who actually had very good 16 memories of the school at that time, and they 17 were supported in managing their haemophilia. 18 And injecting themselves to avoid hospital, and 19 they explained to me how, prior to being able to 20 inject themselves, there were frequent visits to 21 hospital, and that clearly interfered with their 22 education and their ability to spend time in and 23 around other young people.</p> <p>24 So the introduction of the new clotting 25 agents, new clotting products, gave them</p>	<p style="text-align: right;">60</p> <p>1 freedoms that they hadn't previously 2 experienced. Obviously in retrospect they all 3 commented on the Catch-22 of the long-term 4 implications of the resulting infections. So we 5 had this mixed picture of, yes, "We enjoyed 6 being in these schools, and they gave us the 7 freedom that we hadn't otherwise had", and there 8 was a good understanding of their medical needs, 9 but then, as I say, we have the implications of 10 the clotting agents.</p> <p>11 I also met with two women with thalassaemia 12 who actually had very different school 13 experiences, and that may have been due to the 14 fact that there was a 15-year age difference 15 between them. The older woman found that 16 thalassaemia led to fear and exclusion by other 17 children. She required frequent blood 18 transfusions and was absent from school for 19 a significant amount of time, and she doesn't 20 recall any additional support during those 21 years. I actually interviewed this woman while 22 she was having a blood transfusion, I sat with 23 her in hospital during that time, and her whole 24 life has been around sitting in hospitals and 25 having blood transfusions. She was a very, very</p>

<p style="text-align: right;">61</p> <p>1 bright woman, with lots of energy, but her 2 schooling had been entirely wiped out by her 3 need for blood transfusions and then, later on, 4 an awful lot of treatment. 5 The younger woman with thalassaemia was well 6 supported at school and college and her 7 experience at work was not as positive. One of 8 her employers required her to make up the hours 9 missed for her transfusions, resulting in long 10 days, and further exhaustion, which we knew she 11 experienced through the hepatitis C. Clearly it 12 was not sustainable to have to make up her time 13 at work when she'd been to have treatment and 14 blood transfusions. The days just weren't long 15 enough for her to do that, it felt an entirely 16 unreasonable expectation of her. So she moved 17 employers for those reasons. 18 Fortunately, her current employer is much 19 more supportive and flexible and she's able to 20 lead a more regular life with this level of 21 support. But for the two of them, it was very, 22 very restricting, or restrictive. 23 MS SCOTT: Jackie, did you want to add anything 24 about employment? 25 JACKIE: Yes. We saw quite a few examples of people</p>	<p style="text-align: right;">62</p> <p>1 who had had to give up on their education, for 2 example I saw one family where a young woman had 3 been to university and had to give it up after 4 a year because her father was in the end stages 5 of his illness and she couldn't bear to be away. 6 She said that every time she went back to 7 university she feared if she would see him 8 again, and so she gave that up, and wasn't able 9 to pick up with her learning for several years 10 after that. 11 But we also saw people who gave up on 12 education when they were infected. Either 13 because of the pressure of treatment at the 14 time -- I saw one man who was trying to take 15 professional exams whilst he was having 16 interferon and ribavirin treatment, and he said 17 one day he'd just slept in for his exam because 18 he was so exhausted, and there was no quarter 19 given about that. He just had to miss out on 20 his exam. 21 People were experiencing mental health 22 difficulties, and didn't feel able to continue 23 with their studies. And a couple of young men 24 who just said they thought it wasn't worth it 25 because they thought their life expectancy was</p>
<p style="text-align: right;">63</p> <p>1 going to be so limited, and that they didn't 2 want to invest their time in education. 3 On the other hand, several people spoke to 4 us about their absolute determination to keep on 5 working in spite of their debilitating 6 condition. And sometimes this was about wanting 7 to contribute to society, and not giving in, 8 feeling that they didn't want to give in to the 9 illness and allow it to take yet more away from 10 them. But for others, it was a financial issue 11 and they just couldn't afford not to work, and 12 so they had to carry on. And I saw a couple of 13 people who said they felt they had to drag 14 themselves to work in their sixties until such 15 a time as they reached their statutory pension 16 age, because they just couldn't afford not to do 17 that. And they spoke about the -- you know, the 18 impact of trying to work with carrying those 19 symptoms of the illness, and people spoke about 20 a life consisting of working and sleeping, 21 really, for years, just trying to keep going. 22 People having joint replacements, that kind of 23 thing. 24 Several people had to reduce their working 25 hours, or change careers, actually, because the</p>	<p style="text-align: right;">64</p> <p>1 nature of their work or working for five days 2 a week was really just too much for them. 3 And people then spoke about how there was 4 a loss to society as well, because of that. So 5 some of the examples that we saw were about, you 6 know, a woman who was a nursery nurse who had to 7 retire at 49, a nurse who had to retire at 52, 8 a teacher who had to retire early because her 9 mental health problems, as a result of her son's 10 condition, were just too much for her to feel 11 that she could carry on with that. 12 MS SCOTT: So now I'm going move on to the next 13 section, which is treatment, care and support. 14 Can I ask you, Jackie, to start with some of 15 the experiences you heard about the attitude of 16 healthcare professionals to those that you spoke 17 to? 18 JACKIE: Yes. 19 Our view is that anybody who's experienced 20 a serious illness, or any illness, knows the 21 importance of -- the manner in which a person is 22 treated is often as important as the treatment 23 itself. And we heard a range of experiences 24 from people, from sensitive and expert care, 25 which they really appreciated, to brutally</p>

<p style="text-align: right;">65</p> <p>1 delivered information, inappropriate questions, 2 and frankly poor quality care.</p> <p>3 Lots of people described their consultants 4 as lovely. They shared examples of medical 5 nursing staff absolutely going the extra mile to 6 support patients with home visits, open-door 7 access. Some of the consultants attended the 8 funerals of people who had died. One woman was 9 widowed when her husband died, said that she 10 didn't know how she would have survived without 11 the support of the consultant, and in the course 12 of the work that we did, we were able to trace 13 where the consultant had got to in the country, 14 which was nice for her because he'd moved on.</p> <p>15 Quite a few people spoke to us about, 16 particularly those with haemophilia, who said 17 that their own consultants felt a real anger 18 about what had happened to them and they were 19 active campaigners around infected blood and 20 really working hard to find new treatments to 21 tackle hepatitis C in particular.</p> <p>22 One thing that we wanted to stress was 23 almost exclusively, people spoke very, very 24 positively about the specialist nurses that -- 25 the specialist hepatitis C nurses who provided</p>	<p style="text-align: right;">66</p> <p>1 a flexible and practical response to the 2 challenges they faced, and probably came the 3 closest to any kind of therapeutic help for 4 people in the manner in which they conducted 5 their work.</p> <p>6 One family described a really positive 7 experience of care for their uncle who had 8 haemophilia. And this was a man who had been 9 born in the 1920s, so he'd undertaken some 10 extreme treatment in his youth when people were 11 finding a way, and he was under the care of the 12 same two consultants and a very dedicated 13 nursing team throughout his life. And the 14 team -- the family said the team were like 15 a second family to them, and their lives 16 revolved around visiting the unit, and when the 17 family went back to the hospital, as part of 18 their work to support this inquiry, the 19 receptionist remembered them from 30 years 20 earlier, which was an indication of that real 21 sense of family that people had.</p> <p>22 And they felt, in terms of their uncle, that 23 given the extent of his haemophilia, they did an 24 amazing job keeping him alive into his sixties. 25 And he actually died when he was 65, as a result</p>
<p style="text-align: right;">67</p> <p>1 of hepatitis C, unfortunately, and at that stage 2 he was the oldest haemophiliac in his home city. 3 So they had some real mixed feelings about the 4 clinicians had really worked hard over many 5 years to keep him well and to keep his 6 longevity, but it was such a shame that after 7 all that excellent care, that he passed away as 8 a result of the infection.</p> <p>9 Pam has got some other examples.</p> <p>10 PAM: Yeah. I met with a man who had a very 11 positive account and experience of his 12 treatment. He had developed Hodgkins lymphoma 13 in his late teens and had been treated for that 14 very successfully, and enjoyed good 15 relationships with his consultants, but he was 16 contacted by his consultant around '95, '96. 17 The consultant was extremely apologetic that the 18 infected blood had been given at the hospital 19 where the consultant was working.</p> <p>20 And the man I was interviewing was extremely 21 keen to emphasise that the specialist care he 22 had received for his Hodgkins lymphoma and 23 hepatitis had been excellent. And he said when 24 he visits his GP, he welcomes him like a VIP, he 25 is always made to feel very special and</p>	<p style="text-align: right;">68</p> <p>1 certainly his treatment, he said, couldn't be 2 better.</p> <p>3 He of course was very aware that the blood 4 transfusions which were there helping to keep 5 him alive in the first instance, became 6 a roller-coaster of events that, following that 7 heightened feeling that he was being treated 8 successfully, then came the news about this 9 hepatitis C and needing to continue to have 10 different treatment.</p> <p>11 Fortunately, the day that I visited him, 12 he'd just had the all-clear from his hepatitis C 13 treatment and was in a very good place. So we 14 had a good outcome. And certainly we've been in 15 contact around our presentation today and he 16 continues in good health. So, as I say, a very 17 positive experience which was very heartening to 18 hear.</p> <p>19 I think Kay has got an example too.</p> <p>20 KAY: Yeah, I just wanted to add to what Jackie 21 had mentioned about specialist nurses and some 22 of those doctors and nurses that had been there, 23 and were real positive experiences.</p> <p>24 In contrast to that, where specialist 25 facilities were not available, people described</p>

<p style="text-align: right;">69</p> <p>1 being treated in clinics alongside drug and 2 alcohol users, or with cancer patients, and 3 I think that was mentioned earlier on. If they 4 lived in an area with low incidence of 5 hepatitis C, this also limited their ability to 6 establish networks and gain support from other 7 people who were also affected.</p> <p>8 However, in contrast to that, in the 9 families that we met, I met one specialist 10 social worker who is working with the 11 haemophiliac community in that area, and it is 12 a designated post, a specialist social worker, 13 in relation to everything in and around 14 psychological support, financial support, 15 general advice, and to use their words they 16 said, "We'd not be where we are without her 17 today. She's helped us deal with financial and 18 emotional matters. We rely on her and everyone 19 deserves this support."</p> <p>20 And where services didn't have that, others 21 spoke of feeling isolated, and abandoned, and 22 that specialist service made so much difference 23 for a family who were going through bankruptcy 24 because their business had to fold, and 25 actually, through the specialist knowledge out</p>	<p style="text-align: right;">70</p> <p>1 there, they were signposted and got some help 2 and support and managed to keep their home, and 3 obviously their children live with them there as 4 well.</p> <p>5 So it made such a difference, and that is 6 a service that is out there in one of the areas 7 that we came across.</p> <p>8 PAM: In stark contrast to my last example, I've 9 a pretty harrowing example from another family, 10 and one man recounted that his father had 11 leukaemia and received stem cell treatment 12 followed by blood transfusions. He was at this 13 point infected with hepatitis B, which was noted 14 as the primary cause of death on the death 15 certificate, and I think all three of us have 16 seen a number of death certificates throughout 17 this, at our time working in the Inquiry.</p> <p>18 His father had been told by the consultant 19 that an error had been made and the wrong blood 20 taken out of the wrong fridge. This had 21 affected eight people, seven of whom had died. 22 The father was told he may be all right, but in 23 fact he died three months later.</p> <p>24 Again, that sounds like a pretty strange 25 story, but they were able to show me a statement</p>
<p style="text-align: right;">71</p> <p>1 that the father had given to his solicitor at 2 the point that he was informed about this, and 3 they'd still got the statement, which didn't 4 ever go anywhere in legal terms, but was there 5 as a record of this meeting with this solicitor.</p> <p>6 Following on from that, the family were 7 distraught about their father's treatment as he 8 spent his last weeks in an isolation ward at 9 a psychiatric hospital. And this was a man who 10 was a businessman. He'd fallen ill only a few 11 months prior to this, because he was having his 12 successful treatment for leukaemia, and then, as 13 I say, became very ill very quickly. So to have 14 his last days in a psychiatric hospital in an 15 isolation ward, at this was due to the lack of 16 provision to treat his hepatitis B in the main 17 hospital, and the fear from the hospital workers 18 that he was highly infectious, and the father 19 wrote this account when he was told about the 20 infection which as I say was formulated into his 21 statement and I'll read some of the words which 22 are in this statement and they were able to show 23 me:</p> <p>24 "I was told today by the consultant that the 25 blood cells were contaminated. It has not</p>	<p style="text-align: right;">72</p> <p>1 really sunk in what has happened. Now that 2 I have hepatitis B, I cannot be cured, and there 3 is a possibility that it will be passed on to 4 others who come into contact with my blood."</p> <p>5 He died very shortly after this, and I'll 6 come on later to talk about the circumstances 7 under which the family heard about his death.</p> <p>8 Handing over to Jackie.</p> <p>9 JACKIE: Just to pick up a couple of things from 10 what Pam said about death certificates. I had 11 two differing experiences. The young man 12 that I mentioned earlier who'd died from HIV, it 13 wasn't mentioned on his death certificate. His 14 death certificate said that he'd died from liver 15 failure, and the explanation to the family was 16 that the medics had done them a favour by not 17 mentioning the HIV in that respect.</p> <p>18 With another family that I worked with, 19 their doctors were very angry that their 20 patient, who had haemophilia, had been infected 21 with hepatitis C, and they were determined to 22 make sure that that was noted, and on the death 23 certificate itself, the doctor had written 24 diagonally right across it in large letters 25 "hepatitis C", and the woman who I worked with</p>

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1 said that when the registrar opened it she was
 2 quite taken aback, and the message was that the
 3 clinicians really wanted people to know the
 4 cause of that.

