

Friday, 10 May 2019

(9.59 am)

SIR BRIAN LANGSTAFF: I'm told that our first witness would like to be known as Andy.

MS RICHARDS: That's right, sir. Andrew Evans -- Andy.

ANDREW EVANS, affirmed

Questioned by MS RICHARDS

Q. Andy, there's a copy of your witness statement on the desk if you need to refer to it, but I'm not going to ask you to look at it but it's there if you need it as a prompt.

A. Thank you.

Q. You were diagnosed with severe haemophilia A in early 1978 when you were a baby.

A. That's right, yes.

Q. And you were under the care for many years after that of Dr Hill at the Birmingham Children's Hospital.

A. Correct.

Q. And I understand from the documents you have provided to us that you were initially treated with cryoprecipitate but then you were regularly treated with Factor VIII products?

A. Yes, correct, initially Bio Products Laboratory stock but then later on American Armour products.

Q. Do you know if your parents were ever given any

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Q. Now, you have explained in your statement that you were tested or your bloods were tested for hepatitis B on numerous occasions from 1979 onwards and there was a positive finding in relation to hepatitis B in 1981.

A. That's what my notes show, yes.

Q. You have also referred to there being a whole range of tests undertaken in 1981, by way of example.

Could we have up on screen please, Paul, 1213002.

This is one of the documents you've produced along with your statement, Andy, it shows a range of different tests being undertaken in 1981?

A. Yes.

Q. Do you know what, if any, information was given to your parents about the need for such tests?

A. I've never been told by my parents that I've been tested around those dates for anything other than haemophilia clotting levels; so they may be -- my mum, my Dad's passed away, but my Mum may be able to provide more information but I don't think that she knew about these tests either.

Q. You have set out at least a belief or a suspicion in your witness statement that it may be that tests were being undertaken for purposes of research.

A. Yes. Yeah, I'm -- from what we've since discovered,

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information or advice or warnings about any risk of infection associated with the use of those products?

A. Not from official sources, no -- not from any of the staff or doctors at the hospital.

Q. You were taught to self-administer the products at an astonishingly young age. Can you tell us about that.

A. Yes. It used to take five or six people to hold me down to have my injections. I would kick and scream that much I don't think anybody likes having a sharp metal rod poked into their skin, especially when they're a toddler, and one day they were having a particularly difficult time in getting a vein and so I said, "Well, I'll have a go", and I took the needle from them and I think they thought it was just a good way of persuading me to engage with the process and maybe let somebody do it a bit later on but immediately I got a vein and everybody was very astonished. I was three years and ten months at that time.

Q. Is it right you largely self-administered after that?

A. Yes. Yeah, I mean, I tried to self-administer as much as I could. If, for example, I couldn't, for example, if I got a bleed in one of my arms or I had a nose bleed that needed to be pinched or some other reason then my Mum would do it but if I could, I would, yes.

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it seemed that there was fairly common knowledge of at least hepatitis viruses in the blood and so it would be my suspicion that this kind of test was for that purpose.

Q. Now, you understand from subsequent conversations that you've had with your parents that your father became aware of a potential risk associated with the use of Factor VIII products when reading a New Scientist article?

A. Correct, yes.

Q. We have managed to track down the New Scientist article that we think your father had read.

It's 1213005 please, Paul.

It is the bottom of the page.

"AIDS: transfusion patients may be at risk", if we could have that highlighted.

If we just look at this, Andy, and see what it was that your Dad had read:

"American scientists are scouring the country for the first case of the bizarre new disease acquired immunodeficiency syndrome, AIDS, in patients who have undergone major surgery. The hunt for the cause of the disease which was first diagnosed among male homosexuals has now labelled as a prime suspect some unknown blood borne virus. In just one year the list

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of people at risk from AIDS has lengthened from male homosexuals, drug abusers and Haitians to include the entire population. In the last year, a task force under Dr Harold Jaffe at the Center for Disease Control in Atlanta, Georgia, has found seven cases of AIDS amongst haemophiliacs who do not fall into any of the other categories. Jaffe believes that the spread of the disease may be connected with new preparations of Factor VIII concentrate, the blood clotting agent given to haemophiliacs, which are made up from blood from large numbers of donors rather than one individual. If this is correct, any patient in hospital who is given a blood transfusion could be at risk if one of the donors of the blood carries the virus. No cases of AIDS among British haemophiliacs have been reported so far even though 50 per cent of the Factor VIII used in Britain comes from the US."

So that's what the New Scientist was reporting and if we look at the top the page please, Paul, for the date, that is 3 February 1983.

A. Yes.

Q. That you understand caused your parents some concern and a meeting took place at the Birmingham Children's Hospital?

A. Yes.

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SIR BRIAN LANGSTAFF: So the comparison was between arthritis, which does not of itself kill, and AIDS which was thought to be deadly?

A. Correct, sir.

SIR BRIAN LANGSTAFF: Thank you.

MS RICHARDS: Now, you now know from your medical records that blood from 1983, your blood samples from 1983, showed positive HIV as the result.

A. Yes, that is right.

Q. We can see, if we have up on screen please, Paul, 1213003, there's reference there, the document itself is not dated or not legibly dated, but we have reference there:

"HTLV-3 antibody positive, date of specimen 1983."

Andy, I think this right you have shown me this morning, we haven't had time to get it on the system but you've provided them to the Inquiry documents you have very recently received from the UKHCDO, the National Haemophilia Database material at those record a last negative result April 1980 and a first positive result August -- 16 August 1983?

A. Yes, that's correct. I think we discussed we're not really sure how to interpret those results but at least it shows that I was infected by August 1983,

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Q. Based upon what your parents have told you about that, what can you tell us?

A. Yes, some concern would be quite an understatement. I have a recollection, a vague recollection, but I've been told since, that there was an incident where my father spoke to me around about, it would have been around about that date, and said "Please, please, try not to hurt yourself because we think there's something nasty in the blood, in the Factor VIII". I didn't understand, so I went off and did what I was going to do anyway.

But then, as you say, there was a conference, a meeting called between parents of haemophiliacs and the consultants at the children's hospital in Birmingham and during this conference, my Mum stood up and asked Dr Hill outright, "Is there a chance that my son and all of these people's sons are going to get HIV AIDS from Factor VIII", and his reply was, "Madam, your son has more chance of becoming debilitated with arthritis through not taking Factor VIII than he has of getting AIDS".

Q. That was some time after this article in 1983 from the sound of things because it was that which triggered your parents' concern?

A. Correct, yes.

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yes.

Q. Those documents don't make clear when the test was done.

A. No.

Q. And raise the possibility it might have been done on a stored sample?

A. Yes.

Q. But it does show, as you have said, that by August 1983 you were, in fact, HIV positive?

A. Correct, yes.

Q. There came a point when that information, that news, was broken to your parents. Who told them and roughly when from your understanding?

A. My understanding is that it was told to them in a regular clinic appointment at the Children's Hospital for my haemophilia, and it was told to my Mum by Dr Frank Hill who came out and quite bluntly, from what I've been told, said, "I'm very sorry but your son has HIV", quite understandably possibly my parents don't recall much of the rest of that conversation because they were probably quite shell-shocked.

But from what I understand, there was no briefing about what it meant for me or my prognosis or my life from then on, other than the fact that it wasn't going to be a very long life.

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1 Q. In your witness statement, you put that you thought
2 that was in 1985, but I understand from talking to
3 your Mum that she thinks it might have been later.
4 When does she think that conversation took place?
5 A. She -- her most recent recollection is that it was in
6 around about 1987 when I was ten years old.
7 Q. You've described understandably that this was news
8 that put your parents into a state of shock. Again,
9 from subsequent conversations you've had with them,
10 what was the impact of finding out that information
11 about their ten year old son on them?
12 A. My parents were really good parents and I think they
13 very much tried to shield me from the turmoil that
14 must have been going on in their mind, but from what
15 they've told me they were absolutely beside
16 themselves. They didn't know what to do, they didn't
17 know what my prognosis was. All they knew was that
18 they had to try and give me the best life I possibly
19 could before I inevitably died in quite short order,
20 really.
21 Q. As far as you know, were they ever given, for example,
22 any written material that they could take away and
23 consider in less stressful circumstances about the
24 condition or about the prognosis?
25 A. No, I don't recall that they were given anything.

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1 was. It wasn't very far away but it was a nice
2 peaceful spot. We pulled up into the entrance to
3 a field. There was a closed gate in front of us
4 I recall, possibly some sheep milling around, and
5 I thought to myself what's going on? This is not the
6 norm. We don't normally do this. And she turned to
7 me and with a very red face, and you could see that
8 her eyes were welling up as well, she said, "I've got
9 something to tell you", and then she told me. She
10 said, "The Factor VIII that you've had was infected
11 with HIV". She said, "Do you know what that means?"
12 I said, "Well, yes, I know about HIV, a little
13 anyway", and she said, "Well, do you know what it
14 does?" And I said, "Well, yes, it eventually kills
15 you", and she said, "Yes".
16 I don't know whether it was because I was trying
17 to help her. I could see she was in obvious distress
18 but I decided to be the strong person and I said to
19 her, flippantly almost, I said, "I'll just have to
20 become a researcher or a scientist and I'll have to
21 cure myself then, so don't worry about it. It will
22 all be fine", and that was that. We, I guess, hugged
23 and then went home and went about our normal business
24 as much as we possibly could.
25 Q. I am going to ask you in a few minutes about the

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1 There was a fair amount of public information
2 circulating, if you want to call it that, about AIDS,
3 mainly quite graphic and scary commercials with
4 falling tombstones and, you know, the sparse news that
5 there was about it was that it was fatal, that you
6 were quite dirty for having such a thing, that your
7 lifestyle was not the norm, and that really for your
8 safety you shouldn't tell anyone about it and they
9 didn't. They didn't tell anybody.
10 Q. Now, they told you, not straight away --
11 A. No.
12 Q. -- but in 1989 when you were about 12 years old your
13 Mum told you. What can you tell us about how that
14 happened?
15 A. Yes, she told me. The reason that she told me was
16 because, and I'm not sure that she would have told me
17 if it hadn't been for this, but my blood results, my
18 CD4 counts or T cell counts as they were back then
19 T4s, were showing a decline and the hospital told her
20 that I would probably need to go on medication very
21 soon.
22 So they made the decision, the very difficult
23 decision, to tell me and it was left to my Mum. My
24 Dad was at work. So she took me out in the car and we
25 drove out to a country lane. I'm not sure where it

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1 treatment and how things progressed from then on but,
2 just pausing there in 1989 and having been given that
3 information, how did that affect family life from then
4 onwards when you had this knowledge? You, I think,
5 have a sister?
6 A. Yes.
7 Q. Was it something that was discussed? Did it affect
8 the way in which family life was conducted?
9 A. My sister is a fair bit younger than me. She's almost
10 four years younger than me; so the time I was told she
11 would only have been about eight, at the most nine.
12 I honestly do not know when she was told about it but
13 it certainly wasn't then. It was something that we
14 couldn't discuss, obviously, as a family when she was
15 around and, as I recall, we didn't discuss it at all
16 really. We almost ignored the fact that it was there
17 and tried to get on with living a normal life.
18 And I think in retrospect that was my parents'
19 trying to give me a normal childhood as much as they
20 could when they knew that everything else would be
21 stacked up against that, really, and the only time we
22 really ever talked about it is when I had to go for
23 clinic appointments and spoke to the doctors.
24 Q. You have some recollection in relation to your sister
25 being told not to share your toothbrush --

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1 A. Yes.

2 Q. -- and matters such as that.

3 A. Yes, yeah. I think as the illness progressed and it

4 started to manifest itself, there were certain --

5 I think I remember certain sort of skin conditions

6 and, you know, being a haemophiliac I'd probably have

7 a few mouth bleeds and what not and I do remember that

8 she or I was told to keep my toothbrush and my towel

9 separate. But I'm not sure whether it was down to the

10 HIV or just down to the sort of hygiene facts really,

11 but I do recall that quite vividly.

12 Q. In fact, you were also infected with hepatitis C.

13 A. Yes.

14 Q. But you learnt that a number of years later. What can

15 you recall about the circumstances in which you

16 discovered that you had also been infected with

17 hepatitis C?

18 A. I was at a -- I'd transferred to the Queen Elizabeth

19 by this appointed I was under the care of Dr Wilde and

20 I had just seen him in a consultation, and we'd spoken

21 about the HIV, we'd spoken about the haemophilia, and

22 the consultation was over, and I went to the treatment

23 room next to have my bloods taken, which was a routine

24 thing, and he popped his head round the door and he

25 said, "Oh, we must remember to do a genotype for your

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1 Q. -- you have gathered from your records that the first

2 positive test for hepatitis C that you found is

3 8 March 1994.

4 A. Yes.

5 Q. You haven't found any references to any earlier test

6 results?

7 A. No, not as yet, no.

8 Q. Your clear recollection is being told in the way

9 you've described by Dr Wilde?

10 A. Yes.

11 Q. You transferred from the care of Dr Hill at the

12 Children's Hospital to Dr Wilde at the Queen Elizabeth

13 Hospital some time in late 1996?

14 A. Yes, '96 towards '97, yeah.

15 Q. Because we have the transfer summary and that is dated

16 26 November 1996; so that gives us some kind of idea.

17 A. Yes.

18 Q. So if those dates and your recollection is correct

19 there was a significant gap between the test and you

20 being told?

21 A. Significant, yes. I think I'd been at the Queen

22 Elizabeth by that point for at least a couple of

23 years. When I transferred over to the Queen

24 Elizabeth, I was extremely ill. I mean, extremely

25 ill. They didn't realise -- they didn't understand

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1 hepatitis C as well", and that was the first I'd heard

2 about it, and I think he assumed that I had known

3 about it all along but it was the very first I'd heard

4 about it.

5 Q. Do you recall what your reaction was?

6 A. I think I immediately turned to the nurse, because he

7 popped his head in and just as quickly popped it out

8 again, and said, "What's this about the hepatitis C?"

9 I think she seemed to think that I ought to have known

10 as well, so I didn't push it any further. I went home

11 and I asked my parents about it and they didn't have

12 any clue. So I did a bit of research and that was it

13 really. I just I kind of assimilated it into my

14 consciousness that way.

15 But you kind of have to understand that for me

16 in particular and my circumstances was that the HIV

17 was the be all and end all. There was nothing else

18 and whatever hepatitis C was for me at that time

19 wasn't important because it wouldn't have a chance to

20 get at me. It would be the HIV that killed me.

21 So, to be honest, I wasn't, at that point,

22 I wasn't too worried about it.

23 Q. Just so that we can establish the dates in relation to

24 the hepatitis C --

25 A. Yes.

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1 whether or not I was going to survive at that point

2 and I recall being relatively stable and well when the

3 hepatitis C question came up, and so that would place

4 it about two years after I transferred or around

5 '98/99, yes.

6 Q. You have recorded in your witness statement some

7 surprise shall we say given what was known about

8 hepatitis C at least from the early 1990s --

9 A. Yes.

10 Q. -- that it took so long for you to be informed.

11 A. Yes, especially given the transmissibility of

12 hepatitis C through blood to blood contact and, you

13 know, HIV was all generally about sexual transmission

14 but hepatitis C seemed to be more easily transferred.

15 I think it's something about being non-lipid envelope

16 virus or something like that, it stays alive outside

17 of the body for longer than HIV does, and so it could

18 linger outside the body and then be passed on to

19 somebody else.

20 Well, I had no idea about the fact that I'd got

21 it and, therefore, I wasn't taking precautions for it

22 and any person in my family could have become infected

23 because of that, and I thought that that was terrible.

24 How could they not have told me that this was a risk

25 so that I could guard against it?

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1 Q. It's right I should point out that the transfer
2 summary from Dr Hill to Dr Wilde in November 1996
3 states that you were told about the hepatitis C result
4 in March 1995 but you don't think that's right.
5 A. I don't recall being told about it at all and my
6 parents don't recall being told about it either.
7 Q. You have what you've described as a very vivid memory
8 of Dr Wilde telling you in the particular way that
9 you've described.
10 A. Yeah. I can close my eyes and imagine that room right
11 now and I can tell you where I was sitting and I can
12 tell, you know, tell you -- I can see his head coming
13 round the door and making that comment, yes.
14 Q. Now, your Mum having told you about the HIV in 1989,
15 you started treatment for that pretty quickly after
16 that, in about August 1989?
17 A. Yes.
18 Q. You started on AZT?
19 A. Yes, I did, yes.
20 Q. What can you tell us about how that was and how it
21 made you feel and any side effects?
22 A. I can tell you that it was absolutely horrifying.
23 I late learned that I was on I think they'd given me
24 800 milligrammes a day or something like that. I was
25 13 years old. I was a slip of a lad. I didn't weigh

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1 I guess, what the reaction to that would have been
2 from, you know, from my school mates. It was a really
3 difficult time because I couldn't explain what was
4 going on either.
5 Q. Because you didn't tell people?
6 A. I couldn't tell people, I couldn't. It was something
7 that, as a kid, it was something that dirty people
8 had. That was what we were taught. I know that's not
9 the case and, you know, everybody can get it but at
10 that time the stigma was such that if you had HIV or
11 AIDS you were a dirty person. It wasn't like
12 a disease like cancer or something that you could tell
13 people about and get sympathy. This was something you
14 had to keep absolutely secret.
15 Q. There did come a point whilst you were still at school
16 when you did tell a couple of people. You told a girl
17 that you were going out with.
18 A. Yes.
19 Q. What was the reaction?
20 A. She initially seemed to take it well and then very
21 quickly I got a phone call saying she couldn't do it
22 anymore and she decided to break it off, and it was my
23 first sort of serious relationship, I guess. I felt
24 that I had to tell her because we were getting towards
25 sort of 16 years old at that point and there was

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1 very much at all and they gave me 800 milligrammes, at
2 least I think, per day of AZT, and it just knocked me
3 for six. There was fatigue, nausea, headaches.
4 I just felt like I was really ill on AZT, and this was
5 a surprise to me because I'd not actually felt that
6 bad before.

7 You know, the CD4 counts had been dropping I'd
8 been told so I needed to go on this medication, so
9 I go on the medication and all of a sudden I was run
10 over by a truck and I remember going to -- I was still
11 going to school, obviously, at that time and I'd had
12 my pills that morning as you do but I think I'd
13 forgotten to have something to eat and I could feel
14 during the trip nausea building and was trying to
15 contain it and, you know, it was a full coach full of
16 kids. It would have been horrifying to actually be
17 sick on the coach. Then we were probably about
18 halfway there and that's exactly what happened.
19 I couldn't take it anymore, and I was just sick
20 everywhere and it was -- it was projectile and it was
21 just horrible, and it went all over me, it went all
22 over the seat in front, all over the person sitting
23 next to me, and I think that happened two or three
24 times.

25 As a child of 13, you can kind of imagine,

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1 a hint of the relationship becoming sexual and I felt
2 like I had to tell her because it would have been
3 immoral of me to have hidden that from her and put her
4 at risk, so I told her.

5 As I say, she broke it off and that was me
6 completely done for relationships for the next ten
7 years, it was such a body blow that I felt like that
8 was completely off the cards for me, really for --
9 well, long-term, if not the rest of my life.

10 Q. There also came a point at which you told your best
11 friend at school about your infection.

12 A. Yes.

13 Q. What happened there?

14 A. He was really supportive. I felt like I'd got someone
15 to talk to, which was a huge weight off my shoulders
16 and I went on for a couple of years, you know, being
17 able to talk to him and then I started to get very ill
18 and he supported me throughout all of the illness.
19 But I think in his mind he prepared himself for me to
20 die and when I didn't die, I don't think he could cope
21 with that fact. He'd made his preparations, he'd set
22 it in his mind, and we very quickly lost touch after
23 the combination therapies came out and I survived,
24 yes.