5 In another example that I have, I saw a man
 6 who had had successful treatment to clear his
 7 hepatitis C, and he and his family felt they
 8 wanted to move to a city, a new city, for a new
 9 start. So his treatment for haemophilia
 10 transferred to a new hospital. And on his first
 11 appointment the doctor that he saw said to him
 12 "Oh, I see you've got hepatitis C", and the chap
 13 said it was a terrible shock to him, as he
 14 thought the infection had cleared, and he was
 15 told to come back six months later for
 16 a follow-up appointment, and when he went back
 17 after six months he was told that this was
 18 actually a clerical error and what should have
 19 been written on his record was that he was
 20 positive for hepatitis C antibodies and had been
 21 wrongly copied as positive for hepatitis C. So
 22 he spent six more months thinking that, and he
 23 said that really put him through months of hell.

24 Another issue that came up for us around
 25 treatment, particularly in the earlier days, is

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1 people being denied treatment or isolated from
 2 other patients because of hepatitis C, and we
 3 saw quite a few people who had difficulties with
 4 dentists, for example, and Pam has an example
 5 there to share -- oh sorry, it's Kay. It's
 6 Kay's, I'm sorry.

7 **KAY:** Just moving on, we're talking about the
 8 dentistry. One of the families that I met had
 9 had such poor treatment in relation to
 10 dentistry, where the procedure had to be
 11 undertaken in the hospital, the hazardous
 12 stickers were out, it was at the end of a day,
 13 the attitude of staff was not good for him at
 14 all, that it left such a significant impact on
 15 his life that, for the rest of his life, he's
 16 never gone -- he's still alive today, he won't
 17 go to the dentist because the experience was so
 18 poor that this has led to -- when he has needed
 19 a couple of extractions, he's done that himself.

20 And actually, you know, if you think of that
 21 in context to the pain that you must have to go
 22 through in terms of extracting your own teeth,
 23 you would have to have suffered so much of
 24 a psychological impact to do that, that it's
 25 astounding.

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1 that essential tests and equipment weren't
 2 always available on the NHS for people, and
 3 people were expected to fund them privately if
 4 they wanted to have these newly developing
 5 facilities. And in 2005, one patient was told
 6 that a fibroscan would determine the progress of
 7 the disease, but there were no facilities in
 8 this country and she had to travel to Paris in
 9 June of 2005 at the family's expense. The
 10 following year, a fibroscan machine was
 11 installed at a hospital 74 miles away from where
 12 she was, and she had to travel there for scans
 13 for 7 years before she could have them more
 14 locally.

15 Then in June of 2008 a consultant advised
 16 that, due to the level of cirrhosis, she needed
 17 to have an enhanced liver fibrosis test. Again,
 18 this was not available on the NHS, and she had
 19 to pay £99 to have this carried out by a private
 20 contractor in an NHS hospital.

21 And just that -- we wanted to share with you
 22 that the words that people most frequently use
 23 when discussing access to treatment were "leper"
 24 or "pariah". That is how they were made to
 25 feel. And there were many, many experiences of

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1 In contrast, there was an example of one
 2 woman's dental nurse commenting loudly -- in the
 3 infection, but the dentist was challenged -- the
 4 nurse was challenged, I should say. So there
 5 was some good evidence within professional
 6 environments where people were not behaving in
 7 an okay manner, but there was also some evidence
 8 of other professionals challenging them and that
 9 really making a difference for the individual,
 10 in terms of that prejudice and that
 11 discrimination.

12 **MS SCOTT:** We've come to the end of that theme and
 13 we're going to move on to another one, for
 14 treatment of hepatitis C, but I notice the time.

15 **SIR BRIAN LANGSTAFF:** So this would be a convenient
 16 moment to have our lunch break, would it?

17 **MS SCOTT:** Indeed.

18 **SIR BRIAN LANGSTAFF:** Can I thank you very much so
 19 far, and I hope you don't mind having to come
 20 back after lunch. It will be two o'clock. But
 21 what you have so far told us, I think, has been
 22 really valuable and worthwhile listening to. So
 23 thank you so far, and I look forward to seeing
 24 you back at two o'clock.
 25 Two o'clock.

<p style="text-align: right;">77</p> <p>1 (12.58 pm)</p> <p>2 (Luncheon Adjournment)</p> <p>3 (2.05 pm)</p> <p>4 SIR BRIAN LANGSTAFF: Yes, you're moving on to the</p> <p>5 next topic.</p> <p>6 MS SCOTT: Yes.</p> <p>7 Pam, you were going to start us off on</p> <p>8 treatment for hepatitis C.</p> <p>9 PAM: Yes, thank you.</p> <p>10 To take people right back to the beginning,</p> <p>11 when we explained how many people we'd seen with</p> <p>12 various disorders and illnesses, and we actually</p> <p>13 met with 50 people who were infected with</p> <p>14 hepatitis C, and I think it's fair to say on</p> <p>15 behalf of all three of us, that it was truly</p> <p>16 shocking to hear for the first time just the</p> <p>17 experience of these people who had been treated</p> <p>18 with interferon and ribavirin. They described</p> <p>19 it as gruelling, similar to chemotherapy, which</p> <p>20 lasted months and, in some cases, years.</p> <p>21 A small number of these people said they</p> <p>22 were given clear information to help them</p> <p>23 prepare for the impact of the treatment, and</p> <p>24 a good example here was a couple who had both</p> <p>25 been treated and able to plan that so one had</p>	<p style="text-align: right;">78</p> <p>1 the treatment before the other, whereas others</p> <p>2 felt that they entered it quite naively. And</p> <p>3 I think all three of us heard the phrase that we</p> <p>4 had heard from a number of people that said,</p> <p>5 "This was the worst year of my life". People</p> <p>6 certainly articulated suicidal thoughts and</p> <p>7 people seriously had contemplated taking their</p> <p>8 own lives because they could not see an end to</p> <p>9 how they felt ...</p> <p>10 They described a very, very debilitating</p> <p>11 illness, extreme tiredness, staying in bed for</p> <p>12 days and days and days, not coming downstairs,</p> <p>13 literally for weeks, to be with their family.</p> <p>14 Hair loss, significant weight loss, and also</p> <p>15 a profound impact, not surprisingly, on their</p> <p>16 own emotional and mental health.</p> <p>17 Many of the effects of the treatments have</p> <p>18 endured and have become lifelong conditions.</p> <p>19 I need to talk about a young woman with</p> <p>20 thalassaemia who had been engaged to be married</p> <p>21 when she started the treatment. She was in her</p> <p>22 early twenties then. Until that point she'd had</p> <p>23 a life where she had been very successful, she</p> <p>24 had managed her thalassaemia well with a very</p> <p>25 supportive family.</p>
<p style="text-align: right;">79</p> <p>1 Then learning about her hepatitis C and</p> <p>2 starting with the treatment absolutely changed</p> <p>3 her life, to the extent that she certainly</p> <p>4 suffers with a great deal of depression,</p> <p>5 anxiety, loss of confidence, and she talks about</p> <p>6 not leaving her parents' home for a year.</p> <p>7 Her wedding that had been planned had been</p> <p>8 cancelled, was cancelled, the relationship</p> <p>9 ended. She was unable to work or consider any</p> <p>10 career prospects.</p> <p>11 The anticipated future of leading a life</p> <p>12 with a partner and a child, and a professional</p> <p>13 job that she had, were all lost. Sadly, she's</p> <p>14 now got cirrhosis of the liver and is deeply</p> <p>15 pessimistic about her life expectancy. A very,</p> <p>16 very sad story. We heard similar stories time</p> <p>17 and time over.</p> <p>18 I hand over to Jackie to give further</p> <p>19 examples.</p> <p>20 JACKIE: Yeah, I met one lady who was diagnosed</p> <p>21 ultimately with post-traumatic stress disorder</p> <p>22 as a result of the impact of her treatment,</p> <p>23 which she described as traumatic, and that</p> <p>24 resulted in flashbacks and ultimately a very</p> <p>25 significant mental health breakdown.</p>	<p style="text-align: right;">80</p> <p>1 And the effects of the virus and the</p> <p>2 treatment have left her with enduring severe</p> <p>3 depression and anxiety. She describes becoming</p> <p>4 mentally exhausted very quickly and uses the</p> <p>5 word "overwhelmed" a lot in terms of how she</p> <p>6 feels.</p> <p>7 She described the overall result of the</p> <p>8 infection and treatment as "an existence of</p> <p>9 survival and coping with little contribution or</p> <p>10 fulfilment".</p> <p>11 I met one family whose relative had an</p> <p>12 uncommon, we think, reaction from the treatment,</p> <p>13 which was a very significant weight gain, and</p> <p>14 the implications of that. This lady had been an</p> <p>15 average weight, looked after herself very well,</p> <p>16 but throughout the course of the treatment the</p> <p>17 weight gain meant she moved from a size 12 in</p> <p>18 clothes to a size 22. And the significance here</p> <p>19 was that this further led to her isolation. She</p> <p>20 felt very embarrassed, she didn't feel she could</p> <p>21 go out shopping. Her son said to me that she</p> <p>22 felt that people judged her because of her</p> <p>23 weight, and her son said to me that he felt like</p> <p>24 holding up a billboard saying, "This is not her</p> <p>25 fault."</p>

81	<p>1 And so she became, as I said, further 2 isolated, didn't go out. Again, then impacting 3 on low mood, and anxiety as well. 4 As Pam said earlier, lots of families hadn't 5 been informed of the likely impact of the 6 treatment. A few people said to us they'd been 7 told it would be like flu-like symptoms, which, 8 as I'm sure people here know, doesn't go 9 anywhere near describing the impact of that kind 10 of treatment. 11 But particularly, people didn't realise that 12 the mental health and mood changes were related 13 to the treatment, and so they went through 14 agonies in their families in relationships, and 15 self-blame and blame of each other, and some 16 relationship breakdowns, because they hadn't 17 realised that this was not the real them, this 18 was what the medication was doing to them. 19 Kay, you had some ... 20 KAY: Yeah, I was just going to talk and bring it 21 forward to around 2015, and the people who have 22 been able to use the new direct acting 23 anti-viral treatments, and many spoke positively 24 about this, and everyone on this treatment 25 programme that we've met has been cleared of</p>	82	<p>1 hepatitis C, and very few had had serious side 2 effects. 3 Obviously, there was -- you know, people 4 were really glad that it took less time, and 5 some people felt the benefits in a much quicker 6 time frame, with one person feeling after 7 a couple of weeks "I really think this has 8 worked", and it had. 9 With regards to people receiving this 10 treatment there was this kind of double edged 11 sword with this kind of "We're the lucky ones 12 because we're still alive and other people have 13 died", and actually in some situations there 14 were individuals that got the feeling from some 15 of the professionals that they encountered, 16 "Think yourself lucky that you're getting this". 17 And, you know, those kind of feelings didn't 18 leave them in a good place, and obviously those 19 that hadn't had that experience were really 20 appreciative of getting a really good service, 21 and obviously clearing the hepatitis C. 22 One of the gentlemen that I met was really 23 shocked that after I'd visited him early last 24 year, he'd had the need to go to the GP, and -- 25 was really shocked. He's had this condition</p>
83	<p>1 since the early nineties. The GP was kind of 2 telling him that he'd got hepatitis C. Well, 3 he's known that for a long, long time. But what 4 was more shocking was there wasn't a discussion 5 around the new treatment, and to this day this 6 man still has hepatitis C and there's 7 a treatment available there. And that really 8 does bring about the issue of ensuring that 9 everybody is afforded the opportunity to go on 10 the programme in terms of the new treatment and, 11 you know, that's something that was really quite 12 shocking to hear. 13 MS SCOTT: Jackie, some of the people you spoke to 14 discussed liver transplants with you. What were 15 you told? 16 JACKIE: Yes, we saw four people who had had liver 17 transplants, and I wanted to just share two 18 examples of different experiences, really. 19 One man had a successful transplant which 20 really transformed his and his family's life, 21 and his wife said to me that it gave them nine 22 of their very best years together. Sadly, the 23 hepatitis C couldn't be cleared and his new 24 liver became infected, but she was very grateful 25 for those nine years that they did have</p>	84	<p>1 together. 2 Another family I spoke to, who were hopeful 3 for a liver transplant -- it was the lady 4 I spoke to just recently who had the very 5 significant weight gain -- her liver disease 6 progressed to cirrhosis and when she was 7 assessed for a liver transplant the assessing 8 surgeons refused to undertake the procedure 9 because of her weight. And the family were 10 really angry that they -- in their words, they 11 said she was infected by the NHS, the NHS 12 treatment caused her weight gain, and then it 13 was that that made her not qualify to have the 14 transplant that she then needed, and she 15 subsequently died. 16 MS SCOTT: Jackie, you spoke to a number of people 17 about end-of-life care and end-of-life 18 experiences. 19 JACKIE: We did. 20 MS SCOTT: Can you tell us about that. 21 JACKIE: Again, we found a range of experiences. 22 Several people sadly talked about their loved 23 ones experiencing very traumatic deaths. Often 24 related to multiple organ failure. Some of them 25 were treated very appropriately and sensitively.</p>