25 Q. You'd -- the AZT medication eventually was adjusted

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1 and other therapies added in.
 2 A. Yes.
 3 Q. You were able to get through school --
 4 A. Yes.
 5 Q. -- and your GCSEs?
 6 A. Yes. I managed to get through school up until --
 7 well, I was starting to become ill during my GCSEs but
 8 I managed to get them all done. At that point I think
 9 they had lowered the dose of AZT and added in one
 10 called DDI. I don't know if anyone remembers DDI but
 11 it came in two forms. You either had to drink -- it
 12 was a sachet of powder which you dissolved in water
 13 and it was like a sweet salty mixture. You know,
 14 I had to drink that twice a day or three times a day
 15 or it came in pills roughly the size of -- no, even
 16 bigger I think than extra strong mints which you were
 17 told to chew and swallow, that tasted a little bit
 18 like the chemical Germolene, so it was not a nice
 19 thing to take. I think that the adherence to that
 20 pill was very low.
 21 But whatever, you know, I managed to make it
 22 through to the age of 16 and got my GCSEs.
 23 Q. But there's no doubt in your mind that you would have
 24 been able to do a lot better at school if you hadn't
 25 been having to cope with at such a young age with all

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1 A. It began with infections such as, you know, that
 2 manifested themselves as colds or flu or chest
 3 infections that wouldn't go away by themselves, you
 4 know. You expect a chest infection to last probably
 5 maximum three weeks but these went on and on and on
 6 and, initially, they examined me for conditions like
 7 sinusitis and looked at my chest for pneumonias, but
 8 it got to the stage where I was being admitted to
 9 hospital on a pretty much weekly basis, usually by
 10 ambulance because I was running fevers of 41 degrees,
 11 I couldn't keep anything down, I was being sick all
 12 the time, they couldn't give me paracetamol or
 13 ibuprofen or anything like that to keep my temperature
 14 down because I would just bring it straight back up.
 15 I couldn't drink water. There was not fluid in me.
 16 I was dehydrated, so they would get me to hospital by
 17 ambulance, and there I would stay for a couple of
 18 weeks on various intravenous antibiotics, some of
 19 which were quite toxic, some of which I had allergic
 20 reactions to. I remember having full body rashes,
 21 more nausea, terrible pins and needles, itching,
 22 scratching all over, and then during this time there
 23 were several, I guess, remedial operations. They were
 24 really trying to fight the symptoms at this point.
 25 So I had -- I remember one occasion they did

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1 these infections and treatment?
 2 A. It is hard to say but I can't see it having helped.
 3 Yeah, I really think that had I not had all this going
 4 on, both mentally and physically, then I would have
 5 been able to concentrate a lot more on schoolwork.
 6 Q. You were planning to stay on for sixth form. There's
 7 a detail that someone has told you about some kind of
 8 school assembly.
 9 A. Yes.
 10 Q. What was that?
 11 A. I was told this after everybody had left school.
 12 I went to a gathering of old school friends and I had
 13 no idea about what people knew about my illness. They
 14 obviously knew that I hadn't been there for sixth form
 15 for most of the time, and so it came as a bit of
 16 a surprise to me when she said, "Oh, we had an
 17 assembly at school" and the headmaster stood up in
 18 front of at least our year, possibly the whole school,
 19 and said that I'd got AIDS and I wasn't expected to
 20 survive.
 21 Q. You started around this point, around the age of 16,
 22 having planned to be able to continue studying and do
 23 your A levels, you became very ill.
 24 A. Yes.
 25 Q. You tell us, Andy, how your health was at that time.

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1 a sinus wash-out because I couldn't breathe through my
 2 nose at all. My nose was just streaming as if I'd got
 3 a really bad cold, so they took me down to the
 4 operating theatre and they did this sinus wash-out
 5 under anaesthetic and when I came to in the -- it was
 6 one of the side wards, the oncology ward where we were
 7 all kept, there was nobody in the room and all I could
 8 feel that was that there was some kind of packaging,
 9 packing, around my nose. So I groggily went to the
 10 bathroom, still half asleep from the anaesthetic and
 11 took this off and started tugging at what was up my
 12 nose and it was long pieces of gauze and I got it all
 13 out, and then the blood came and it was everywhere and
 14 nobody was there and I was pushing my buzzer and it
 15 was in a side room, I was on my own, nobody was coming
 16 to see what was going on.
 17 So, eventually, to get someone's attention,
 18 because I thought I'm going to bleed to death, I had
 19 to pull the cardiac arrest button and then they came
 20 kind of rushing down telling me I shouldn't have
 21 pushed the cardiac arrest button, but eventually got
 22 me kind of stable, you know. The nose bleeds were
 23 stopped and I was okay but -- and then they had to do
 24 sinus wash-outs again a couple of times in the future
 25 but at least I knew what to expect and didn't pull the

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stuff out of my nose. But that was one such occasion.
Then there was -- I think I had to have grommets put in my ears as well because the eustachian channels were blocked and this was all through -- I think they detected a virus or a bacterium called pseudomonas was just something I couldn't get rid of because I'd got no immune system whatsoever.

I developed nasty chest infections and pneumonias for which they gave me high dose steroid treatment so, I mean, I remember a tub full of tiny red pills, prednisalone it was, and I had to swallow these a couple of times a day.

The side effect of those initially was to make my cheeks puff out like a hamster, which everybody found very amusing. It helped a little bit with appetite as well, which I was struggling with, but then later on I found out that they had caused a condition called avascular necrosis of the femoral heads, which means the blood supply to my hip bones was killed off and the hip bones themselves started to crumble away, so I was left unable to walk really, not walk very easily anyway. The hip bones had become deformed. They were all jagged, and it was very painful to put weight on. Eventually, later on, after several treatments that didn't work, they tried to

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care nurse who said that the solution really was to be fed overnight via drip feed via nasogastric tube. So that was my life for a good couple of years having that nasogastric tube in, and one day I was completely fed up with it and I think I'd been sick and when you are sick with a nasogastric tube, the bit that's in your stomach comes out of your mouth and it's horrible trying to -- sorry to be so graphic, but it's horrible trying to remove that it goes back through your mouth over your tongue and then you've got to pull it out and it's really not a nice thing to have and I'd gotten fed up with it and I said, "I don't want this thing anymore". There was a little bit of a conference with the nurses and my Mum and they said, "Well, you know, we'll support you in whatever you want to do but you do realise if you don't have this tube, you probably won't last much longer".

So I digested that for a little bit and then the following morning they came back in, my Mum tells it, and the tube was in. I'd put it in. I wanted to survive, I guess.

Q. The years that we're talking about are really in the course of the '90s from the age of about 16 onwards, your late teens and early adulthood?

A. Yes.

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drill out a core of bone to try to stimulate the blood supply. That didn't work.

They tried to use magnetic therapy which meant a machine by the bed every night connected to a large magnetic shield, if you like, which was about that big (*indicated*), a dinner plate-sized thing which I would have to put down a specially designed pair of shorts, one side per night, for many months, trying to get the magnetic field to stimulate bone and blood growth. That didn't work.

Then eventually they were -- I mean, they were very reluctant to perform hip replacement surgery on me because I was still very young but eventually I persuaded them to do that and I have had two hip replacements now, one in 2001 and one in 2007.

Yes, so I mean a couple of the other things that happened during those four years, I was diagnosed with candidiasis, which is like a thrush-type thing but goes -- it's on the back of your throat and it goes down your oesophagus, which makes it very difficult to eat, and then also -- that was an AIDS-defining illness I found out later, and then there was also the weight loss and the fact that I couldn't eat at all.

Whatever I ate I would bring up, and in order to survive that, I was put in touch with a nutritional

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Q. You had what was often then referred to as full-blown AIDS?

A. Correct, yes.

Q. We get a snapshot of hospital admissions from the transfer summary that you've produced as part of your evidence which shows that, for example, just between July 1994 and the date of the transfer summary in late '96 you had been admitted to hospital 24 times.

A. Yes.

Q. Those weren't one-off short admissions, those were admissions in which you would stay in hospital, often for prolonged periods of time.

A. At least a week, probably two or three, yes.

Q. You've described a range of the -- in your statement, a range of the drugs that you were given. One was a drug that was a leprosy drug?

A. Yes. I became allergic to -- they used to give you prophylaxis for a condition called PCP pneumonia, which was an AIDS defining illness, and they used to give you a drug called Septrin, and that was supposed to guard against getting PCP but, in my case, after I'd been taking it for a couple of years, it suddenly decided to react on me and I had a full body rash and they immediately took me off it because apparently once you manifest this symptom it can get dangerous

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quite quickly.

So they had to do something else. They had to give me some other kind of prophylaxis against PCP and the first one that they tried was called dapsone. I think that was the anti-leprotic drug, so it was an anti-leprosy drug but I forget now why they took me off it. I think I was having a reaction to that as well. I couldn't tolerate it.

The next one they tried was Thalidomide. Again, I don't think -- maybe that one didn't work properly. From what I'd heard about it, it was supposed to be an anti-emetic and, of course, we know about the foetal development issues with it, but it was still quite a good anti-emetic and, apparently, it was supposed to guard against PCP as well but for whatever reason it didn't with me.

So the third and final attempt at guarding against PCP was a drug called pentamidine. Pentamidine was taken by nebuliser, which means that you put the liquid into a device. It turns it into a gas and you breathe it in, so the procedure was that I would take salbutamol first which would open up the pores in the lungs, I would have that for half-an-hour by nebuliser and then I would take pentamidine for the next maybe half-an-hour to an hour, something like

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my mobility and so that was a bit of a body blow to have that taken away as well.

Q. Can I ask you about something you say in your statement, talking about the wheelchair. You said this:

"It was one of the things that the bothered me most because although I knew I wouldn't survive my illness, the wheelchair took away my mobility and any independence."

I wanted to ask you about a phrase, "I knew I wouldn't survive my illness".

A. Yes.

Q. You believed then, based on everything that was happening to you, that you were going to die?

A. Yeah. If I hadn't made the conscious thought that that was the case, then somehow subconsciously I knew it. I was under no illusion how ill I was. It didn't stop me from having a fighting spirit and wanting to get better but that was the reality that was facing me, yes.

Q. Your parents were told on more than one occasion that your next infection would in all likelihood be your last?

A. Correct, yes, yeah.

Q. There was -- after your transfer to the Queen

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that. But the problem with pentamidine is that it's extremely toxic. I had to be put into a separate room within the hospital. The nebuliser had to be exhausted out of a window because the drug was so toxic. Bearing in mind that I'm breathing this directly in and then the room had to be kept vacated for about four or five hours after I'd finished the treatment as well.

It wasn't a nice experience. It was -- it made my nose bleed. It made me shake. It made me cough, but at least it was only once a month and so I managed that for several months, yeah.

Q. One of the things that bothered you most during all this time was when, because of your mobility problems, you had to use a wheelchair for quite a prolonged period of time.

A. Yes. I tried to make my way around on my feet as much as I could but because of the hip problems, it was very difficult to go long distances and so -- I mean, I'd been used to being in a wheelchair for the haemophilia, but it was only for a period of two or three days at a time when I went to school, but at this point it was almost a necessity that I would have to be in it for any kind of long journey. Despite everything, despite the haemophilia, I've always had

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Elizabeth Hospital, there was some change in your drug treatments for the HIV.

A. Yes.

Q. You were moved on to 3TC; is that right?

A. Yes, also known as lamivudine.

Q. You began to see some improvements?

A. I did. I began to see that the -- I think I'd still got *Candida* by that point in my throat and that had started to clear up a little bit. I started to feel a little bit more well in myself but I think the double combination of the AZT and the 3TC didn't last that long because they had protease inhibitors coming on line at that point as well, the first of which was ritonavir, and so they put me on that fairly quickly afterwards as well.