<p style="text-align: right;">85</p> <p>1 Others had less pleasant experiences.</p> <p>2 One lady spoke to me about her mum not</p> <p>3 having a peaceful or pleasant passing. And</p> <p>4 a few people talked to us about the cruelty, how</p> <p>5 it seemed very cruel at the end of -- people</p> <p>6 having to have their fingers really squeezed</p> <p>7 hard, for example, to have their blood tested,</p> <p>8 et cetera.</p> <p>9 One lady described to me her mum, who was</p> <p>10 dying from liver failure at the age of 51 and</p> <p>11 she was in the last days of her life. And the</p> <p>12 daughter was outside of the room, leaning up on</p> <p>13 the wall, on the wall outside of the room, and</p> <p>14 one of the doctors came out and he tapped her on</p> <p>15 the shoulder and said, "Cheer up, it might never</p> <p>16 happen."</p> <p>17 And she just felt it was so cruel for anyone</p> <p>18 to say that, as her mum was so close to her</p> <p>19 life. But in contrast, she then said there was</p> <p>20 another lovely doctor who sat with them one</p> <p>21 night and very gently explained that he didn't</p> <p>22 think her mum would reach the morning, and</p> <p>23 explained to them exactly what would happen over</p> <p>24 the coming hours. And this felt like a really</p> <p>25 respectful and compassionate discussion.</p>	<p style="text-align: right;">86</p> <p>1 And what she described was just that</p> <p>2 contrast, within a 24-hour period, of the two</p> <p>3 different approaches, in that respect.</p> <p>4 I saw another lady whose husband had had</p> <p>5 hepatitis C for a long time, and was -- then</p> <p>6 unfortunately contracted hepatitis E through</p> <p>7 food poisoning and so he became very ill very</p> <p>8 quickly.</p> <p>9 They had a very poor experience in hospital,</p> <p>10 no specialist beds were available, and he</p> <p>11 remained in A&E. And although she was very</p> <p>12 concerned about the decline in his condition,</p> <p>13 she said, in an echo of the original experience</p> <p>14 about hepatitis C, the nurses said he was just</p> <p>15 very tired. And he actually passed away during</p> <p>16 that period.</p> <p>17 And she tried to speak to the hospital</p> <p>18 afterwards. The family complained to the</p> <p>19 hospital about the quality of care that had been</p> <p>20 received, and it took a year for this complaint</p> <p>21 to be dealt with. And the hospital said that</p> <p>22 they'd done all they could do and they couldn't</p> <p>23 find any learning from that. The family felt</p> <p>24 really strongly fobbed off.</p> <p>25 And this seemed to -- this is similar to</p>
<p style="text-align: right;">87</p> <p>1 another example that we saw, where a widow whose</p> <p>2 husband had died from hepatitis C went back to</p> <p>3 the hospital to ask if it had been caused by</p> <p>4 a blood transfusion which he'd had as a result</p> <p>5 of an injury. Obviously they found out</p> <p>6 subsequently that it had. And she was asked to</p> <p>7 sit in front of a panel of four doctors -- and</p> <p>8 this is a lady who'd just been widowed, and she</p> <p>9 was in her late sixties/early seventies -- and</p> <p>10 she said -- her daughter said that they all</p> <p>11 backed each other up. She was there on her own</p> <p>12 against this panel of four doctors, and she just</p> <p>13 felt intimidated and humiliated, really.</p> <p>14 And in both of those situations, both of</p> <p>15 those families said the family just did not have</p> <p>16 the energy to carry on with those complaints,</p> <p>17 because of where they were in their bereavement</p> <p>18 and coping with the condition.</p> <p>19 PAM: Which leads me on to my example, which is</p> <p>20 not dissimilar. I mentioned earlier about the</p> <p>21 man with leukaemia who had got hepatitis B from</p> <p>22 a blood transfusion, who spent the last weeks of</p> <p>23 his life in a psychiatric ward because of the</p> <p>24 perceived need to nurse him in isolation.</p> <p>25 His wife visited the hospital, needing to</p>	<p style="text-align: right;">88</p> <p>1 travel on two different bus routes. It took her</p> <p>2 certainly upwards of two, two-and-a-half hours</p> <p>3 either way. At the point that he was ending his</p> <p>4 life, his family weren't informed that he was --</p> <p>5 that his death was imminent. On the day that he</p> <p>6 died, his wife took her usual lengthy bus route,</p> <p>7 and she had taken flowers to celebrate the fact</p> <p>8 it was their wedding anniversary, and when she</p> <p>9 arrived at the hospital, she went to the ward</p> <p>10 and saw the empty bed. And that's how she'd</p> <p>11 been told that he'd died. She's still alive,</p> <p>12 and I met with her, a very stoic lady, and a bit</p> <p>13 similar to what Jackie has just mentioned:</p> <p>14 hadn't got the energy and the emotional energy</p> <p>15 to take this matter forward.</p> <p>16 So a truly tragic death for this man and his</p> <p>17 family.</p> <p>18 Kay, I think you wanted to ...</p> <p>19 KAY: I just wanted to move on. We've touched</p> <p>20 on -- a number of people spoke about the impact</p> <p>21 of losing loved ones to early and traumatic</p> <p>22 deaths. And one of the families that I met had</p> <p>23 lost their child. This was a family whose</p> <p>24 teenager had had an accident, needed to have</p> <p>25 a blood transfusion, and very quickly after that</p>

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1 transfusion she became very, very poorly, and
 2 after a few months she died, and she was 14.
 3 Losing anybody is difficult. Losing a child
 4 is something that people will say is forever
 5 life-changing as well, in terms of that. And
 6 there was a sibling as well, and the impact on
 7 the sibling was significant.
 8 Her voice in this process, I would like to
 9 share with you:
 10 "There is nothing worse than the loss of
 11 your child. It destroys your whole life. I had
 12 so much time off work. I was almost sacked. It
 13 changes your personality, and it's devastating,
 14 and you just function day-to-day, and there are
 15 no words to describe it."
 16 I just want to say a little bit about this
 17 lady, who again, we have described about all our
 18 families, was a lady -- she is now 80 years
 19 old -- the death was quite a significant number
 20 of years ago, and she has had to
 21 compartmentalise how she deals with that, to be
 22 able to go on for her other child and obviously
 23 the family.
 24 But she felt so strongly for this inquiry
 25 that she had a voice, and, Sir Brian, she was so

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1 said:
 2 "I know that had he lived, he would have
 3 made a huge contribution somehow. He studied
 4 medicine at Oxford and then changed courses to
 5 study law and achieved a first class degree. He
 6 was a polymath. His death at 23 meant the whole
 7 country missed out on what he could have
 8 contributed."
 9 **MS SCOTT:** Kay, can I ask you then to move us on to
 10 the next topic, which is access to psychological
 11 support.
 12 **KAY:** I just wanted to start this area looking
 13 at -- kind of historically. So looking at those
 14 that were infected in the seventies and eighties
 15 and nineties. There was quite a common theme
 16 with regards to there were varied examples of
 17 those that received or were offered
 18 psychological services. And some did, but may
 19 have had to seek that out themselves. So one of
 20 the other things that I encountered was some
 21 people I spoke to who would have found it really
 22 hard to ask for help and support, and the need
 23 for specialist psychological services can never
 24 be underestimated, in terms of those people who
 25 need to have that time and that longer

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1 grateful that the intermediary process was
 2 available for her to be able to honour her
 3 daughter's memory and be able to have a voice in
 4 this process.
 5 I think that is a really, really important
 6 part of -- you said earlier on this was a new
 7 process. It was so important, in particular in
 8 that case, and I would say in all cases, that
 9 this option was available.
 10 **JACKIE:** One of the things we recognised, and
 11 something that people said to us, was those
 12 losses are tragic and traumatic for the
 13 individual families, but we recognise as well
 14 that those deaths were a loss to the wider
 15 community and to society itself, really. There
 16 were examples of the local undertaker who was
 17 such a support to his local community, the
 18 much loved school lunchtime supervisor, the
 19 nurse who died too early at 51, all people who
 20 provided excellent services to their community
 21 and to society overall.
 22 One man spoke to us about the lost potential
 23 of his brother, who died at 23. This young man
 24 was a talented musician and singer with
 25 excellent academic achievements. His brother

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1 therapeutic period in their lives to be able to
 2 work through some of the issues that have been
 3 around for many, many years.
 4 The whole issue nationally I know has been
 5 addressed around mental health and stigma, and
 6 I know there's lots of efforts nationally now,
 7 and some spoke of how positive that is, and we
 8 can open the doors for some of those people that
 9 need that service now, even if it was 30 or
 10 40 years ago, as well as those more recent.
 11 Some spoke of, if it was a tailored
 12 psychological support for people, it's important
 13 for people to know the history of infected blood
 14 and blood products and the whole history of
 15 that. Others may have commented on actually
 16 those professionals can learn some of that away
 17 from the therapeutic environment, but actually,
 18 it's important that they have some knowledge
 19 of it so they can work with clients and work
 20 with them, and their experience of the
 21 environment.
 22 I'll hand over.
 23 **MS SCOTT:** Kay, can I just ask, were any of the
 24 people that you spoke to offered psychological
 25 support in the early days of the infections?

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1 **KAY:** In the early days, for myself, that was
 2 a no.
 3 **MS SCOTT:** No. Is that the same for the --
 4 **JACKIE:** Almost exclusively, yeah. I saw one lady
 5 who was asked to go to a group in respect of her
 6 condition, and when she got there she was in
 7 a group of people who had addiction problems,
 8 and she felt that was highly inappropriate for
 9 her, for her situation. And then another one
 10 where an infected person who was themselves
 11 a health professional was asked to lead a group,
 12 and again, she felt that that blurred the
 13 boundaries between herself as someone who was
 14 experiencing the issue.
 15 I did speak to one woman who had two
 16 different experiences. She was referred to an
 17 NHS psychologist who told her that she must have
 18 had a death wish because she'd had
 19 a relationship with somebody who was infected.
 20 But she then later sought help through the
 21 Hepatitis C Trust, who were incredibly helpful
 22 to her, and supportive, and arranged for private
 23 counselling for her, which was excellent in
 24 taking her forward. So some very different
 25 experiences there.

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1 she felt fit and healthy, and at that point he
 2 and the surgery hosted a tea party for her and
 3 her family to go to the surgery and have this
 4 tea party. And she said again, it was
 5 a lifeline, that the GP and the surgery got her
 6 through those times.
 7 So we do have these exceptional experiences
 8 from some of the people that we saw.
 9 **MS SCOTT:** For those people that you spoke to that
 10 hadn't had any psychological support or
 11 counselling, was that something they'd be
 12 interested in if it was available?
 13 **JACKIE:** Yes.
 14 **KAY:** Yes.
 15 **PAM:** Yes.
 16 **MS SCOTT:** Across the board?
 17 **PAM:** Yes.
 18 **JACKIE:** Yes.
 19 **KAY:** I think there may be some work to do around
 20 those that maybe say, you know, "Oh, I feel like
 21 I'm lucky, I'm alive", and just some gentle work
 22 there to do around just how important they are
 23 and how much they deserve that, but I think in
 24 the main, the majority would say yes, but I know
 25 of one gentleman that I spoke to, when the issue

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1 **PAM:** I can end this section on two positives.
 2 The young woman I've talked about intermittently
 3 with thalassaemia, she had received counselling
 4 intermittently over the years. In the first
 5 instance around the treatment around
 6 thalassaemia and how that impacted on her life,
 7 but then, of course, as she became hepatitis C,
 8 she began to have a different type of bespoke
 9 therapy around her particular needs. And that
 10 has continued, the therapy -- or the counsellor
 11 has been flexible in the sense of being able to
 12 to be responsive to what she's needed at that
 13 time and she feels that has been a lifeline.
 14 My second example is quite different.
 15 A woman who had the treatment, she'd had
 16 interferon and ribavirin, had been through
 17 a horrendous time, one of those people who
 18 talked about it being the worst year of her life
 19 and being suicidal. It wasn't successful. She
 20 then had the new treatment a number of years
 21 later. Her doctor, her GP, she describes as
 22 being fabulous and had talked her through how
 23 she needed to exercise and said, "Do 100 yards
 24 this week, do 200 yards next week, go round the
 25 lake, et cetera, et cetera", to the point that

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1 of the enhanced financial arrangements came
 2 around for the psychological impact, really
 3 struggled in even recognising his own
 4 depression. His wife saw it, as did another
 5 family I can think of with the couple, but they
 6 were struggling because they just felt so lucky
 7 they were alive that they weren't recognising
 8 their own depression and anxiety. And that had
 9 manifested itself in so many ways, in particular
 10 being housebound, that there'd just be some work
 11 to do and they deserve that.
 12 **MS SCOTT:** So the people you spoke to aren't being
 13 offered any psychological support?
 14 **JACKIE:** No, not then and not now.
 15 **MS SCOTT:** Not then and not now.
 16 **JACKIE:** The key thing was that people just would
 17 like to have been offered and then they could
 18 have exercised their judgment about whether to
 19 accept that, but for the great majority of the
 20 people we saw, they were never offered. It was
 21 never discussed.
 22 **MS SCOTT:** Kay, can I ask you then to move us on to
 23 what I think is the last theme in your report,
 24 which is financial support.
 25 **KAY:** Okay, so the majority of people that we

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1 heard from with regards to hepatitis C had been
 2 told by professionals about the Skipton Fund.
 3 Others found out through the press or through
 4 relatives, and some didn't know about it until
 5 it became a bigger part of the inquiry. So
 6 there was kind of a group of people, the
 7 majority, who did know, but there were others --
 8 and I even add one gentleman who found out
 9 because his -- it was through reading somebody's
 10 story in a magazine, and then thought, "Oh,
 11 right, I can apply for this", and did, and
 12 obviously was awarded.

13 People spoke positively about the current
 14 schemes, but all expressed anxiety that this
 15 support might be reduced as part of austerity
 16 measures, meaning that they can't rely on it for
 17 long-term financial plans, and there were some
 18 who felt that payments were inadequate, for
 19 others, across the differing areas, different
 20 awards, and they'd like some kind of agreement
 21 moving forward, that there's parity with that.