Q. There was an episodes in the late 1990s when you were at home and you had something that was almost like a stroke.

A. Yes.

Q. What can you recall about that?

A. They'd just changed my combination therapy and I think they'd put me on to one called indinavir (Crixivan, I think it was called), and I had only been taking it a day, two days, something like that. My Mum had had a friend over so she was quite preoccupied. The

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friend lived quite a long way away so she was staying over and they were doing whatever they were doing and I was kind of left to my own devices and I started to feel very strange. I started to feel tingling down my left-hand side. Whenever I stood up, I would -- it was like the blood had all rushed from my head and I got dizzy, and that kind of -- those feelings progressed throughout the day until I stood up at one point and completely fainted. I collapsed. I don't know what had happened. I guess I'd just fainted.

But at that point, you know, I got my Mum involved and she said, "Well, you know, we think we really need to get you to the hospital", so we went to the hospital and the symptoms were still relatively in the early stage then. I was still having the issues with my left-hand side and feeling dizzy but it was to get a bit worse and I saw Dr Wilde and he didn't seem particularly concerned and he sent me home.

So this would have been mid-afternoon, something like that and then I woke up later that night and my whole left side was in spasm. This was before I'd had my first hip operation, so every spasm in my left leg would cause shooting pains up and down my body because it was messing with my hips, and so I was crying out in pain and so I can't remember whether it was another

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a sudden I was getting ingrowing toe nails and I had to have one operated on actually. But, yes, all of the other symptoms were quite prevalent during that time. These were very early combinations. The protease inhibitors in particular were quite full of side effects, one of which was, ironically enough, exacerbated bleeding in haemophiliacs.

So, yes, it was an interesting time.

Q. Now, 1999/2000 you have described in your statement that your health started to level out?

A. Yes.

Q. But you said this in your statement:

"The most formative years of my life had been spent in a hospital."

A. Yes, I believe -- yes, that's pretty much exactly it.

It was the time when you turned from being a child to an adult. It was the time where you stop being at school, go to university or get a job, and you're supposed to do that alongside all of your peers. You are supposed to get your life experience at that point. It's where you leave the apron strings of your parents and go and find your place in the world alongside everybody else and that I hadn't done.

Everybody else that I'd grown up with had done that. They'd moved on but I was left as almost

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trip in the ambulance or not. It might have been just in the car, but we eventually got back to the hospital and they admitted me and did CT scans and things like that.

They couldn't initially find anything and then later on they said they thought it might have been some sort of epileptic issue that manifested as a stroke but that it was quite likely it was caused by the change of drugs, that it was the indinavir that did it.

Q. It took you a while to regain any strength in the left side of your body and hand?

A. Yes, it was a fair old time with rehabilitation and, actually, to this day I'm left without much feeling on some parts of my left side but certainly in my fingertips and my hand.

Q. Although the medication that you were by now receiving was resulting in some improvements in your CD4 count --

A. Yes.

Q. -- you did experience a number of side effects still, brain fog, nausea, headaches and ingrowing toe nails?

A. Yes, ingrowing toe nails, that was a strange one. I did later find out that that was an issue with one of the drugs. I couldn't understand it though, all

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a 20-year old 16-year old, if you like. I was still back at that stage but with nobody then to experience those years with.

Q. You signed up for a course with the Open University because you say in your statement you didn't really know what else to do with your life.

A. I had no idea. I had no idea. I had expected to die. Simple as that. I hadn't expected to be there or at least I hadn't expected to get better. There was no plan for the future and there I was, at home with the prospect of a future and I'd never had it before and I had not a clue what to do with it. I'd got nobody to kind of advise me, should I just try to live my life to enjoy as much as I possibly could in case the virus comes back to bite me? Should I try and plan for some sort of future where I'm alive long-term? Is there a point in doing that?

Eventually, the only thing I had to fall back on was the plans that I had before I became ill and I'd planned to go to university and study computer science and that was the closest thing I could think of to do, was to do that Open University course.

Q. But you found that very isolating?

A. It was isolating. I'm not a person that can motivate themselves very well and it was a lot of dry text.

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1 I got through a lot of the modules but eventually
 2 I decided that, if anything, this was holding me back
 3 more than helping me; so I would try to maybe do
 4 something else that would get me out of the rut that
 5 I was in, get into life a little bit more.

6 **Q.** You started some what you described as tiny
 7 businesses. You would help people in relation to
 8 offering technical support with their computers?

9 **A.** Yes.

10 **Q.** You would print business cards at home and you made
 11 a very modest amount from that whilst you were at
 12 home?

13 **A.** Oh, I had a little cottage industry going in the
 14 hospital. You know, I'd got my computer in there and
 15 people from other wards would come and ask me if
 16 I could make them business cards and notelets and
 17 things like that, and that's what I'd be doing.
 18 I would be designing them on the computer, printing
 19 them out, folding them up, cutting them, yes.

20 I didn't get paid for it but it was something
 21 for me to do. I think somebody bought me a CD once or
 22 something to say thank you. But it seemed that that
 23 was something that fitted with me. I could still use
 24 a computer no matter what my physical health and so
 25 that was the route that I decided to go down.

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1 visit her, which I did in February of 2002.

2 In person we hit it off as well and I stayed out
 3 there for a couple of weeks with her and then I came
 4 home and then I subsequently found out that she'd been
 5 diagnosed with primary pulmonary hypertension, that's
 6 right, and she was quite ill in hospital, so I flew
 7 back out there immediately in about the April and
 8 I stayed by her side really. She got -- she improved
 9 from that. It wasn't curable but we decided that we
 10 would try to make the best of the situation and make
 11 a life for ourselves together, so we did and we got
 12 ourselves a place out there and, you know, tried to
 13 make the best of the combination of our bad
 14 situations, if you like.

15 Then in April 2003 she began to get very ill and
 16 we took her into the hospital and it was discovered
 17 that she'd got sepsis. She was taken to intensive
 18 care. She was Greek Orthodox so the priest was called
 19 in and she was given her last rites. We expected her
 20 to hold on for another day or so, so I went home to
 21 take a break and an hour later we got a phone call to
 22 say she had sadly passed away.

23 **Q.** Two weeks after that you received a call from your
 24 Mum.

25 **A.** Two weeks to the day, on the evening, to say that my

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1 I learnt a lot about computers during that time
 2 because there was nothing else to do and once I got
 3 out I tried to make the best of that, offering
 4 technical support and helping people with stationery
 5 requirements in my very small modest way, yes.

6 **Q.** You ended up living in the States then for about
 7 14 months?

8 **A.** Yes.

9 **Q.** How did that come about?

10 **A.** I -- being the nerd, the computery, geeky nerd that
 11 I was, probably still am, the only way that I could
 12 think of to get myself out there was through the
 13 internet and so I started to seek out online
 14 hang-outs, if you like, and I found one that was
 15 specifically for people with HIV, and we would chat
 16 and various people would come online and offline and
 17 the one particular person stood out to me and she --
 18 we got chatting privately online and I found out that
 19 she had thalassaemia and that strangely enough she'd
 20 also -- she was about my age and she'd also been
 21 infected with HIV and hepatitis C through her blood.

22 So we got that in common. We didn't have to
 23 explain it to each other. You know, we knew what our
 24 prognosis was. It was an easy thing to fall into and
 25 we got along so well that I decided to go out there to

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1 Dad who I knew had been in hospital, had also passed
 2 away. So I kind of collapsed with the phone clutched
 3 to my ear on to the sofa and tried to assimilate this
 4 news. And then it was a case of, immediately almost,
 5 back to practicalities because I'd got a life there
 6 that I almost immediately needed to pack up and get
 7 out of the United States to go back there for his
 8 funeral and that became -- it was a really horrendous
 9 time. It was horrible.

10 **Q.** You came back to the UK to support your Mum.

11 **A.** Yes.

12 **Q.** One of your regrets is because you had overstayed on
 13 your American visa you weren't able to go back there
 14 to see how your girlfriend's family were coping?

15 **A.** Yes. I'd had difficulty getting in and out of the
 16 States during that time, partially because of the visa
 17 I had to have in my passport because of having HIV and
 18 it being a communicable disease, every trip that
 19 I wanted to go on, I had to go down to the embassy in
 20 London and wait in line and pay my money and bring my
 21 evidence from the doctor and the fact that I could
 22 support myself while I was out there and I wasn't
 23 going to be a burden on their health system, and then
 24 if I was lucky I would get the rubber stamp and they
 25 would put a visa in my passport and send it on to me.

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1 So there was that to begin with and every time
 2 I went into the States they would pull me aside
 3 because of that because nobody really knew why. It
 4 was the same sort of visa you would have if you had
 5 a criminal record and so they were obviously
 6 questioning about that.

7 But then as time went on I weighed up the odds
 8 and I thought, well, I'll try to stay in the
 9 United States to be with her because that's the most
 10 thing to me at the moment. But I ended up staying
 11 beyond the terms of that visa and so I had extreme
 12 difficulty in getting back in the last time that
 13 I went back in during 2002 and although he let me in
 14 on compassionate grounds, the INS guy with the gun in
 15 his holster, I didn't want to chance it again,
 16 I didn't think that they'd let me back in and so
 17 I felt like I could not go back after that.

18 Q. Having been infected with HIV, having been infected
 19 with hepatitis C, in 2001 you received a communication
 20 about vCJD.

21 A. Yes.

22 Q. What do you recall being told?

23 A. Initially, it was a letter asking whether or not
 24 I wanted to know my vCJD status. I think they'd --
 25 I think it was up to individual hospitals as to

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1 "You will recall that I wrote to you in
 2 January 2001 informing you that you had previously
 3 been exposed to a batch of Replenate UK Factor VIII
 4 concentrate that had been contributed to by a donor
 5 who subsequently went on to develop variant CJD. As
 6 part of the present risk assessment exercise, the risk
 7 of this particular batch has been reviewed and it has
 8 now been decided it should no longer be regarded as an
 9 implicated batch, therefore, it is now considered that
 10 you have not been exposed to a batch of concentrate
 11 that was contributed to by a donor who subsequently
 12 went on to develop variant CJD."

13 So for nearly four years you understood that you
 14 had been exposed to such a batch of concentrate?

15 A. Yes, yes.

16 Q. And then in October 2004 you were told that you had
 17 not.

18 A. Yes.

19 Q. What can you recall about that?

20 A. Which I suppose was a call for celebration, but I was
 21 pretty angry really that they'd let me suffer in that
 22 knowledge, really, that I'd had to contend with yet
 23 another threat to my life after all this time, after
 24 all this rebuilding that I'd done, and I didn't know
 25 what to believe, you know. They'd said, "Yes, you

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1 whether or not they told people but our hospital took
 2 it in the way that they would ask people if they
 3 wanted to know their status. So I wrote back and said
 4 yes, I did and they wrote back to me and said, "You
 5 have had blood from a donor who later went on to
 6 contract new variant CJD".