22 One of the things we discussed was around
 23 financial support, but also financial impact.
 24 So many of the people that we spoke to had
 25 suffered financial impact because a partner had

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1 **JACKIE:** I met a family who had to borrow money from
 2 friends, and this was because during the period
 3 that the husband was having interferon and
 4 ribavirin treatment -- this took two years,
 5 altogether, because he had to keep having pauses
 6 to allow his immune system to recover -- and
 7 they had no income for 18 months. And they used
 8 up their savings within six months. His wife
 9 worked part-time, and that meant that they
 10 weren't able to access any benefits. They
 11 didn't know about the Skipton Fund or anything
 12 like that, and the only help they got was
 13 a ten-pound reduction on their Council Tax
 14 during that time.

15 So, as I said, they had to borrow from
 16 families. And they found out about the Skipton
 17 Fund in a happenstance way as well, and
 18 thankfully were able to repay their relatives
 19 for the money that they'd loaned to them during
 20 that period.

21 **PAM:** Just to finish off in this section, we had
 22 a situation for two particular families who'd
 23 lost their fathers through the infected blood
 24 resulting in hepatitis B. And currently, there
 25 is no financial support available for this

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1 had to give up work to look after their husband,
 2 and I think that the lady I met said, "I love my
 3 job but I love my husband more", and that
 4 financially impacted on them but she had to give
 5 up work because he was so poorly in terms of his
 6 mental health and physical health.

7 It was common for issues such as not being
 8 able to get life insurance, mortgages, holiday
 9 insurance. Some people didn't apply for jobs
 10 because of the fear of being asked the questions
 11 around their medical health and they didn't want
 12 to share that.

13 And I had one particular professional that
 14 worked in the medical field that says, "I've
 15 been ill all my life. I'm always having tests.
 16 My life revolved around work at a hospital as
 17 a professional nurse and being a patient.
 18 I love my work but it affected by prospects, so
 19 I couldn't progress in my career, and it's what
 20 I really wanted to do."

21 At the end of that section there's also, in
 22 the report, mention of the family who lost the
 23 child not being able to afford the funeral, and
 24 having to get a loan and borrow money to
 25 actually be able to bury their child.

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1 condition. One of the dependents sadly died,
 2 the other dependent is still alive, and very
 3 much in need of financial support, having lost
 4 her husband, who I referred to earlier on as
 5 a self-employed businessman, and having lost all
 6 access to any type of benefits and payments.

7 So that's an anomaly within the system still
 8 as well.

9 **MS SCOTT:** The end of your report you set out the
 10 hopes of those you spoke to, their hopes for the
 11 inquiry.

12 Pam, I wonder whether you can just emphasise
 13 on some of those key themes emerging from that.

14 **PAM:** Yeah, to return to where we started off, and
 15 the fact that we felt very humbled and
 16 privileged to be part of interviewing these
 17 people and represent them at the inquiry, the
 18 majority of people we know describe themselves
 19 as the lucky ones because they'd survived, and
 20 we heard this at the beginning of so many of our
 21 interviews.

22 Now, the interviews, the people we met, they
 23 were stoic, they were resilient, but also
 24 sensitive to the situation of those who had
 25 died, very much so, and their bereaved families

<p style="text-align: right;">101</p> <p>1 and people currently who were ill and receiving 2 treatment ... so their messages to the inquiry 3 are messages that I think the Inquiry has heard 4 throughout its time, throughout the time you've 5 been hearing evidence from those infected and 6 affected until this point. 7 I won't go through all of what our folks 8 said because you've already heard them so some 9 of the message is the same but we know as 10 experts by their experience, they're the 11 experts, not we three, they're certainly the 12 experts, and they gave a very powerful 13 collective picture revealing those common 14 patterns and themes, and their commonality. 15 They'd like to see a clear timeline of when 16 infected products were first used and when they 17 stopped, along with an understanding of how 18 decisions were made along this timeline, to 19 continue using those products, how risks were 20 considered, and whether this was assessed as 21 a risk worth taking. 22 They particularly want to know what people 23 in authority knew about the risks of infected 24 blood when making strategic and clinical 25 treatment decisions to continue its use. They</p>	<p style="text-align: right;">102</p> <p>1 want the people responsible to be held to 2 account and to explain whether their decisions 3 were made in good faith on the basis of what was 4 known, or whether there were other drivers such 5 as finance. 6 Some were concerned about a cover up, and 7 wanted to know if this had happened, and who was 8 responsible. 9 They wanted the public to know more about 10 their experience to replace myths with facts, 11 and thereby to reduce the stigma associated with 12 infections. They want the public to know that 13 they were infected through no fault of their 14 own, and that was certainly a theme throughout. 15 Many people said that they would like the 16 financial support arrangements to be reviewed, 17 to make it less of a battle for people to get 18 help. They would like certainty that their 19 current support would not be withdrawn. 20 Many suggested that the attempts of 21 government organisations to reach people 22 possibly infected with hepatitis C had been 23 ineffective, and I think we were probably most 24 surprised by that, that there was no reach-out 25 programme for those people who had had blood</p>
<p style="text-align: right;">103</p> <p>1 transfusions or received blood during those 2 critical years. 3 They spoke about people carrying infections 4 they do not yet know about and how the lack of 5 recall scheme following transfusions left them 6 with a ticking time bomb for years and an 7 irreversible progression in their disease. They 8 would like to see a scheme in which everyone who 9 received blood products or blood transfusions 10 from the 1970s until screening was fully 11 effective would be offered a blood test. 12 We certainly know from our work with this 13 group that the Inquiry has given them confidence 14 to speak out, and interestingly, those people 15 who were very, very keen to remain anonymous at 16 the beginning of this process, by the end, and 17 they've had contact with us, say, "I feel able 18 to now to speak out," and they feel able to now 19 to be identified. 20 I'm not suggesting that we identify those 21 people today, but you can see, those of you that 22 looked at our report, some people have 23 identified their loved ones who have died, 24 because they feel able, now, to be identified as 25 people who have had hepatitis B, C, or HIV, as</p>	<p style="text-align: right;">104</p> <p>1 a cause of death of their loved ones. 2 So this process, Kay already touched upon 3 it, has given them the strength and self-esteem 4 and the confidence, some of that confidence, 5 back to be able to talk about this more openly, 6 and are very grateful for the Inquiry having 7 heard their voice. 8 MS SCOTT: Is there anything else that either of you 9 two want to add before we finish? 10 JACKIE: We just want to say we are so grateful to 11 the people who allowed us into their lives, 12 really, and to pay testimony to them. This has 13 been a tremendous experience for us 14 professionally and personally, and we take our 15 hats off to you folks. 16 KAY: Yeah, I agree. 17 JACKIE: We do. 18 SIR BRIAN LANGSTAFF: Ms Scott, do you wish to check 19 with those behind you whether anyone has any 20 further questions? 21 MS SCOTT: Yes. 22 I think that's a no, sir. 23 SIR BRIAN LANGSTAFF: Well, I have one. It's been 24 said to me in a number of statements that the 25 author has lost trust in the doctors and</p>

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1 clinicians who have treated him and, therefore,
 2 finds it difficult to accept or take medical
 3 treatment now. I think one person has described
 4 it as the single greatest loss arising out of
 5 the infected blood events.
 6 What, if any, reflection did you have of
 7 that idea from those that you were speaking to?
 8 **KAY:** I think, Sir Brian, it's around building
 9 that trust and confidence for people to be able
 10 to step into now, in particular the gentleman
 11 who has still not had treatment, step into an
 12 environment where some trust can be built to
 13 work towards eventually going and having some
 14 treatment.
 15 I found it absolutely heartbreaking that
 16 there's a treatment that somebody can have but
 17 because of their experience, they won't have it.
 18 And that was further made worse by last year's
 19 experience for the same individual. So I think
 20 it's about building trust and confidence and the
 21 psychological services is an opportunity to
 22 engage, but to really engage with individuals to
 23 say what's the way that you would want to access
 24 some services? Because for some people it would
 25 be group. For some people it would be

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1 particular for three things. The first and
 2 perhaps most important is for giving people
 3 a voice who would not otherwise have had one,
 4 and by goodness you've given them not only
 5 a voice but a powerful one. Thank you.
 6 Secondly, for the empathy which you have,
 7 each of you in your own way, shown. Perhaps
 8 I may be forgiven for thinking that on occasions
 9 there was just a quaver in your voice and that
 10 comes despite having listened and prepared and
 11 rehearsed, but you're thinking obviously about
 12 the people that you have spoken to, and that is
 13 a tribute to you as well as to them.
 14 Thirdly, thank you for putting it in
 15 a structure which has condensed in many ways the
 16 evidence which I can tell you in many ways
 17 summarises, echoes, I think, everyone would
 18 probably agree, I shall be told in due course if
 19 they don't, the evidence that we have listened
 20 to over several weeks from individuals who have
 21 spoken here and given us their own voices.
 22 So it's presenting very much the same
 23 picture with all its nuances arising out of the
 24 various different events that lots of different
 25 people in their own ways have been through.

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1 individual one-to-one, but it is about reaching
 2 out rather than just people getting access to
 3 the psychological services because they filled
 4 out the form and ticked the box that's in there.
 5 I think it's that two-way process of reaching
 6 out to those that we know about.
 7 **JACKIE:** I saw a family whose son had had leukaemia
 8 in his early childhood when he was six, five or
 9 six. And had a blood transfusion as a result of
 10 that which resulted in hepatitis C infection and
 11 then obviously all of the treatment thereafter,
 12 and he wasn't even able to see me. He had such
 13 a mistrust of anybody that he saw associated
 14 with authority or anything formal. And I had to
 15 see his parents, who very eloquently described
 16 his situation, but they said that his lack of
 17 trust extended into much broader avenues of his
 18 life, into relationships, personal
 19 relationships, as well as the more formal
 20 relationships with professionals.
 21 **PAM:** Nothing to add from me.
 22 **SIR BRIAN LANGSTAFF:** Can I thank you collectively,
 23 Kay, Jackie, Pam, for what you have done for us,
 24 as I've said before lunch. It's been very, very
 25 valuable indeed. But I wanted to thank you in

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1 Thank you very much indeed.
 2 **KAY:** Thank you.
 3 **JACKIE:** Thank you.
 4 **PAM:** Thank you.
 5 **SIR BRIAN LANGSTAFF:** We'll take a slightly earlier
 6 break for half an hour or so. Shall we say
 7 3.20. Can I say to anyone who might be thinking
 8 that they are under pressure to get away this
 9 evening that we shall finish this evening no
 10 later than 4.30 and it may be that we finish at
 11 a convenient moment before then. But I shall
 12 see you for the psychosocial experts to start at
 13 3.20.
 14 **(2.47 pm)**
 15 **(A short break)**
 16 **(3.26 pm)**
 17 **SIR BRIAN LANGSTAFF:** As I said earlier this
 18 morning, it is enormously gratifying for me to
 19 be able to put before you a panel of experts of
 20 those who are at the very top of their field.
 21 And you'll see from the evidence which we call
 22 first of the expert panels who will give
 23 evidence this week, why it is that the
 24 psychosocial group follows on so naturally from
 25 the evidence we have just finished.