7 Q. If we just put up own screen, please, Paul, 1213006.
 8 We can see this is a letter from
 9 24 September 2004, Andy, from your doctor to you.

10 A. Yes.

11 Q. It refers to -- the doctor writing to confirm that you
 12 did receive UK sourced plasma derived Factor VIII
 13 between 1980 and 2001?

14 A. Yes.

15 Q. "As I had previously informed you in a letter in 2001
 16 you have previously received concentrate from a batch
 17 that had been contributed to by a blood donor who
 18 subsequently went on to develop variant CJD."

19 A. Yes.

20 Q. So you had been told that information in 2001?

21 A. Mm-hm.

22 Q. It's repeated in this letter of 24 September 2004 and
 23 then if we just have on screen please, Paul, 1213007,
 24 not long after that on 1 October you received this
 25 letter:

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1 were exposed. No, you're not exposed", is there going
 2 to be another letter coming in a couple of weeks
 3 saying, "Actually, the last letter was wrong. You're
 4 going to ..." You know, you just don't know what's
 5 going to happen.

6 So I really tried to put the whole CJD thing
 7 towards the back of my mind. It wasn't something at
 8 that point that I was equipped to cope with.

9 Q. You'd started, on your return from the States in 2003,
 10 you had started doing bits of IT work for the
 11 Macfarlane Trust?

12 A. Yes.

13 Q. You were creating -- you created a website and a chat
 14 room.

15 A. Yes.

16 Q. Through that you got to know people and that led to
 17 the establishment of the Tainted Blood Organisation?

18 A. Yes, that was directly --

19 Q. Can you tell us about that.

20 A. Yeah, it was directly as a result of that chat room.
 21 You know, it was probably the first, apart from the
 22 conferences that the Macfarlane Trust and the
 23 Haemophilia Society used to organise where people
 24 could get together for a weekend, this was the first
 25 real communication medium that we'd got that would

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bring people in the same situation together.

You know, we could compare stories, we could compare the treatments that we'd had, we could tell each other how we were feeling without judgment, and it just seemed to me that, because the Macfarlane Trust was for people with HIV only, that the wider community could really benefit from something like this and, you know, we banded ideas about.

There was -- in 2006 there was a large media -- they cottoned on to the story as they do from time to time. We'd had the Observer newspaper follow us for several weeks in a row. News outlets had decided to follow people's stories and get interviews, and we got quite a lot of media that we wanted to have archived, and so, initially, the Tainted Blood website we came up with to kind of put all that into one place, and then followed what I called the blog although it's a bulletin board, like a forum, if you like, and that started to attract people because of the news that we had had who weren't originally part of the Macfarlane Trust; so people with hepatitis C through haemophilia. We didn't know so much about whole blood infections back then.

So Tainted Blood as a website came about and

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Q. It's Michelle.

A. Yes.

Q. I think you wanted to tell us just a little about Michelle's background and how the two of you came together.

A. Yes. I was at the bereavement weekend for two reasons. I was there because I'd been bereaved from my then fiancée in the States, so I'd got the -- I was kind of part of the community but not through that, I was part removed because of the country separation, but I'd also been asked there to speak as a delegate on the campaign and Tainted Blood and she was there because sadly her brother, Andrew, had been in the same situation as me. He'd gotten HIV and hepatitis C when he was a boy. He died at the age of 24 in 1996.

So again, I guess, there was the removal of that necessity to explain. There was never the elephant in the room about the HIV or the hepatitis C. It was known from the outset, which was amazing. It meant that -- I mean, we saw each other and it was pretty much love at first sight, but it probably would have been something that I could not have slipped into, I guess, as easily with anybody else who didn't have that knowledge of the background that we'd both been through and we could have, for want of a better word,

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then as part of my research into it I contacted a solicitor in Manchester through a contact of mine and we looked into judicially reviewing the Government's decision not to call, ironically enough, a public inquiry.

He said, "Well, if you're going to do that, you're going to need the backing from a lot of people, the official backing from a lot of people". So we sent out, through the Macfarlane Trust and the Skipton Fund, mandates for people to say that we would represent them to a solicitor to say, you know, "We'll back this judicial review", and floods of these things came back in and because we put phone numbers on I received a lot of phone calls from people telling their stories to me.

And I and another guy who set up Tainted Blood, Gareth Lewis, who is sadly no longer with us decided to form the campaign group proper. We started up a bank account in both of our names. He as chairman and me as secretary, and that's how Tainted Blood came about really and we started our research and work from then on.

Q. You met your wife, your now wife, at a bereavement weekend with the Macfarlane Trust in October 2006?

A. Yes.

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a normal relationship, and it was amazing.

Q. You married in 2007?

A. Yes.

Q. And you've got three kids?

A. Yes. She was already the mother to my step-daughter [redacted] who is 15 now and we, very soon after we got married, decided that we want to try for our own kids and so we started to investigate the Chelsea & Westminster's sperm washing process.

Sperm washing is an amazing breakthrough but the emotional roller-coaster that we both went through in trying to for our first child was horrendous really. Just thinking back to it, you know, you've got such expectations that this is going to work and then it doesn't work and then it doesn't work again.

Each time you're waiting on that pregnancy test and it's negative every time and each time the funding that you've been allocated is getting less and less and your chances are running out and we had to apply for funding a couple of times and, eventually, we ran out of what they call RUI chances and went for our only IVF cycle.

So Michelle had to undergo egg harvesting, which meant lots of hormone drugs beforehand and a little bit of an operation to harvest in eggs and then we had

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1 the sperm washing for that and then the foetuses were
2 created and some were frozen and then it was a case of
3 how many viable ones have you got. Everything was
4 kind of fingers crossed, fingers crossed right up
5 until the last moment and the first IVF cycle also
6 failed, and so we decided to pay then for
7 transplantation of one of the frozen embryos and it
8 was a miracle but it worked and we had our daughter
9 through it.

10 Q. You and your wife and your children, what's the impact
11 on a day-to-day basis now, in general terms, of your
12 illness and infection?

13 A. I think like my parents tried to do with me I try to
14 put on as brave a face as possible and try to make
15 life as absolutely normal for everybody as I possibly
16 can.

17 Whatever I'm going through, I will, unless
18 I really can't, I will try and hide it as much as
19 possible so that we can have that normal family life
20 so the kids can have a normal childhood.

21 I don't hide it with them. They know that I've
22 been on the TV. I'm not sure they, at least the
23 younger ones, understand quite what for yet. They
24 know that there was something nasty in the blood and
25 daddy has to take tablets for it every day. I don't

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1 A. That treatment made me somebody that I wasn't. It
2 made me angry. It made me anxious. The physical side
3 effects were horrendous. Initially for the first 12
4 weeks I was on a drug called telaprevir and I've never
5 been on a drug before that comes with its own
6 help-line and then posting a bottle of Aveeno cream
7 through the post to you every week. They knew how
8 horrendous this drug was and they were doing things to
9 mitigate it. This was a help-line you could phone at
10 any time day or night if you were struggling with the
11 symptoms, the side effects of the drug. I did once,
12 on one occasion I did phone it and, to be honest, it
13 wasn't a great deal of use. They said contact your
14 liver specialist in the morning or something.

15 I came out in bright red rashes that was
16 exacerbated by sunlight. You're supposed to take as
17 well with telaprevir a certain amount of fat with the
18 pill equivalent to about half a cup of olive oil every
19 time you take it and if you don't take fat with it, it
20 wrecks your lower bowel and colon and I had that
21 happen no matter how much fat I took with it and going
22 to the toilet was a horrendous experience.

23 Then the 12 weeks of telaprevir finished.
24 I think that was about three months into it. By that
25 point, though, I had already become so anxious and was

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1 think they quite get the seriousness of what might
2 happen if I stopped taking those tablets. They know,
3 obviously, that I went through the horrendous
4 hepatitis C treatment and what that did to me. It
5 almost took away their Dad for a year.

6 But, yeah, I try to make it as absolutely normal
7 for them as possible.

8 Q. Can I ask you about that hepatitis C treatment. That
9 was in 2013?

10 A. Yes.

11 Q. It was triple therapy?

12 A. Yes.

13 Q. How did it come about that you entered into that
14 treatment process?

15 A. My consultant at the liver team, Dr Mutima was quite
16 insistent, really, that -- my fibroscan wasn't too bad
17 at that point. I think it was 10.5 or something like
18 that, but he said that it had been working its way
19 upwards for quite a long time and that if I didn't
20 have treatment now, at that time, then it could be
21 much harder to treat later on. And the newer
22 therapies were still some way off and so he -- because
23 he was quite persuasive I said, yes, I would undergo
24 the treatment.

25 Q. What was that treatment like?

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1 having such severe panic attacks that they decided
2 they'd have to put me on antidepressants. So they put
3 me on, initially, while the antidepressants kicked in,
4 I was on Valium or Diazepam, which didn't really do
5 anything for me.

6 I was curled up on the bed in absolute terror of
7 what was happening to me for about two weeks before
8 the pills kicked in and then the Citalopram that they
9 put me on, the antidepressant, started to work and
10 although I was still having the panic attacks they
11 were more manageable. And then they had to up the
12 dose because they were coming back, so obviously some
13 brain chemistry had changed with these drugs and
14 I don't think that they think that can be changed back
15 now because I'm still on the antidepressants so many
16 years later.

17 But then the interferon and the ribavirin over
18 48 weeks and it had to be 48 weeks because I'm HIV
19 positive apparently. Had I just had hep C it would
20 have been six months but in their wisdom 48 weeks. By
21 the time I came out of it I was absolutely wrecked.
22 From the very early days, I was so tired that even the
23 thought of looking after the kids on my own would send
24 me -- I'd just burst into tears. I didn't think
25 I could be left alone with them. I wasn't safe to be

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left alone with them because I couldn't help them if they needed anything and, at one point, I seem to remember they put it down to migraine caused by the drugs but I completely lost my vision and had to be rushed into A&E. Luckily that came back fairly quickly but just such a scary, horrible life-altering time really and it had an impact not just on me but everybody around me.

I don't know how people cope with more than one go at this, I really don't.

Q. You've told us about everything you went through in terms of treatment and illness in the 1990s.

A. Yes.

Q. But you've said about this treatment in 2013:

"Taking those drugs caused me to feel the worst I have ever felt in my entire life."

A. Yes, I stand by that, yeah, because I think it was --

a lot of it was down to the -- in the days of AIDS

I could -- I actually got quite good at being ill, you know, it was almost my thing. I could be ill.

I could cope with it. I could get through this

because I still had my mental faculties about me and

I -- with the hepatitis C treatment that was removed.

It was completely taken away from me. I had no control and it was horrifying. It was terrifying.