<p style="text-align: right;">109</p> <p>1 No need for me to introduce them</p> <p>2 individually because their names are in front of</p> <p>3 them where they will sit. Could they please</p> <p>4 come forward and be sworn.</p> <p>5 PROFESSOR MYFANWY MORGAN (affirmed)</p> <p>6 DR NICKY THOMAS (affirmed)</p> <p>7 DAME LESLEY FALLOWFIELD (affirmed)</p> <p>8 MS SIAN EDWARDS (affirmed)</p> <p>9 PROFESSOR JOHN WEINMAN (affirmed)</p> <p>10 Examined by MS RICHARDS</p> <p>11 MS RICHARDS: Can I ask each of you to just briefly</p> <p>12 introduce yourselves and explain what your</p> <p>13 qualifications and areas of expertise are,</p> <p>14 starting at the far end with Professor Weinman</p> <p>15 and then moving through the table.</p> <p>16 PROFESSOR WEINMAN: Okay, I'm a professor of</p> <p>17 psychology as applied to medicine, so I'm</p> <p>18 someone trained in psychology, originally in</p> <p>19 clinical psychology, but more recently in health</p> <p>20 psychology, and so my areas of expertise are</p> <p>21 very much about understanding the psychological</p> <p>22 impact of illness and healthcare and treatment</p> <p>23 on the individual and how people cope with and</p> <p>24 adjust to illness, and how that impacts on</p> <p>25 recovery or outcome.</p>	<p style="text-align: right;">110</p> <p>1 MS EDWARDS: As you know my name is Sian Edwards.</p> <p>2 I am here -- I've been a nurse in -- as an HIV</p> <p>3 specialist nurse since 1986, in various</p> <p>4 countries in the world, and much of that nursing</p> <p>5 has also been education of healthcare workers,</p> <p>6 and nurses specifically. I worked for 5 years</p> <p>7 as an -- no, as a community haemophilia nurse at</p> <p>8 St Thomas', and I followed that up with two</p> <p>9 research projects looking at life histories of</p> <p>10 people who had HIV and haemophilia, and also the</p> <p>11 partners, the siblings, the children, and</p> <p>12 parents of those who had died from HIV, who had</p> <p>13 had haemophilia. I'm now a research nurse in</p> <p>14 Australia in HIV.</p> <p>15 DAME LESLEY: Hello, I'm a professor of psychosocial</p> <p>16 oncology, which means psychology as applied to</p> <p>17 cancer, and I am the director of a health</p> <p>18 outcomes research group at Brighton and Sussex</p> <p>19 Medical School. This group looks at the quality</p> <p>20 of life issues for patients undergoing different</p> <p>21 cancer treatments. We also develop psychosocial</p> <p>22 support services for patients and their</p> <p>23 families, coping with life threatening illness,</p> <p>24 and importantly and relevant to this Inquiry, we</p> <p>25 do a lot of work developing communication skills</p>
<p style="text-align: right;">111</p> <p>1 training programmes for healthcare</p> <p>2 professionals, and as a part of that, sometime</p> <p>3 ago I worked very closely with National Patient</p> <p>4 Safety Agency on designing a programme to run</p> <p>5 for healthcare professionals on how they should</p> <p>6 communicate with patients when there was medical</p> <p>7 error.</p> <p>8 DR THOMAS: My name is Nicky Thomas, and I'm</p> <p>9 a consultant health psychologist at Guy's and St</p> <p>10 Thomas'. I recently retired as head of</p> <p>11 psychology there. My expertise really, as it</p> <p>12 applies to this hearing, is around supporting</p> <p>13 people to cope and adjust to physical health</p> <p>14 problems. I was instrumental in starting</p> <p>15 a specialist psychology service for people with</p> <p>16 sickle cell disorders and that service was then</p> <p>17 extended to people with haemophilia, so I bring</p> <p>18 that perspective to this inquiry today.</p> <p>19 PROFESSOR MORGAN: I'm Myfanwy Morgan, I trained as</p> <p>20 a medical sociologist in London and United</p> <p>21 States, and then held a variety of clinical</p> <p>22 posts, academic posts. My research has mainly</p> <p>23 been with different clinical specialties</p> <p>24 focusing on the management of chronic</p> <p>25 conditions, and my particular contribution has</p>	<p style="text-align: right;">112</p> <p>1 been in terms of eliciting the patients' and</p> <p>2 families' perspectives and experiences to inform</p> <p>3 the development of interventions and to assess</p> <p>4 the outcomes of interventions for patients, and</p> <p>5 I've also been involved in developing methods of</p> <p>6 research in order to better further this</p> <p>7 process.</p> <p>8 MS RICHARDS: Thank you.</p> <p>9 Some of you I know attended hearings last</p> <p>10 year where you heard firsthand some of the</p> <p>11 evidence of those who were infected or affected.</p> <p>12 You've also, between you, watched video</p> <p>13 transmissions on YouTube of the evidence of</p> <p>14 a number of witnesses, and you were supplied by</p> <p>15 the Inquiry with 47 witness statements and</p> <p>16 41 transcripts covering a range of issues to</p> <p>17 help inform your report; is that right?</p> <p>18 PROFESSOR WEINMAN: Correct.</p> <p>19 MS EDWARDS: Yes.</p> <p>20 DAME LESLEY: Yes, that's correct.</p> <p>21 DR THOMAS: Yes, that's correct.</p> <p>22 PROFESSOR MORGAN: Yes.</p> <p>23 MS RICHARDS: Can I ask you how you went about</p> <p>24 preparing the report, perhaps Professor Weinman.</p> <p>25 PROFESSOR WEINMAN: Yes, I took on the role, I'm not</p>

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1 quite sure how, as convener. And what we did
 2 was to first of all have a telephone conference
 3 where we all looked at the -- we were asked
 4 a whole series of questions, where we looked at
 5 the questions and thought about the expertise we
 6 had, and a sort of mixture of joint decision
 7 making and a bit of cajoling from me led us to
 8 end up with taking charge of different areas of
 9 the report, which we've sort of indicated.
 10 **MS RICHARDS:** But ultimately it is a collective
 11 report?
 12 **PROFESSOR WEINMAN:** Very much so, yeah.
 13 **MS RICHARDS:** You've all looked at all of it?
 14 **PROFESSOR WEINMAN:** Yeah.
 15 **MS RICHARDS:** And as I understand it there are no
 16 areas of disagreement professionally between
 17 you?
 18 **PROFESSOR WEINMAN:** No.
 19 **MS RICHARDS:** You're also going to be producing
 20 a supplemental report responding to what's
 21 described as part 2 of the questions in
 22 a supplemental letter of instruction dated
 23 23rd December.
 24 **PROFESSOR WEINMAN:** Correct, yes.
 25 **MS RICHARDS:** Now there are essentially five areas

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1 or, indeed, any threat to our health is a sort
 2 of threat to one's sense of self and who you
 3 are, and your place in the world. And anybody
 4 who, you know, either has sudden onset or slow
 5 onset or whatever of a condition, tries to make
 6 sense of it. In the first place they need to
 7 try to understand what's going on.
 8 So what we know is that people have their
 9 own ways of perceiving or making sense of their
 10 condition in terms of what they think is
 11 happening, what they think has caused it, how
 12 much they think they can do something about it,
 13 or other people can do something about it, how
 14 long it's going to last and so on and so on, its
 15 likely impacts. So everyone will have their own
 16 what we call representational way of
 17 understanding their condition.
 18 That's fundamental in a way but that really
 19 happens in parallel with a whole set of
 20 emotional changes that people have, because
 21 a threat to one's health is a threat to one's
 22 sense of self and who you are.
 23 So everybody who becomes ill or -- shows
 24 some sort of emotional reaction, whether it's
 25 mild anxiety, through to, you know, full-blown

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1 I'm going to ask you about based upon the themes
 2 and issues explored in your report: psychosocial
 3 impact, social impact, stigma and
 4 discrimination, loss of trust and communication,
 5 and care and support. And we'll broadly follow
 6 that order.
 7 And so I wanted to start, perhaps by asking
 8 Professor Weinman but, please, anyone else who
 9 feels able to, please chip in at any stage with
 10 any of the questions, to ask you about what
 11 you've set out in section 13.1 of your report
 12 under the heading "Psychological impacts of
 13 infection on people infected and affected".
 14 You've said, Professor Weinman, in that
 15 section, that:
 16 "All long-term illnesses have psychological
 17 impacts on those with the illness, and any one
 18 illness will have effects on an individual's
 19 emotional state and their self-identity, as well
 20 as giving rise to adjustment to the pain,
 21 incapacity and demands of long-term treatment
 22 and lifestyle change."
 23 I wondered if you could elaborate on that
 24 for us please.
 25 **PROFESSOR WEINMAN:** Well, for any of us, an illness

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1 depression, really serious psychological impact.
 2 But all of that really will be very much
 3 governed by how much the illness impacts on
 4 one's sense of self and one's self-identity.
 5 It's absolutely crucial. For some people they
 6 are able to somehow negotiate that and work
 7 around the illness and accommodate the illness.
 8 For others, it's much more of an invasive
 9 process, and the self can be almost completely
 10 obliterated in some cases because the impact of
 11 illness is so huge and pervasive in terms of
 12 themselves and their family.
 13 Those are really fundamental things that
 14 happen, that set of emotional changes, that set
 15 of what I will call cognitive or thinking
 16 changes, the way you think about yourself and
 17 your health, and both drive very different sorts
 18 of coping. You know, coping with the emotions,
 19 in an attempt to try to keep things together, to
 20 keep oneself going as an individual, but also to
 21 try to deal with whatever it is you're
 22 confronted with, and that making sense of the
 23 process leads very directly to a whole range of
 24 different ways of coping. You know, ways of
 25 either, you know, learning more, taking

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1 treatment, you know, reaching out to people for
 2 support and so on. There are a whole -- very
 3 complex number of processes, and that happens to
 4 everybody, regardless, and I think obviously in
 5 the case of people who already had an illness
 6 and then were then infected further with, you
 7 know, a blood product, then the process becomes
 8 even more complicated.

9 Now you're dealing not just with one,
 10 sometimes two and sometimes three conditions,
 11 with a whole range of treatments. And the
 12 having to adjust to things like pain, incapacity
 13 and treatments which sometimes can be truly
 14 horrible, as we've heard many times in these
 15 hearings, takes a huge toll on the individual
 16 and those around them. So I think that's -- you
 17 know, what you've really summarised from that,
 18 you know, the review on how people cope with
 19 illness, involves all those processes which are
 20 complex, they're not fixed in time, they change
 21 over time, as new events emerge, as people
 22 perhaps who you were relying on become less
 23 reliable and other people become important in
 24 your life. So the whole social impact as well
 25 was very much part of that process.

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1 like a broken arm or whatever, that often
 2 I think we know that people are having to cope
 3 with pain very much on their own, with other
 4 people perhaps not realising the extent of what
 5 they're having to cope with. We know that
 6 people cope with pain in many, many different
 7 ways. There are questionnaires and assessments
 8 which look very specifically at pain coping and
 9 particularly how pain in itself activates a lot
 10 of those processes I was talking about earlier,
 11 the different sorts of thoughts and fears and
 12 worries, about oneself and one's future. And
 13 pain can generate a huge amount of fear. You
 14 know, fear of the future, fear of what you can
 15 and can't do, and so on.

16 So pain itself, although one can think of it
 17 in quite biomedical terms, as an experience it's
 18 a very individual and very demanding process,
 19 which takes -- people cope with in many, many
 20 different ways. And I know that when -- later
 21 on we hear about support for patients, you know,
 22 it's very much -- something I think Nicky will
 23 talk about.

24 **MS RICHARDS:** One of the other factors you touched
 25 on, both in your report and in your answer, is

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1 **MS RICHARDS:** And that which you've described, that
 2 all long-term illnesses have psychological
 3 impacts in the way that you've touched on, that
 4 is not as I understand it any kind of a new
 5 idea; that's something that's been known and
 6 understood for many years.

7 **PROFESSOR WEINMAN:** Yeah, very much so. I think
 8 what's new is that we understand more about some
 9 of those ways that people think and ways that
 10 people cope. And particularly ways that they
 11 can be supported through an understanding of
 12 those very individual processes. Yeah.

13 **MS RICHARDS:** Can I ask you a little more about what
 14 it is about having long-term illnesses that can
 15 have the consequences you describe. You've
 16 touched on some of them already.

17 First of all, pain. The psychological
 18 impact of coping with pain. What can you tell
 19 us about that?

20 **PROFESSOR WEINMAN:** There is a huge amount that's
 21 known about, you know, the impact of pain on
 22 individuals. We know that -- because, in a way,
 23 pain is a very hidden thing, you know, that
 24 people who are experiencing it experience it
 25 hugely -- but pain is not out there, it's not

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1 incapacity. So the individual who is often
 2 suddenly, but sometimes gradually, no longer
 3 able to do that which they could previously do.
 4 How does that bear upon the psychological
 5 experience of the individual?

6 **PROFESSOR WEINMAN:** It's absolutely central, in the
 7 sense that -- I mean, disability sort of works
 8 at two levels, in a way: what the individual can
 9 and can't do, and then how that can impact on,
 10 again, their identity or as a competent person
 11 or as someone who can do things, work, be
 12 a parent, whatever it is, all those roles,
 13 disability impacts all those roles. But it's
 14 also very much something -- and again we'll hear
 15 about this more I think particularly from
 16 Myfanwy -- something which occurs in a social
 17 setting. People are often defined by their
 18 disability because of things they can't do, out
 19 there in the real world, and the limitations
 20 that are placed upon them.

21 So again, it's, you know, extremely
 22 pervasive. It's something which has a very
 23 strong impact, both on people's moods, their
 24 emotions, so it's not surprising that people
 25 with disabling conditions are often very