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I have once a year which is supposed to fortify the bones but that in itself comes with side effects, one of which is fractures, believe it or not, of the jaw bone. I haven't managed -- I've managed to steer clear of that but I've been told that that could be an issue and I can't have any dental surgery because it won't heal because of the zoledronic acid and that will stay within me for about ten years now.

So I mean the osteoporosis itself is something that I have to be aware of every day because of my illnesses my balance isn't particularly good so I'm at quite high risk of falling and so that's something I really have to be aware of.

Q. You received treatment currently from the Royal Orthopaedic Hospital, from Worcester Royal in relation to your HIV treatment and the Queen Elizabeth Hospital for liver monitoring, endocrinology, dental and haemophilia care.

A. Yes.

Q. You have said this in your statement just attending appointments can be a full-time job?

A. It is. It's a career, yes, absolutely.

Q. You've drawn a distinction in your statement between people who were infected at an older age and you have described them as having had their world ripped

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Q. The treatment did clear the hep c virus?

A. Yes, thank goodness.

Q. Obviously you continue to have to take medication in relation to the HIV --

A. Yes.

Q. -- for, as far as you are aware, the rest of your life?

A. Yes.

Q. What other ongoing physical effects do you have from your illnesses or from the treatments you have received for them?

A. I don't think I'll ever quite recover from the days of having AIDS. My chest is not as it should be. I can't put weight on evenly. The HIV drugs have done something called lipodystrophy to me and so my body shape is very strange. But also, you know, the fatigue has always been ongoing.

I don't think my body can control its internal temperature very well so I have to take paracetamol quite regularly just to keep fever down and then I found out in 2014, Christmas time, by way of a fall which fractured both of my wrists and my ankle that one of the HIV drugs had caused me osteoporosis as well, and so I've had to be put on to intravenous infusions of a drug called zoledronic acid, which

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apart --

A. Yes.

Q. -- and your own situation and you've put it this way in your statement:

"As I've always suffered from medical issues it is simply all I've ever known."

A. Yes.

Q. I wondered if you could tell us a little more about that.

A. I've tried to put myself in the position of somebody who had grown up with, yes, with, you know, the complications that haemophilia brings but despite that being able to create a normal life, and then having this diagnosis placed upon them and having everything that they've known before completely ripped apart.

It's difficult for me to do because I haven't had that experience but I can imagine to some extent how life-destroying that could be; whereas for myself, you know, in some ways I think it's been easier for me because it's all I've ever known. I've not known a time really or at least I don't remember a time when I didn't have HIV and AIDS, when I, you know, I wasn't looking at a lifetime of illness and possibly an early death.

Q. The employment and the financial repercussions of your

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1 illnesses have been that you've not been able to
 2 establish the career that you would have wanted to
 3 establish.
 4 **A.** Correct, yes.
 5 **Q.** You do some work, I think, still?
 6 **A.** Yes. The only way that I've been able to come up with
 7 to -- to normalise my working life is to create my own
 8 business and the only way I've been able to do that is
 9 with the help of somebody else who is in very similar
 10 circumstances to me.
 11 I taught myself web development. He taught
 12 himself and at university how to draw, how to
 13 illustrate and together we set up a web development
 14 company and it's -- it's what we could do. It's not
 15 a career. We understand each other. We know that
 16 we're going to be ill. We know that we're going to
 17 have time off. We know we can be flexible. We know
 18 we have to go to the hospital appointments that we've
 19 got to go to.
 20 But it's something to tell people as well, "What
 21 do you do?"
 22 "Oh, I'm a web developer."
 23 Not, "What do you do?"
 24 "Oh I sit at home and feel sorry for myself."
 25 I had to have that in my life. I couldn't be

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1 family have, the four of them, apart from me have
 2 managed to get travel insurance for about £30. Mine's
 3 come back at about £176.
 4 **Q.** Can I just ask you next about your experiences in
 5 relation to the trusts and schemes, Macfarlane,
 6 et cetera. You have made some reference to them
 7 already.
 8 Just starting with the litigation, the HIV
 9 litigation in 1991, you've explained in your statement
 10 how your parents had to sign a waiver. You wanted,
 11 I think, to share a little more information about that
 12 with us.
 13 **A.** Yes. So from what I've been told -- and I was not
 14 involved in this in any way, this was one of the
 15 things I think they tried to protect me from -- they
 16 were offered as part of the litigation a financial
 17 settlement, a scaled financial settlement depending on
 18 the circumstances of the victim, and they were told
 19 that they would have to sign an undertaking which said
 20 that they would not take the Government back to court
 21 for any -- for the HIV infection or any future viral
 22 infections, and they were also told that this was
 23 a circumstance in which nobody would be given the
 24 settlement unless everybody agreed to it. It wasn't
 25 something they could check because nobody knew each

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1 somebody who, just for outward purposes I had to have
 2 it. I had to be somebody who was contributing to
 3 society in some way and so that's what we do. We're
 4 never going to make a lot of money out of it but I at
 5 least feel like we're doing something.
 6 **Q.** You've, in terms of the practical financial
 7 arrangements of life, you've looked into the
 8 possibility of getting life insurance but, you've put
 9 it this way in your statement, nobody would touch you
 10 with a barge pole?
 11 **A.** Quite right, yes, yes. I mean, "Can you tell us about
 12 any of your previous medical conditions?"
 13 "Haemophilia."
 14 "Oh, yes, okay, we can probably workaround that,
 15 yes."
 16 "Hepatitis."
 17 "Ah, mmm, we might have to take that to our
 18 specialist medical assessors and see what we can come
 19 back with."
 20 "HIV."
 21 "Right ... no, I'm not sure we're going to be
 22 able to help you on this occasion, Mr Evans."
 23 **Q.** You used to be unable even to get travel insurance.
 24 Now you can but it's very expensive.
 25 **A.** Yes, I'm hopefully off on holiday later this year. My

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1 other at the time. She might have been -- my Mum
 2 might have been able to talk to other parents at the
 3 hospital and I think probably did, but certainly the
 4 wider community, we had no way of verifying this.
 5 So they felt so pressured to sign it that that's
 6 what they did. They were absolutely desperate. They
 7 thought that people who were possibly in an even worse
 8 situation than I was, that they wouldn't get any money
 9 and they needed that money desperately and they
 10 couldn't be the ones to hold that back from them.
 11 **Q.** This was in about 1991, as far as you know?
 12 **A.** Yes, yes, 1991.
 13 **Q.** Were your parents, as far as you know or based upon
 14 the discussions you have had with them subsequently,
 15 were they given any understanding or any information
 16 about the possible risks of infection with hepatitis C
 17 at the time they were being asked to sign that waiver?
 18 **A.** No, none at all, as far as I'm aware. The
 19 hepatitis -- I think, was it mentioned on the waiver?
 20 I think it was mentioned on the waiver but I think
 21 that was the first they heard of that particular
 22 threat, and the circumstances were that they didn't
 23 expect me to live very much longer and so even so
 24 I don't know whether that would have been a factor in
 25 them, even if they'd known about it, a factor in them

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1 not signing because they didn't expect to have their
 2 son for much longer and they were just trying to do as
 3 much as they could.

4 **Q.** What's your experience been of making applications to
 5 the Macfarlane Trust?

6 **A.** In the early days when I finally found out that there
 7 was a Macfarlane Trust to go and claim from it seemed
 8 fairly straightforward. It was just a case of writing
 9 them a letter saying, "I need some money for such and
 10 such", and they would reply with a yes or no. In
 11 fact, that was the first application I made from them
 12 was, around the time I was doing my Open University
 13 course and they paid for some of that.

14 It seemed much easier to access back then. They
 15 didn't have the funding but, you know, if there was
 16 a reason behind them saying no, it was because of that
 17 rather -- or, you know, they would lower the amount
 18 they would give you rather than, you know, bureaucracy
 19 as it seems to have come to in the later days, when --
 20 well, maybe in the second to last CEO to the last CEO
 21 of the Macfarlane Trust, the bureaucracy around the
 22 application process became absolutely unbearable. It
 23 was a case of having to justify really your lifestyle
 24 to them in order to be able to access any funds by way
 25 of an income/expenditure form, so that they could see

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1 **A.** Yes, I'm obviously in contact with a lot of people and
 2 people have been through the process and it seems very
 3 similar to what went on before; so no, I'm not going
 4 to engage with that.

5 **Q.** You do get regular monthly payments and top-up
 6 payments from the EIBSS --

7 **A.** Yes.

8 **Q.** -- which you have said allow you to sustain
 9 a reasonable standard of living?

10 **A.** They do.

11 **Q.** But you have a particular concern about those
 12 payments.

13 **A.** Yes. I mean as of late the payments have been
 14 increased to a point where I can see myself being able
 15 to live with some sort of security as someone with
 16 what they call the SCM, the special category
 17 mechanism, and HIV payments, they are at a level which
 18 is probably something we should have had for a long
 19 time, but they're there now, but my specific fear is
 20 that the rug could be pulled out from under us at any
 21 point.

22 There's no guarantee that these payments will
 23 last beyond the next spending review and the
 24 uncertainty that that creates is very frightening
 25 actually. I need to know that when I'm not here

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1 exactly what money you'd got coming in and exactly
 2 what money you'd got going out and what you spent that
 3 money on.

4 I know that through previous trustees of the
 5 trust have told me, that that column was looked at in
 6 detail to see if there was anything particularly
 7 frivolous on that outgoings list, in which case the
 8 likelihood would be that the grant would be turned
 9 down.

10 **Q.** You have got to a stage when you just didn't have the
 11 energy to apply for any further grants.

12 **A.** Yeah, I think I might have done the income/expenditure
 13 form twice for different things. I think I was
 14 accepted once and turned down once, and then
 15 I couldn't face it anymore. I couldn't face this
 16 probing to justify the needs that I very clearly made
 17 clear to them that I had for these funds, and all they
 18 wanted to do was to probe into my life. I couldn't
 19 cope with that anymore and so I just withdrew
 20 completely from them.

21 **Q.** In relation to the current EIBSS scheme, you've also
 22 not had the energy to apply for any specific grants --

23 **A.** No.

24 **Q.** -- because you think it will result in the same kind
 25 of process?

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1 anymore that my wife will be okay, and I need to know
 2 that my kids will be okay and at the moment I don't
 3 know that. I don't know that I can put money aside
 4 now to make sure that they're okay because I don't
 5 know if it's going to continue and I don't know if
 6 when I die they will be receiving anything.

7 **Q.** You've made some observations in your witness
 8 statement about your medical records.

9 **A.** Yes.

10 **Q.** You've been told and you've seen references I think to
 11 there being multiple volumes of records?

12 **A.** Yes.

13 **Q.** But what you have received when you've asked for them
 14 doesn't appear to add up to the volume that you've
 15 seen described.