<p style="text-align: right;">121</p> <p>1 psychologically affected by those.</p> <p>2 But also, you know, it's very much affected</p> <p>3 by the attitudes of other people and the support</p> <p>4 they get from other people.</p> <p>5 I don't know whether, Sian, you wanted to</p> <p>6 sort of add to that, really?</p> <p>7 MS EDWARDS: Well, I think whenever we talk about</p> <p>8 things like this, that we talk about individuals</p> <p>9 and different people react in different ways to</p> <p>10 these issues, but the support they get, as we've</p> <p>11 heard, from health services, from family, from</p> <p>12 friends, from social groups like churches, are</p> <p>13 all fundamental on how they're going to be able</p> <p>14 to cope, and where those groups or those</p> <p>15 services are not there for them, then you get</p> <p>16 this idea of separation and isolation and trying</p> <p>17 to cope with this pain, this incapacity alone.</p> <p>18 And we know that dealing with things alone has</p> <p>19 very major psychological impacts on people, on</p> <p>20 a long-term basis. And of course, when many of</p> <p>21 the things that we have been hearing and talking</p> <p>22 about, many of these people were children,</p> <p>23 adolescents and young people, as well as adults.</p> <p>24 DR THOMAS: If I can add to that, in terms of my</p> <p>25 work as a clinician, I think a really important</p>	<p style="text-align: right;">122</p> <p>1 area which John has identified as around the</p> <p>2 notion of being a competent person. So you may</p> <p>3 have this chronic illness but you are still</p> <p>4 a mother, a father. You're also maybe holding</p> <p>5 down a job and you are still expected to hold it</p> <p>6 down. So you're managing multiple roles. And</p> <p>7 how do you move from those roles in a seamless</p> <p>8 fashion and then manage a chronic illness as</p> <p>9 well? Something which is very disabling, like</p> <p>10 pain and distress. So I think that's a really,</p> <p>11 really big thing, of helping people to move</p> <p>12 through, and if the support isn't there, then it</p> <p>13 becomes really overwhelming, and difficult.</p> <p>14 MS RICHARDS: And how does incapacity potentially</p> <p>15 bear on the concept that you touched on, the</p> <p>16 concept of self-identity?</p> <p>17 PROFESSOR WEINMAN: Massively, massively. Because</p> <p>18 self-identity is quite a complex things, but</p> <p>19 essentially what it boils down to is how you</p> <p>20 think about yourself, your sense of self-worth,</p> <p>21 and as Nicky just said, that can be based around</p> <p>22 different -- you know, we all have different</p> <p>23 selves, you know, parents, workers, brothers,</p> <p>24 sisters, whatever, and incapacity can erode any</p> <p>25 of those bits of oneself in all sorts of very</p>
<p style="text-align: right;">123</p> <p>1 striking ways, and I think we heard very much</p> <p>2 from -- well, both our intermediaries today and</p> <p>3 also from what we read in terms of people just</p> <p>4 feeling they were no longer, you know, that</p> <p>5 person, that parent, you know, that worker. So</p> <p>6 that erosion can take place.</p> <p>7 That change in one's sense of who you are</p> <p>8 has huge effects on self-esteem. I mean</p> <p>9 massive. Because we derive our self-esteem from</p> <p>10 those roles, from our sense of who we are.</p> <p>11 MS RICHARDS: What role in the processes have you</p> <p>12 described as fear and uncertainty about the</p> <p>13 future have?</p> <p>14 PROFESSOR WEINMAN: Again, this something that runs</p> <p>15 through our report, whether we're looking at</p> <p>16 communication or whether we're looking at the</p> <p>17 psychological impact, but just in the context of</p> <p>18 psychological impact, I think as I was saying</p> <p>19 right at the beginning, as people try to make</p> <p>20 sense of what is happening to them, and have</p> <p>21 their own version of what's happening to them in</p> <p>22 their heads because they need to have that</p> <p>23 because that's how they are going to -- that's</p> <p>24 where their behaviour comes from that determines</p> <p>25 what they're going to do.</p>	<p style="text-align: right;">124</p> <p>1 One of the sort of crucial components of</p> <p>2 that is something we call timeline, so your</p> <p>3 sense of how long is this going to last. If you</p> <p>4 have an uncertain condition, one that flares,</p> <p>5 one that maybe responds to treatment but where</p> <p>6 maybe treatment makes things worse, that whole</p> <p>7 sense of the future just remains completely</p> <p>8 problematic. You know, what's going to be</p> <p>9 happening in six months? What's going to be</p> <p>10 happening? A year? Can I still do this? Can</p> <p>11 I keep up with school work? Can I keep up with</p> <p>12 my ... all of those things then become</p> <p>13 challenged, none of those sort of certainties</p> <p>14 that were there.</p> <p>15 So, you know, the fear about, and the</p> <p>16 uncertainty about the future arises I think from</p> <p>17 that very fundamental set of changes that happen</p> <p>18 to the individual, and their sense of who they</p> <p>19 are.</p> <p>20 MS RICHARDS: Many of those that the Inquiry has</p> <p>21 heard from are individuals who were told or</p> <p>22 whose family members were told that they had</p> <p>23 a condition that was life threatening,</p> <p>24 particularly if we go back to the '80s and being</p> <p>25 told that they had been infected with HIV, being</p>

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1 told that there was no treatment available,
 2 being told that they were likely to die within
 3 a very short period of time. How does that
 4 impact both upon the sense of self-identity and
 5 the broader psychological condition of the
 6 individual?
 7 **PROFESSOR WEINMAN:** I mean one of the reasons why
 8 people develop that way, their own way of
 9 thinking about an illness is to develop some
 10 sense of mastery and control, to get that back,
 11 because that what goes, you know, when you
 12 receive that sort of information.
 13 And obviously being given that sort of, you
 14 know, very clear, you know, that you haven't got
 15 long to live or, you know, you have
 16 a life-threatening illness, absolutely really
 17 impacts on that control, which is very
 18 important. Control is really important in all
 19 our lives, control is important whatever we're
 20 doing. But in the context of illness that
 21 really eats into that process hugely.
 22 I think the other rather crucial bit of that
 23 is the life stage of the individual, and we
 24 don't -- we've two colleagues missing from our
 25 group today who will be here tomorrow. One of

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1 year or, you know, sort of for the summer, but
 2 if you have a physical disabling illness, that
 3 you can put the plans in place, but the rug is
 4 going to be moved from under your feet when the
 5 holiday arrives and so on. Time and time again
 6 that's been experienced and it's come through in
 7 some of what we've heard in hearings and also in
 8 the transcripts that people's inability to plan
 9 just takes away the sense of, you know, living
 10 life, really. You can't plan for tomorrow. You
 11 can't plan for next year. It's just very, very
 12 difficult for people, I think.
 13 **MS EDWARDS:** One of the things that does come across
 14 quite clearly is that lots of people were given
 15 that information when they were not actually
 16 ill, and I think that was key, because the
 17 diagnosis of being told "You're HIV positive",
 18 many people were given the misinformation "You
 19 have got" -- for some people were told -- "six
 20 months to live" when actually at that moment
 21 they were healthy individuals dealing with maybe
 22 their haemophilia, but were given, yeah,
 23 18 months to live, six months to live. And that
 24 is extraordinarily shocking to try to negotiate,
 25 and to navigate around that sort of information.

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1 those is Professor Deborah Christie who works
 2 with children and adolescents at Great Ormond
 3 Street and I think in the report some of the
 4 parts she's written about are very much either
 5 about, you know, parents having to protect
 6 children from that dreadful, you know,
 7 prognostic information, or when the children or
 8 adolescents had that, and I certainly heard this
 9 in one of the hearings I attended, when you have
 10 that in your heads, that the sense of well,
 11 giving up, not making an effort, that just, you
 12 know, the lack of motivation to do anything
 13 becomes huge. Because you end up, you're very
 14 likely to end up thinking, "Well, whatever I do,
 15 I have no control. This is going to happen.
 16 This is inevitable", so that sort of fatalistic
 17 view, if you like, again is very undermining in
 18 terms of one's motivation, one's sense of
 19 future, one's sense of self.
 20 So again, very big effects.
 21 **MS RICHARDS:** Dr Thomas, I see you nodding.
 22 **DR THOMAS:** I was just agreeing with John, really,
 23 just the control is so important, but the
 24 ability to plan one's life. We all take it for
 25 granted, you know, we plan our holiday for next

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1 And actually as time goes on, that six months
 2 comes and that year comes, and having to live
 3 through that channel of uncertainty is
 4 a constant for many people, particularly in the
 5 early days when there was no treatment.
 6 **MS RICHARDS:** You've noted in the report that the
 7 cumulative effect of multiple medical problems
 8 and conditions has been less well studied and is
 9 less well understood.
 10 **PROFESSOR WEINMAN:** Mm.
 11 **MS RICHARDS:** But that research has shown a close
 12 response relationship between the number of
 13 health problems a person experiences and the
 14 likelihood of depressive symptoms and impaired
 15 quality of life. Can I just invite you to
 16 expand on that?
 17 **PROFESSOR WEINMAN:** Sure. It's quite curious, you
 18 know, particularly now, as people get older and
 19 develop many, you know, conditions, not just
 20 one, that a lot of the research in my field has
 21 just focused on, you know, people with diabetes,
 22 people with rheumatoid arthritis, haemophilia,
 23 whatever, and that lack of research on people
 24 with multiple problems is quite staggering and
 25 it's -- I think I alluded to a big review from

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1 last year that really pointed out. And it also
 2 partly reflects the way hospitals work, people
 3 are treated in one department, in another
 4 department as if they're somehow split up, and
 5 it's the same person.
 6 Where people have looked at people with
 7 multiple conditions, certainly the probability
 8 and the severity of psychological impact is
 9 greater, not surprisingly, as people go -- have,
 10 say one or two or three conditions. So there
 11 is -- but it's not a linear effect. It's not
 12 a stepwise effect. And in fact -- and you might
 13 go on to ask me this now -- what we do know is
 14 that the actual severity of someone's condition
 15 doesn't necessarily predict their psychological
 16 response. There are a whole lot of intervening
 17 factors, many of which I spoke about at the
 18 beginning. You know, the way people make sense
 19 of it, the support they have, how they cope and
 20 so on.
 21 So broadly, you know, if we look across at
 22 a sort of population level, certainly we know
 23 people with more and more conditions are more
 24 and more psychologically affected. We know
 25 that. But the relationship is quite complex.

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1 dealing with the, you know, consequences of
 2 haemophilia. And I think the disconnect between
 3 all the different sources of information the
 4 patients and families get can lead to further
 5 anxiety. How can I plan, what can I do, when
 6 I'm getting all this different information from
 7 different sources?
 8 And I think that's got a major role in, as
 9 I say, exacerbating the uncertainty and anxiety
 10 that some individuals feel.
 11 **MS RICHARDS:** You've said also in the report that
 12 the timing and pattern of psychological impact
 13 may be different but no less profound for those
 14 who are being treated for an ongoing condition.
 15 Again, can I ask you to just perhaps elaborate
 16 upon that a little?
 17 **PROFESSOR WEINMAN:** Yeah, I think it's just this
 18 difference between those people who, let's say,
 19 are having to cope with haemophilia, which
 20 already would be having some pretty profound
 21 impacts on their life, and then the next problem
 22 arises. So they're already in that situation
 23 with an accumulation of problems, and so they're
 24 now having to cope with more, deal with more,
 25 often deal with harsher treatment. But what one

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1 **MS RICHARDS:** And you've identified in your report,
 2 as you say, in particular, four factors that
 3 might bear upon the nature or extent of adverse
 4 psychological impact: one was severity in terms
 5 of clinical conditions and symptoms; patients'
 6 perception of their condition; patients' coping
 7 responses; and the quality of their support.
 8 **PROFESSOR WEINMAN:** Yeah, exactly.
 9 **MS RICHARDS:** We'll come on to talk about support in
 10 particular later.
 11 **DAME LESLEY:** May I just add something to that, to
 12 pick up on what John has just been talking
 13 about, people being treated in silos depending
 14 on one condition rather than the multiple
 15 co-morbidities that they might have, it leads to
 16 another problem for them, which is that they
 17 will bump into a whole plethora of different
 18 healthcare professionals who will give them all
 19 sorts of different and sometimes competing
 20 information, and one of the anxieties that many
 21 people find is exacerbated by this is the fact
 22 that they no longer have any continuity of care
 23 or information. And therefore, an expert in,
 24 you know, HIV, AIDS, might give totally
 25 different information to the haematologist

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1 is looking at there, if we go back to our sense
 2 of one's self and the identity, people whose
 3 self-system has already been quite severely
 4 challenged by having an illness, having to
 5 accommodate to an illness, and then another one
 6 comes along which -- it's no less devastating,
 7 but for someone who is just, you know, living
 8 a life without illness and all of a sudden needs
 9 a blood product, you know, through accident or
 10 childbirth or whatever the situation is, that
 11 very sudden onset can be extremely harsh, and
 12 that first period of adjustment can be -- you
 13 know, people are sort of caught in the
 14 headlights very much by that, and it can take
 15 time to really get one's head around that.
 16 So I'm not saying that the impact is any
 17 greater or less, but it's a different sort of
 18 impact, a different sort of transition of, you
 19 know, thinking about who you are and what the
 20 future looks like now.
 21 **MS RICHARDS:** The psychological impact described by
 22 individuals to the Inquiry, both orally and in
 23 writing, include witnesses who have been
 24 diagnosed with recognised psychiatric disorders,
 25 including post-traumatic stress disorder, OCD,

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1 bipolar affective disorder, anxiety and
 2 depression, in particular anxiety and
 3 depression.
 4 I'm not going to ask you to comment
 5 obviously on the circumstances of any individual
 6 or the causal link between infection and
 7 psychiatric disorder in any individual, but is
 8 this fair: that it's entirely plausible to think
 9 that infection with HIV, infection with
 10 hepatitis C and the kind of circumstances that
 11 we've seen described in the statements might
 12 lead to the development of a psychiatric
 13 disorder of that kind?
 14 **PROFESSOR WEINMAN:** Yeah, I mean we know that for
 15 any major long-term health problem, a proportion
 16 of people will develop, you know, major mood
 17 change. Typically anxiety in the early stages
 18 but often leading to depression. So, you know,
 19 a group of patients I know well, patients with
 20 rheumatoid arthritis, something like 20, 25% of
 21 those patients we know will develop those major
 22 mood problems, because of the changes that are
 23 brought about by the condition.
 24 But I think what we're dealing with here is
 25 not just the psychological reaction to the

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1 with a very distrustful healthcare system, where
 2 you go and, as we've heard, going to many
 3 different departments for treating of various
 4 problems and that in itself is very, very
 5 traumatic. So you can see how, again, it adds
 6 to the complexity and makes the depression move
 7 into another area.
 8 **MS RICHARDS:** Other psychological or emotional
 9 impacts described by infected individuals to the
 10 inquiry, again in written and oral evidence,
 11 include mood swings, panic attacks, fear, anger,
 12 paranoia, loss of confidence, tearfulness,
 13 insomnia, nightmares, loss of libido, anhedonia,
 14 hopelessness, despair, shock.
 15 Those are all, again the kind of responses
 16 that you would understand and expect, given the
 17 range of different factors and circumstances
 18 you've identified.
 19 **PROFESSOR WEINMAN:** Very much so and I think, you
 20 know, we know quite a lot about the
 21 psychological responses of people with, for
 22 example, we know quite a lot about psychological
 23 responses of people with HIV and AIDS, that's
 24 a very big literature there, and that same range
 25 of factors would be present in that group as

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1 condition, and I think, you know, in that sense
 2 the whole of the report needs to be sort of
 3 perhaps thought of here. What you're dealing
 4 with are people who experience massive stigma,
 5 people who have -- where communication has been
 6 poor, where they've perhaps not felt supported
 7 or even felt rejected by the healthcare system.
 8 I think it's the whole plethora of changes that
 9 are really responsible for, you know, the
 10 likelihood that much greater likelihood of
 11 people developing, you know, serious
 12 psychological problems and reactions.
 13 **MS EDWARDS:** And then add treatment.
 14 **PROFESSOR WEINMAN:** And treatment, yes.
 15 **MS EDWARDS:** You add the treatment and specifically
 16 these treatments, particularly interferon and
 17 ribavirin, which are debilitatingly -- the
 18 depression is of an extreme type, so as John
 19 said you're dealing with stigma, you're dealing
 20 with loneliness, you're dealing with isolation.
 21 So the amount of factors that actually result in
 22 a depressive and sometimes serious psychotic
 23 illness is not surprising.
 24 **DR THOMAS:** Yeah, and just to add that the
 25 traumatising experience of multiple contacts

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1 well as in obviously the group of people we're
 2 talking about here.
 3 I don't know, I mean you're much more
 4 experienced with that group of patients's.
 5 **MS EDWARDS:** Yeah, HIV is a debilitating illness
 6 with some very difficult treatments to take.
 7 But added on is that stigma. You add on to that
 8 the haemophilia, you add on the hep C, you add
 9 on the hep C treatments, and I think as John
 10 alluded to earlier, sometimes it's not the
 11 severity of the illness that causes the problem,
 12 it's the perception of the illness and the
 13 self-perception. And many people that we read
 14 and in my own experience, it was the association
 15 with as we heard earlier on, I needed to say who
 16 I was and how I became infected, and we live in
 17 a world, and certainly we did live in a world
 18 that was more severely stigmatising than we do
 19 even today, with regard to homosexuality and
 20 also towards drug users, and when these are
 21 associated with these illnesses you're dealing
 22 with an awful lot of factors.
 23 **MS RICHARDS:** Can I ask about the psychological
 24 impacts of treatment and a number of different
 25 ways. So you've referred in your report, and

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1 we've heard from multiple witnesses, of the very
 2 severe physical and mental effects of in
 3 particular the early treatments -- and when
 4 I say "early", this was over a number of
 5 years -- for HIV and for hepatitis. So in
 6 addition to coping with a life-threatening,
 7 serious illness, individuals then had to endure
 8 treatment which in many cases brought symptoms
 9 worse than the illness itself.

10 How may that affect the individual's
 11 psychological experience and condition?

12 **PROFESSOR WEINMAN:** One of the areas I work in I do
 13 a lot of work in now because I'm linked to --
 14 not only to a school of medicine, to the school
 15 of pharmacy, is looking at how people cope with
 16 and deal with treatments, and what we know is
 17 that amongst people with long-term -- any
 18 long-term major condition, around 40, 50% of
 19 people actually don't -- decide, make a decision
 20 not to follow that treatment long-term. That's
 21 what we call non-adherence. Because in many
 22 cases that treatment -- you know, they feel
 23 worse when they're on the treatment. So it's
 24 sort of a decision that people can and do make,
 25 quite commonly. And obviously, what we heard

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1 with, and I work across a range of conditions,
 2 are very critical of people who don't adhere to
 3 treatment, "Here we're offering them the
 4 possibility of getting better, and they're not."

5 And we know, you know, from huge reports,
 6 WHO and otherwise, that many make that choice
 7 because they don't -- in the end either don't
 8 believe in the treatment -- also issues about
 9 not trusting the provider of that treatment,
 10 which I know we'll get on to -- and -- so people
 11 are then left with, you know, sometimes a bit of
 12 a sense of guilt, "I'm not really doing what
 13 I should be doing", sometimes the people around
 14 them can be critical because they may not be
 15 thinking that the person is making sufficient
 16 effort with the treatment and so on.

17 So it's quite a complex set of issues,
 18 there, apart from the actual psychological
 19 impact, as you say, the pain, the side effects
 20 and other aspects of treatment, there are a
 21 whole load of issues about having to continue
 22 with something which doesn't seem to be doing
 23 you any good. In fact, making you actually feel
 24 worse.

25 **MS RICHARDS:** And you've identified various

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1 from many of our witnesses, particularly in the
 2 early days when some of those very harsh
 3 treatments that didn't really seem to actually
 4 even be working, and they were relentless and
 5 went on -- and where symptoms didn't clear and
 6 so on, and sort of, you know, people again weigh
 7 up in their own minds: is it really -- at the
 8 end day, is it really worth me going on with
 9 this?

10 So that's one set of issues. The treatments
 11 themselves cause a lot of symptoms that people
 12 then have to cope with in a whole range of ways.
 13 And there's this terrible conflict which can
 14 happen inside people's heads about, well,
 15 needing and wanting to take the treatment, with
 16 the possibility of getting better, but then
 17 actually all the evidence that comes back, the
 18 feedback, is that (a) either the condition --
 19 the hep C has not cleared, or that there's no
 20 difference in the viral load, or whatever the
 21 issue is -- and I think that set of conflicts
 22 that people are faced with is huge, and, you
 23 know -- and when we look at non-adherence to
 24 treatment, which is often criticised, you know,
 25 by -- a lot of my medical colleagues I work

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1 subcategories of that in your report. People
 2 completing the treatment, enduring it for
 3 prolonged periods of time, only for the
 4 treatment to be unsuccessful. And what's that
 5 experience, potentially, like for an individual
 6 psychologically and emotionally?

7 **PROFESSOR WEINMAN:** I mean, truly awful, because you
 8 have -- you've struggled with that terrible
 9 conflict and you've stuck with it and stuck
 10 with it in the belief -- and, you know, beliefs
 11 are huge in illness, beliefs in treatment,
 12 beliefs about the nature of the condition and so
 13 on -- in the belief that ultimately you're going
 14 to get the benefit. So you've struggled for
 15 a long period of time. So when it turns out
 16 that actually, nothing has changed or sometimes
 17 things have actually become worse, then that is
 18 a really devastating, having gone through that
 19 struggle.

20 And I mean, you know, even when -- I don't
 21 know, maybe you're going to come on to this, but
 22 even when people have been through a major
 23 treatment and actually, let's say, some symptoms
 24 have cleared or a condition has cleared -- and
 25 I think Lesley will know more about this from

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1 working in cancer -- that people can still be
 2 left with quite major doubts about whether this
 3 thing has really gone away. You know, because
 4 their experience is still there. They might be
 5 getting symptoms and so on. So -- and I think
 6 we referred to that as a fear of recurrence.
 7 People worrying that somehow -- you know, we're
 8 not experts on our own bodies, we don't know
 9 what's happening inside us, so this whole notion
 10 that there could still be something in there,
 11 that fear of recurrence, which is quite
 12 a crippling, quite a ruminative sort of process,
 13 can really stop people in their tracks as well.
 14 **DAME LESLEY:** It also makes people hyper vigilant
 15 about any symptoms as well. I think one of
 16 the -- there's two other difficult things here,
 17 I think, that we're -- we ought to touch on,
 18 which is that, certainly at the beginning of
 19 many of the treatments, the likely benefits were
 20 very uncertain. Medicine anyway is not the
 21 certain science we'd love it all to be. And
 22 those treated sort of in the early stages, when
 23 people were offering them some, they had very
 24 little evidence that it would be beneficial.
 25 And as John says, it's the same in cancer. Some

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1 of trust and poor communication and stigma and
 2 discrimination, but I just wanted to ask you
 3 about one observation you made in your report on
 4 page 2. You've talked in this context of the
 5 negative effects on academic behavioural and
 6 social adaptation, and I wondered if you could
 7 elaborate upon that, please.
 8 **PROFESSOR WEINMAN:** I think there's sort of two or
 9 three main elements to that, really. One is
 10 that -- and obviously this is we're looking at
 11 school-aged individuals -- and when you, you
 12 know, what we heard from, certainly from parents
 13 and from, you know, people who have been
 14 infected, that when you feel so bad, you know,
 15 you're fatigued, you've got pain, you've got
 16 symptoms and so on and you're feeling nauseous,
 17 (a) you don't want to be at school so we know
 18 there are a lot of school absences and, again,
 19 we see this in other conditions, when you're at
 20 school, you're not -- you can't really engage
 21 that well. Sadly, children pick that up. Those
 22 people often are not supported unless, you know,
 23 fellow children are well informed.
 24 I mean there are some good examples of where
 25 schools did make a huge effort and provided

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1 people, even if they do get some respite from
 2 the disease, isn't showing signs of progression,
 3 nevertheless can't enjoy that sort of freedom or
 4 the fact that some of the tests look quite
 5 positive, because they are so anxious about when
 6 it's going to actually re-emerge. And that
 7 becomes paralysing in terms of enjoying life and
 8 what is in front of you.
 9 **MS EDWARDS:** The other thing about particularly
 10 these treatments with interferon and ribavirin
 11 is that for many people, they didn't have
 12 symptoms, and so their illness could be -- it
 13 could remain anonymous. You didn't have to tell
 14 anybody. But once you start a treatment like
 15 that, you are so unwell, and often people
 16 weren't aware they were going to be that sick.
 17 And it changes everything: your work, your
 18 parenting, everything in your life, if you are
 19 that unwell with the fatigue and depression that
 20 comes. That means that you then have to
 21 disclose the reason for your ill health and so
 22 there's major complexities to some of these
 23 treatments and the psychological impact that
 24 they have, because you can't hide it any more.
 25 **MS RICHARDS:** We'll come back to the impact of loss

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1 support but they were very much in a minority,
 2 and, I think -- so then school becomes a really
 3 aversive experience for individuals. Not only
 4 is it hard going, you have patchy attendance so
 5 you fall behind. So there are a whole lot of
 6 social effects, if you like, of the, you know,
 7 the symptoms that get in the way of, you know,
 8 consistent schooling and so people are falling
 9 behind with all the negative reactions that
 10 follow.
 11 I think that's one aspect. But the other is
 12 that for some of those treatments, and
 13 certainly -- well, we know with HIV, HIV can
 14 have neuro-psychological effects. It can impact
 15 on brain function in a range of ways, but
 16 certainly a lot of those very harsh early
 17 treatments also had, you know, negative effects
 18 on cognitive functioning, the ability to
 19 concentrate, to remember, to problem solve. All
 20 those basic skills that one needs to assimilate
 21 school work from and so on.
 22 So I think, you know, at a functional level
 23 and at a social level, school becomes very
 24 challenging for a lot of individuals. I think
 25 those -- they're not separate because those

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1 things interact very much, but both have
 2 profound effects on people's ability to both
 3 engage and benefit, and process all the
 4 information that one needs, because, you know,
 5 whatever we think about schooling, it is very
 6 much a time when we have to process a lot of
 7 information and do stuff and keep up.
 8 I think that becomes very hard when all
 9 those other negative things are going on.
 10 **MS RICHARDS:** You've picked up in this section of
 11 your report on evidence that you read or saw
 12 about the effects of watching others die, and we
 13 know from the evidence that we've heard, that in
 14 the absence of formal support networks, people
 15 formed their own support networks through
 16 a range of different groups or organisations.
 17 People within the haemophilia community knew
 18 each other through attending centres or through
 19 attending Treloar School and you've picked up
 20 and quoted in your report the experiences of
 21 those going to multiple funerals. I wanted to
 22 ask you two aspects, about two aspects of the
 23 psychological implications of that.
 24 The first is survivors guilt. Could you
 25 explain that concept further for us.

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1 **MS EDWARDS:** Essentially you go to a support group
 2 for support, and friendship, and to share your
 3 experiences, but when that support group slowly
 4 diminishes because people are getting sicker and
 5 then dying, the impact can change. So you are
 6 no longer getting the support, you're actually
 7 witnessing what may well be happening to you
 8 very soon. So, yes, it can be very
 9 counter-productive, but without a doubt, support
 10 groups are there, and they're very powerful.
 11 And peer group support -- and I know throughout
 12 the haemophilia community that has been very,
 13 very strong, but it does have the side effects
 14 of having to watch your friends -- and of
 15 course, in this situation, your brothers, your
 16 uncles, your schoolmates, die. It's a very
 17 unusual and very, very difficult thing to go
 18 through, which is not usual with health.
 19 **MS RICHARDS:** You've touched there on a second
 20 element of experiencing multiple friends dying,
 21 attending multiple funerals. Witnesses have
 22 talked about how they wondered when it was going
 23 to be their turn. Their turn next. So
 24 presumably it increases that sense of fear and
 25 uncertainty and lack of control, loss of

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1 **PROFESSOR WEINMAN:** It's something that's, you know,
 2 widely reported in a lot of different areas, not
 3 only in illness but also in military situations
 4 and so on, that people -- and I think we heard
 5 it a little bit from our intermediary panel
 6 earlier -- that people who are in a dreadful
 7 situation but survive it, feel very -- often
 8 feel very bad about those, you know, who didn't
 9 make it. And there's that whole -- whereas
 10 often, you know, when something awful happens to
 11 us we go through the "Why me? Why has it
 12 happened to me", and that whole self blame. But
 13 here the self-blame is of a very curious sort.
 14 It's almost blaming yourself for surviving and
 15 feeling bad that you weren't part of the group
 16 that were left behind.
 17 I mean it's a very powerful set of emotions
 18 that can be very debilitating. But because it's
 19 sort of blame, a sense of blame towards oneself
 20 it's a very potent source of depression, and we
 21 know that when people experience that, that the
 22 likelihood of becoming depressed is very high.
 23 I don't know, Sian, if you -- because you
 24 must have seen a lot of people in that
 25 situation.