16 **A.** Correct.

17 **Q.** You believe that you haven't been provided with all of
 18 your medical records?

19 **A.** I can only assume that that is the case. I remember
 20 them wheeling them in on trucks, in small trucks, you
 21 know, in the clinic appointments. There were volumes
 22 and volumes, probably a good 4 inches thick each and
 23 I think what I've sent to you does not come anywhere
 24 near that amount.

25 **Q.** Now, a very important part of your life in recent

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1 years has been as you've described in part already,
2 Tainted Blood and providing support for the community
3 of people who have undergone experiences similar to
4 your own.

5 A. Yes.

6 Q. Is there anything further you wanted to say at this
7 stage about that work and how it's impacted upon your
8 life?

9 A. I think campaigning has been, for me, a crutch upon
10 which I've lent. Once I started to discover the truth
11 about what happened in the early days, it wasn't
12 something that I could with good conscience leave
13 behind.

14 Once I started hearing the stories of how people
15 had been affected by this, it wasn't something that
16 I could put aside and move on with my own life and so
17 I threw myself into the campaign really back in 2006.
18 A few of us did and we've gone hell for leather ever
19 since, just to try to get -- well, to try to get where
20 we are today really, you know, and -- this is a really
21 surreal experience for me because this is something
22 that I had maybe imagined but never thought would
23 actually come true, that we're sitting here in a room
24 with Sir Brian over there and an audience and people
25 watching across the internet, and people are finally

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1 A. Yes.

2 Q. -- were you or your parents ever offered any form of
3 counselling or other support?

4 A. No, no form of counselling or support at all. There
5 wasn't a counsellor available at the time we were
6 told. We weren't offered counselling. They weren't
7 offered counselling. My social worker actually put
8 me -- I was having some issues around anger. I was
9 very snappy and very angry at the time, so I went to
10 see him, having recognised that this was a problem,
11 and he put me in touch with another charity called
12 Freshwinds who do complementary therapies in
13 Birmingham and they set me up with reiki and goodness
14 knows what else, but one thing that they did do was to
15 put me onto a small mindfulness course and that really
16 has been the only thing that's kind of helped with
17 that.

18 But again it's had to be done through the
19 private sector and charities. There's nothing
20 official to support the mental stuff that we've been
21 through and there never really has.

22 Q. Andy, those are the end of the questions I have for
23 you.

24 Before I ask Mr Snowden if he has anything to
25 add, is there anything further that you would like to

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1 getting to hear what happened in this story.

2 And it's official now. It's not something that
3 people can dismiss as, you know, a bunch of haemos
4 moaning about, well, they got a couple of viruses, so
5 what, nobody was to blame.

6 This is real now and I think that's helped a lot
7 of people. From my experience, since the Inquiry was
8 announced it's helped a lot of people to come forward
9 and tell their stories because there's not the shame
10 and the stigma there anymore. And so if -- if this
11 Inquiry has done only that it's been successful
12 already in my eyes and if it goes on then to expose
13 the real truth about what happens, the icing on the
14 cake.

15 I think this is the start of the end for many
16 people and I really, really appreciate being here.

17 Q. It's very clear from what you said and from your
18 statement that there's been a huge amount of mutual
19 support from people through campaigns and
20 organisations such as the ones you describe.

21 A. Yes.

22 Q. Other than that, other than I think you had some
23 support from a social worker at the Queen Elizabeth
24 Hospital who you said in your statement was incredibly
25 helpful in all sorts of practical ways to you --

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1 add?

2 A. I did scribble something down.

3 So emotionally coping with all that's happened
4 to me and all that's still going on is difficult.
5 We've spoken about my antidepressants because the
6 hepatitis C treatment altered my brain chemistry.
7 I've no doubts about that. It's not a case that
8 talking therapy because can help. It's physiological,
9 but then you have to compound that with the life
10 experience which to date hasn't exactly been smooth
11 sailing. People talk about post traumatic stress
12 disorder and I think for a lot of us that's entirely
13 appropriate.

14 As far as the antidepressants go, it seems to me
15 that it's almost a decision between crippling anger,
16 anxiety and depression or the levelled out almost
17 non-life that antidepressants bring.

18 My body's been changed by the viruses and all
19 they bring, all the consequences of the treatments,
20 all the damage treating the indirect damage causes and
21 that's bad enough, but I've dealt with that for quite
22 a long time. I've become good at being ill or
23 disabled or in pain without relief but the one thing
24 that I've been banking on all that time is this, my
25 mantra, that you may not take -- you may take my body

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1 but you must not take my mind. I've maintained that
2 all of my life and now it feels that since the
3 hepatitis C treatment that I have even had that taken
4 away from me and I feel like there's really very
5 little left to take.

6 But speaking for myself and everybody else, you
7 know, we take that little piece of what's left and we
8 put a smile on it and we do the absolute best that we
9 can and sometimes that's enough and sometimes it
10 isn't. So if the Inquiry can even partly understand
11 that then for me it's been worthwhile.

12 This stands as one of the worse peacetime
13 disasters in the history of the UK because of the
14 number of fatalities alone, but it remains unique as
15 one that has kept taking for four decades in terms of
16 both life itself and the ability to live.

17 We deserve the truth. History deserves the
18 truth and I have every confidence in this Inquiry to
19 give us that truth, not only for those of us that are
20 in this room today but for those that couldn't be,
21 those that have gone before us, for Gareth, [redacted]
22 the members of the Tainted Blood committee that have
23 died since then. They are not here today, so we are
24 and I hope this is the end.

25 Q. Thanks, Andy, I am just going to ask Mr Snowden if he

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1 later than you might have expected today. We simply
2 had to listen to what we've just heard.

3 (11.46 am)

4 (A short break)

5 (12.22 pm)

6 SIR BRIAN LANGSTAFF: Our next witness will give evidence
7 underneath the protective cover of a restriction
8 order. Those of you who have been here before or been
9 following the Inquiry on the internet will know what
10 this involves, but for those if you who haven't,
11 I need to explain it again.

12 The Inquiry takes very seriously the protection
13 of the anonymity of a witness who would wish it and
14 our next witness, Mrs D, does.

15 The order provides as follows: that the name and
16 address of witness W1921 (she will be known to us as
17 Mrs D) and any other identifying information such as
18 her image or a description of her appearance cannot be
19 disclosed nor published in any form unless express
20 permission is given by me or by the solicitor to the
21 Inquiry acting on my behalf.

22 She must be referred to only as Mrs D. This
23 order will remain in force for the duration of the
24 Inquiry and at all times thereafter unless otherwise
25 ordered, though I may vary or revoke the order by

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1 has anything else.

2 No. Thank you.

3 A. Thank you.

4 SIR BRIAN LANGSTAFF: Andy, you've said you appreciate
5 being here. I think the Inquiry appreciates it every
6 bit as much.

7 A. Thank you, sir.

8 SIR BRIAN LANGSTAFF: Thank you so very much for showing
9 us your impressive resilience and for not sparing us
10 some of the details which must have been difficult for
11 you to recount and have not been easy for us to listen
12 to, but needed to be said. So thank you very much
13 indeed.

14 A. Thank you, sir.

15 SIR BRIAN LANGSTAFF: Two things, Ms Richards. First, it
16 occurred to me listening to that to ask whether you
17 know whether there was ever any approval of the
18 settlement in court before a judge that was reached in
19 respect of the settlement which has involved the
20 waiver.

21 MS RICHARDS: I don't think we currently know, sir. It is
22 one of the matters under investigation.

23 SIR BRIAN LANGSTAFF: Thank you very much.

24 We will take a break until 12.15. Can I just
25 say that it's likely that lunch will be a little bit

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1 making a further order during the course of the
2 Inquiry.

3 She is content to give evidence before you, as
4 other witnesses have done, but her image will not be
5 live streamed. Her voice will and the transcript will
6 record her words but nobody will see her image. For
7 that reason, if you are in and around the Inquiry
8 afterwards and happen to have your mobile phone out to
9 take photographs for whatever reason, could you please
10 just take care to make sure that you don't, however
11 accidentally capture her image.

12 Mrs D.

13 MRS D, affirmed

14 SIR BRIAN LANGSTAFF: I understand, Mrs D, that for your
15 comfort you would wish to have a break after 25/30
16 minutes, something like that, at a convenient moment?

17 A. I may do.

18 SIR BRIAN LANGSTAFF: If you do, and when you do, please
19 indicate. Do not sit there in discomfort if you feel
20 that you would like a break.

21 A. Thank you.

22 Question by MS FRASER BUTLIN

23 Q. Mrs D, on 19 May 1986 you went into early labour with
24 your first child.

25 A. I did, yes.

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1 Q. You were admitted into hospital?
 2 A. Yes.
 3 Q. And on 23 May you were told you had to have
 4 a transfusion?
 5 A. That's right, yes.
 6 Q. Before the transfusion was completed it was
 7 disconnected and you were sent for an ultrasound?
 8 A. Yes.
 9 Q. And you describe in your statement that it was all
 10 rather strange and you didn't really understand what
 11 was going on.
 12 A. Yes, that's correct.
 13 Q. Can you tell us a little more about that.
 14 A. Well, I wasn't actually told why I'd got to have the
 15 transfusion in the first place. I was just told the
 16 doctors said that you're having it. They put the
 17 cannula in. They started the transfusion and -- but
 18 three-quarters of the way emptying, when the same
 19 sister came in and said, "You've got to have it out.
 20 You've got to go for a scan".
 21 She disconnected me, gave me a cellular blanket
 22 to put over the gown that they'd given me, and told me
 23 to walk without help, without, you know, anybody else,
 24 to the scanning for an ultrasound.
 25 That actually involved going down a corridor out

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1 no reason, as I knew then, why I should be having one.
 2 So I thought at the time when they took it out, part
 3 way through, was it meant for somebody else? Had they
 4 made a mistake? Was I that person, you know, and
 5 especially getting me out of the building. I mean, it
 6 did raise concerns.
 7 Q. Before you were given the transfusion, were you warned
 8 about any risks of having it?
 9 A. I wasn't told anything about it at all, even to the
 10 point I didn't know why I was having it.
 11 Q. As a result of that transfusion you were infected with
 12 hepatitis C.
 13 A. Yes.
 14 Q. About a year after the transfusion in June 1987 you
 15 didn't feel quite yourself.
 16 A. No.
 17 Q. Can you tell us what was wrong.
 18 A. I just started feeling down, depressed, lacking in
 19 energy. I just wasn't me. Before I'd been full of
 20 life, you know, I did clubs, I was sporting. I'd got
 21 a young daughter who'd survived the pregnancy because
 22 I wasn't sure, and I should have been full of life.
 23 There was nothing wrong in my life, except for me.
 24 I felt just like there was -- I wasn't me anymore.
 25 Q. You've described that you felt like you were carrying