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1 self-identity again.
 2 **PROFESSOR WEINMAN:** Yeah, massive increase in
 3 vulnerability, I think. But I think also, you
 4 know, really it was a lot of, you know, people
 5 of -- in adolescence, in young adults, who are
 6 having to see -- I mean it's so unusual in our
 7 lives to see -- maybe watch grandparents, we --
 8 you know, there are certain people perhaps where
 9 death is expected, but to see so many of your
 10 colleagues taken away, it's a huge multiple
 11 bereavement.
 12 You know, a bereavement itself, it's again
 13 something I know we'll talk about, has, you
 14 know, quite a big psychological toll, that whole
 15 grief process, but to have that again and again
 16 and again, you know -- again, there is very
 17 little research literature on that but the
 18 little that is there shows that that can be, you
 19 know, again, very, very overwhelming for
 20 individuals to have to go through it in a serial
 21 sort of way, you know, not only taking support
 22 but actually experiencing all that
 23 multiple-layered grief, really.
 24 **MS RICHARDS:** There are, I think I picked this up
 25 from your report, very few studies specifically

<p style="text-align: right;">149</p> <p>1 looking from a psychosocial perspective at the 2 experiences of those infected through blood and 3 blood products, and you've drawn attention -- 4 I won't take time with putting it on screen, but 5 it's now part of the Inquiry's material -- to 6 one short research paper by Riva and others from 7 2017. Are you aware of whether there's been any 8 broader research, whether from a psychological, 9 psychosocial or psychiatric perspective into 10 these issues, specifically in relation to those 11 infected through blood or blood products? 12 PROFESSOR WEINMAN: I tried very hard to find a good 13 research base for that and it wasn't there. 14 I contacted journal editors. For example I know 15 the editor of a big American journal called 16 HIV Behaviour, and asked him to go back through 17 his records. I looked very widely -- that Riva 18 paper, it's not really a paper, I mean, it's 19 a sort of an overview on some of the 20 psychological consequences, the 21 neuropsychological effects and then looking at 22 medical and legal issues, so it's not even an 23 empirical paper. So I don't know whether 24 colleagues had similar -- we've had very hard -- 25 you know it's ...</p>	<p style="text-align: right;">150</p> <p>1 DAME LESLEY: Yes -- (overspeaking) -- 2 DR THOMAS: I spoke to a psychologist in the field, 3 and they also didn't have anything to recommend 4 as well. So it's very poor, poorly researched. 5 MS RICHARDS: One particular feature from the 6 evidence that the Inquiry has heard, and this 7 may be particularly relevant to the concept of 8 self-identity that you have described, is that 9 for many people their whole lives have become 10 defined by the condition with which they were 11 infected, and treatment for it, the symptoms, 12 and so on. But the result that they have had to 13 live a life completely different from the life 14 that they would otherwise have expected to do, 15 and they have lost opportunities, been unable to 16 fulfil a potential that would otherwise have 17 been there. Again, how does that bear upon 18 their psychological experiences? 19 PROFESSOR WEINMAN: Again, hugely, because the -- 20 going back to what I was talking about earlier, 21 about one's sense of self, one's sense of 22 self-identity, I think some people have said, 23 you know, if you think of illness as a sort of 24 set of things and oneself as a set of things, 25 and for some people, you know, the sense of</p>
<p style="text-align: right;">151</p> <p>1 oneself can be completely obliterated -- and 2 I think we heard this by -- you know, because 3 day-to-day, this is what's happening to you, 4 there is nothing else, so those multiple selves, 5 one's future selves, all those really important 6 dimensions become pretty well wiped out. And 7 again, that is, from an experiential point of 8 view, but also in terms of, if you like, 9 people's aspirations, particularly young people, 10 absolutely devastating. The idea of having, you 11 know, no obvious future or incredibly uncertain 12 future which is completely dictated by this 13 thing which now, you know, defines you, it's 14 massively impactful. 15 MS EDWARDS: There is a point, of course, where that 16 may not happen to some individuals, you know, 17 and people can redefine themselves, and go on to 18 be parents, to be -- you know, to go to 19 universities, to get careers, to get good jobs, 20 and I think although many of the things we're 21 talking about are in generalisations, are very 22 valid generalisations, there are individuals who 23 have overcome enormous challenges to have a very 24 strong identity, and I think we need to 25 acknowledge that as well.</p>	<p style="text-align: right;">152</p> <p>1 DAME LESLEY: But there are internal processes that 2 give you yourself identity but I think one of 3 the things that I think we were all struck by 4 were the external processes that defined 5 somebody as being "the AIDS boy", you know, "the 6 woman with hep C", and sometimes they assumed 7 titles from outside that defined them, no matter 8 how much they struggled to actually define 9 themselves in other terms. People having, you 10 know, sort of, "AIDS" painted on their houses 11 and everything, that's an external process 12 that's going to really affect how you feel 13 internally as well. 14 PROFESSOR WEINMAN: I think, just going back, 15 really, to look at what I've said and what Sian 16 and Lesley just said, that notion of "the self, 17 the illness", what we know is -- and in fact you 18 can do this, there are number of -- where you 19 say to people, "Just draw your sense of 20 yourself, draw the illness", and some people 21 literally draw one on top of the other. They 22 are consumed by it. But there are other people 23 who put the illness out there somewhere or with 24 a little bit of an overlap. And so they're 25 coping with it in different ways, maybe they</p>

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1 have better support and so on. So there is huge
 2 variation, I think we need to stress that
 3 variation. And I think we also alluded to the
 4 fact -- and I've seen this in quite a number of
 5 major illness groups -- some people go on
 6 actually to derive benefit from having gone
 7 through that process, and that process of
 8 so-called benefit finding, seeing, you know, the
 9 sort of silver lining, if you like, in this
 10 horrible cloud, is something that can really get
 11 people through. And it's not that uncommon, you
 12 know, certainly in the cancer literature, in the
 13 heart disease literature, is benefit finding.
 14 You know, you go through something dreadful but
 15 you emerge from it stronger, you do other
 16 things, you cope well.
 17 It really goes back to this huge variation,
 18 and that we must not generalise. Yeah.
 19 **MS RICHARDS:** Can I ask, you have talked about the
 20 position of children and adolescents and we'll
 21 come back to that with Professor Christie
 22 tomorrow, but can I ask you about what might be
 23 the particular psychological psychosocial
 24 challenges for those who have survived, who have
 25 aged with infection, who didn't expect to

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1 ready for that. It was really confusing, really
 2 confronting to be able to have" -- or have to
 3 need to stand up and go, "Okay, you mean I'm now
 4 going to live? Then I need to make some more
 5 major adjustments to the life in front of me,"
 6 and had many wasted opportunities because they
 7 did not believe they were going to live.
 8 **MS RICHARDS:** Can I ask you about the psychological
 9 impact of everything you've described on family
 10 members, partners, parents, children, siblings
 11 and others.
 12 Many of the -- those who were affected
 13 through the infection of a loved one, who have
 14 given evidence to the inquiry, have described
 15 psychological and emotional symptoms similar to
 16 those described by the person who was infected.
 17 Does that surprise you?
 18 **PROFESSOR WEINMAN:** Not at all, no.
 19 **DAME LESLEY:** No.
 20 **PROFESSOR WEINMAN:** We know that it's very hard for
 21 patients -- sorry, parents looking after
 22 children with major illness. We know that's not
 23 just in this area, but I think a lot of the
 24 challenges for the parents and the families we
 25 heard from were as much about how one managed

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1 survive and who made their life decisions
 2 accordingly, but who find themselves several
 3 decades on still here.
 4 What could you tell us about the experience
 5 of people who might fall within that category?
 6 **MS EDWARDS:** I think throughout the HIV patient
 7 group specifically, there was so much
 8 information in the early days about death,
 9 "You're going to die. Spend your money. Don't
 10 bother going to school, you know, you have two
 11 or three years to live. Live it. Live it well,
 12 because you're not going to be here".
 13 Many of those people did die, but there are
 14 many people, who are sitting here today, who,
 15 you know, come the late 1990s, and treatment was
 16 at last effective, who although that was a huge
 17 celebration in many ways, it was a major
 18 readjustment, major.
 19 People had not planned for that future, and
 20 basic things like finance, they spent money that
 21 had been given, that travelled the world, had
 22 made decisions based on the fact that their life
 23 would not be long. I am very aware of the
 24 amount of conversations I've had with people who
 25 would discuss that point and say, "I wasn't

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1 that in the broader setting of their lives, and
 2 the need for secrecy, the often distortions of
 3 communication that went on, somebody knew and
 4 somebody else didn't know, and so on.
 5 So I think apart from, you know, the very
 6 serious impact of having a child with a life
 7 threatening condition, I think some of the sort
 8 of distortions in communication that almost --
 9 I don't even want to call them games, but the
 10 things people had to do just to keep their heads
 11 above water, not telling people and a lot of
 12 avoidance went on, both by people who were --
 13 you know, avoidance in the sense of "Don't talk
 14 about it, don't deal with it". The avoidance
 15 seemed to be a very common response, and a very
 16 understandable response, because, you know, why
 17 would you want other people to know about
 18 something which, you know, potentially is very
 19 stigmatising?
 20 The problem with avoidance, you know, people
 21 cope, as I said earlier, people with illness in
 22 a whole range of ways, avoidance being quite
 23 a common way of responding, you know. I've
 24 certainly seen lots of patients who say,
 25 "I don't really have the problem", but the

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1 problem with avoidance is early on, when you
 2 first have a major problem, avoidance is not
 3 a bad thing. It can sort of keep you going for
 4 a bit. But avoidance in the long-term, we know
 5 from a huge number of studies now, is something
 6 that does not lead to good outcomes. Because
 7 actually, whatever it is is still there, and you
 8 haven't dealt with it. You haven't worked out
 9 as a family or as a parent how you're going to
 10 be coping with it. That, you know, is one of
 11 the many sort of threads, I think, that run
 12 through a lot of those family experiences, the
 13 secrecy, the avoidance, and so on.
 14 I didn't really see it, but I'm sure there
 15 would be families out there, where that wasn't
 16 the case. Where communication was open and good
 17 and people felt supported, but we did hear a lot
 18 about, you know, really quite problematic
 19 aspects of communication, secrecy, avoidance,
 20 all those sorts of issues.
 21 **SIR BRIAN LANGSTAFF:** It's very fascinating. It's
 22 riveting. I made a promise we'd finish at 4.30.
 23 It's now 4.31.
 24 **MS RICHARDS:** I'm very sorry, I was going to say
 25 that I was going through some of the literature

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1 relating to impact upon parents and spouses and
 2 other family members. Sir, the perfect time to
 3 do that would seem to be tomorrow morning.
 4 **SIR BRIAN LANGSTAFF:** Thank you very much so far.
 5 What I was saying about its being riveting and
 6 fascinating is certainly, as far as I'm
 7 concerned, so thank you very much thus far.
 8 Everyone else, it will be 10.30 tomorrow
 9 morning. So please, if you wish to -- if you
 10 are as fascinated as I am and you have the
 11 arranged to be here, then 10.30.
 12 **(4.32 pm)**
 13 **(Adjourned until 10.30 am the following day)**
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<p>DAME LESLEY: [7] 110/14 112/19 130/10 141/13 149/25 151/25 155/18</p> <p>DR THOMAS: [6] 111/7 112/20 121/23 126/21 134/23 150/1</p> <p>JACKIE: [39] 11/7 12/6 12/11 13/3 13/17 13/21 16/17 17/8 18/13 19/8 24/1 31/21 33/2 36/2 36/25 37/5 40/17 43/22 50/6 54/16 55/22 61/24 64/17 72/8 79/19 83/15 84/18 84/20 90/9 93/3 95/12 95/17 96/13 96/15 98/25 104/9 104/16 106/6 108/2</p> <p>KAY: [28] 10/21 11/21 12/3 12/24 16/15 17/4 17/15 21/17 29/15 36/24 37/6 37/11 41/22 48/25 54/3 57/14 68/19 75/6 81/19 88/18 91/11 92/25 95/13 95/18 96/24 104/15 105/7 108/1</p> <p>MS EDWARDS: [11] 109/25 112/18 121/6 127/12 134/12 134/14 136/4 142/8 146/25 151/14 154/5</p> <p>MS RICHARDS: [33] 6/20 109/10 112/7 112/22 113/9 113/12 113/14 113/18 113/24 117/25 118/12 119/23 122/13 123/10 124/19 126/20 128/5 128/10 129/25 130/8 131/10 132/20 135/7 136/22 139/24 142/24 145/9 147/18 148/23 150/4 153/18 155/7 157/23</p> <p>MS SCOTT: [53] 10/6 10/20 11/6 11/14 11/25 12/4 12/9 12/13 12/25 13/15 13/20 14/3 15/8 15/11 15/22 16/8 16/12 16/18 17/5 17/9 18/11 19/9 21/14 23/23 32/19 32/24 36/21 37/1 37/7 40/14 41/19 55/18 58/13 59/2 61/22 64/11 76/11 76/16 77/5 83/12 84/15 84/19 91/8 92/22 93/2 95/8 95/15 96/11 96/14</p>	<p>96/21 100/8 104/7 104/20</p> <p>PAM: [31] 10/11 14/7 15/10 15/13 16/1 16/11 16/16 17/7 18/19 19/16 27/14 32/23 33/1 33/4 37/4 39/2 47/13 52/3 58/14 59/5 67/9 70/7 77/8 87/18 93/25 95/14 95/16 99/20 100/13 106/20 108/3</p> <p>PROFESSOR MORGAN: [2] 111/18 112/21</p> <p>PROFESSOR WEINMAN: [31] 109/15 112/17 112/24 113/11 113/13 113/17 113/23 114/24 118/6 118/19 120/5 122/16 123/13 125/6 128/9 128/16 130/7 131/16 133/13 134/13 135/18 137/11 140/6 143/7 145/25 148/1 149/11 150/18 152/13 155/17 155/19</p> <p>SIR BRIAN LANGSTAFF: [13] 1/2 9/25 40/13 76/14 76/17 77/3 104/17 104/22 106/21 108/4 108/16 157/20 158/3</p> <p>'80s [1] 124/24 '95 [1] 67/16 '96 [1] 67/16</p> <p>... 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