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1 of the building, past the workmen who had got
 2 scaffolding up, across the grounds to a small single
 3 storey building where I had to have the ultrasound.
 4 Q. When you got to the place you needed to have the
 5 ultrasound, the radiographer was concerned that you
 6 were alone?
 7 A. She was very, very concerned. She was shocked, and
 8 she said that she was going to call to complain and
 9 ask for a porter with a wheelchair to take me back.
 10 Q. Somebody did that and you went back to the ward?
 11 A. Yes, that's correct, yes.
 12 Q. When you got back to the ward, you understood that
 13 there had been some raised voices amongst the staff?
 14 A. Yes. The lady in the next bed, because I'd already
 15 been on the ward for three or four days so I'd made,
 16 you know, a relationship with the woman in the next
 17 bed and she said, in her words, there had been a bit
 18 of a hoo-ha, raised voices, it sounded somebody had
 19 been having a go so I thought, oh, the radiographer
 20 had phoned and made a complaint and it hadn't gone
 21 down too well.
 22 Q. You were never sure whether the hoo-ha was whether you
 23 had gone to the ultrasound on your own or whether it
 24 was about the transfusion itself?
 25 A. Yes, because I hadn't been told why I got -- there was

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1 ten other people around with you?
 2 A. That's it. I was just -- everything was exhausting.
 3 Q. So you went to the doctor.
 4 A. Yes.
 5 Q. What did the doctor say?
 6 A. You're a working Mum, because I was working, I was
 7 working full time, you're a working Mum, you're going
 8 to be tired. That was it, sort of go away because
 9 there's nothing more.
 10 Q. Over the years you have had a number of physical
 11 conditions.
 12 A. Yes.
 13 Q. Thyroid cancer, several miscarriages, irritable bowel
 14 syndrome, fibromyalgia, an enlarged spleen,
 15 undifferentiated connective tissue disease, as well F3
 16 liver disease.
 17 A. Yes.
 18 Q. You are not sure whether they are related to the
 19 hepatitis C but you often wonder whether they are?
 20 A. I very much believe, and it has been said to me in the
 21 rheumatology department that it was probably the
 22 hepatitis C infection that trigger the autoimmune
 23 conditions, which in itself have put me on immune
 24 suppressants and that in itself causes you get a cold,
 25 you get sepsis, you don't -- and it makes you feel

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1 very ill.

2 Q. You believe that there's been a really a cycle of

3 illness all arising from the hepatitis C?

4 A. I do, yes.

5 Q. You had to stop work in 1998. Why was that?

6 A. I hadn't felt any better from the time I was tired in,

7 you know, years earlier, but I started getting more

8 achey, I was exhausted, I was collapsing on the floor

9 at work. I'd been really pushing myself because I had

10 been doing really well at work, working up for

11 promotion, and after collapsing a few times, I went to

12 the doctors and they gave me sick notes at the time it

13 was called for exhaustion, and it literally was the

14 most awful exhaustion. I just couldn't stand anymore,

15 which actually felt really embarrassing because it was

16 just like saying, "I can't work anymore because I'm

17 too tired", but it was far more than that, but that's

18 how it felt and I think that's what other people

19 thought as well. It's just like, you know, you're

20 just tired.

21 Q. If we fast forward to 2016 because that continued and

22 went on but by 2016 you were really very unwell.

23 A. I was. I was very, very ill.

24 Q. What can you tell us about your symptoms at that time,

25 just before your diagnosis?

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1 Q. Then what happened?

2 A. Then I received a phone call from my GP's surgery

3 saying they had received a letter and could I go in to

4 discuss it, which I made an appointment and went in.

5 I was expecting this to be a letter from any one

6 of the departments that I was going, either orthotics,

7 rheumatology, anything like that, I went in and I sat

8 down and the GP held up a Public Health England letter

9 and said, "You're drug taking or a sex worker. You

10 are at risk of infecting everybody. You've got HCV".

11 I didn't even know what that was. They said, "You've

12 probably passed it on to your kid and husband and you

13 might die from this".

14 Q. You said to him that that's not right, that's --

15 A. I said, "That's not right, no, no, no. That's a false

16 positive. My haematologist told me 100 per cent.

17 I've had a second test", and he said, "No, no, no",

18 and he said, "No, it's definitely the second test has

19 proved positive".

20 I mean, I was kind of freaked because all was

21 going whizzing round my head was, "I am going to die

22 but I've actually killed my kids and husband". That's

23 all I could think, "That's it, we're all going to

24 die". But it was -- I asked what it is and he didn't

25 know. I said, "What can be done?" He said, "You'll

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1 A. For months I had been being sick, physically sick.

2 I couldn't eat anymore. I was losing weight. I went

3 down to just over six stone, which was half my body

4 weight, and there was just no reason. I couldn't

5 find -- you know, I was having monthly blood tests for

6 my autoimmune conditions but nothing was showing up,

7 but I just literally, as my family said, I was dying

8 in front of them.

9 Q. Eventually you were referred to a haematologist --

10 A. Yes.

11 Q. -- who did a series of tests.

12 A. Yes, quite a few.

13 Q. And you were then told that the test for hepatitis C

14 had come back as a positive. With that first test

15 what did the haematologist tell you?

16 A. Well, he actually phoned me up and told me this over

17 the phone. He said not to worry everything else come

18 back clear but this one had come back as a positive

19 but he didn't believe it was a true positive. He

20 thought it was a false positive because of my immune

21 conditions and the medication I was on and he could

22 see no reason why it would be positive, so he'd like

23 to do a second test.

24 Q. So you had that second test?

25 A. I went back and had the second test, yes.

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1 be referred to somebody", and that was it.

2 I mean, I can still picture the room. I can

3 picture the jumper he was wearing, the pen on the

4 desk, everything, the letter, but it was just -- it

5 was like he'd called me in to say, "You're a dirty

6 disgusting person, a danger to society. I don't know

7 what it is myself but that's what they're saying so go

8 away. You'll get an appointment from somebody else",

9 and I left.

10 Q. As you say, you can still remember vividly the details

11 of that?

12 A. I can remember everything about the room. I won't go

13 in that room. I can remember even the stitching.

14 He'd got a hair on his jumper. The whole lot became

15 stuck in my brain. I can still picture it now.

16 Q. And you still have flashbacks to that day?

17 A. I do have flashbacks and I was later diagnosed with

18 PTSD from that point.

19 Q. You have described in your statement that you walked

20 out of the surgery feeling suicidal.

21 A. I did. I left, I could not -- I could not compute or

22 work out what I'd just heard, the consequence, I'd

23 been given nothing to help me understand any of this

24 and I just had the GP who'd known me a few years

25 basically say I was a drug-taking prostitute and, you

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(20) Pages 77 - 80

1 know, I'd put everybody at risk with something
 2 I didn't even understand, and I left and I drove which
 3 now thinking about it I really shouldn't have done,
 4 driven in that state, and all I could think of was
 5 there was a local viaduct which I was going to go and
 6 throw myself off.
 7 **Q.** In order to get to that viaduct you had to drive past
 8 your own house.
 9 **A.** Yes.
 10 **Q.** As you passed by you realised you couldn't do that to
 11 the children?
 12 **A.** Actually, my son was looking out of the window waiting
 13 for me because he knew I was desperately ill, he knew
 14 I'd gone to the doctors', and he was just, sort of,
 15 "Where's Mum? Is she going to know what it is", you
 16 know, and I just saw his face and I thought, "I can't,
 17 however bad it is, I can't leave them to deal with
 18 this without me", so I went into the house instead.
 19 **Q.** It then took a month before you saw anybody again and
 20 on that occasion you saw the haematologist again?
 21 **A.** Yes, I did.
 22 **Q.** What was their reaction to how you'd been told about
 23 the hepatitis C?
 24 **A.** They were horrified. They were furious. They were
 25 really, really angry, as he'd asked for the tests.

81

1 had this transfusion in 1986, and she said that that
 2 was more than likely the reason that I'd caught this,
 3 and she also gave me the numbers for the Hepatitis C
 4 Trust and mentioned the online support groups.
 5 **Q.** You then had a liver scan and established the extent
 6 of the damage?
 7 **A.** Yes.
 8 **Q.** Did any of the doctors explain to you the ways in
 9 which hepatitis C can be transmitted?
 10 **A.** Well, no. I mean, obviously, first off I had the
 11 letter saying it was through drugs and sex, and then
 12 my hepatologist nurse said, you know, it's
 13 a blood-borne thing, but no -- but even she didn't
 14 give me any leaflets, information, or anything to tell
 15 me how you get it really or what precautions you
 16 should take or anything. There was just no advice at
 17 all. It was just HCV actually means hepatitis C.
 18 That's about what I learned but there was nothing, no.
 19 I got given no advice.
 20 **Q.** You didn't have any leaflets or anything to take with
 21 you?
 22 **A.** There was nothing at all, absolutely nothing.
 23 **Q.** You have two very particular concerns about your
 24 infection. Firstly, you have questioned why the
 25 infection wasn't identified earlier, given that you

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1 He'd asked me if I could -- you know, have the tests,
 2 he'd had the tests, he'd had the results, and he was
 3 so angry that the GP had told me because he was going
 4 to tell me in a situation where he could explain
 5 a little bit about it and he was just literally
 6 furious. He was going to explain about it he said.
 7 **Q.** He was able to tell you a little more about what
 8 hepatitis C was.
 9 **A.** Yes. He said, "I don't know. I'm a haematologist",
 10 because he had actually been checking for blood
 11 cancers, but he'd just screened me for that, for
 12 everything. He said it was a liver illness and there
 13 were treatments for it and he was going to refer me
 14 off to a hepatologist.
 15 **Q.** You then had to wait for a few more weeks to see the
 16 liver specialist?
 17 **A.** Yes.
 18 **Q.** You saw the specialist nurse?
 19 **A.** Yes, I did.
 20 **Q.** What happened at that appointment?
 21 **A.** She was actually brilliant. She was really, really
 22 helpful. She discussed what it was that I'd got,
 23 where I'd, you know, just talked to me to find out
 24 about me and we worked back and found out. Then she
 25 asked if I'd had a transfusion and I said, yes, I'd

82

1 were receiving treatment for a number of conditions
 2 over the 30 years between the transfusion and the
 3 diagnosis.
 4 **A.** Yes, I mean, through every pregnancy you get, randomly
 5 really, just checked for HIV and Hep B and it wasn't
 6 picked up on. I mean, rheumatology, all that, all the
 7 tests I had, all the diagnosis, and I know now that if
 8 you get -- if somebody is going to be started on
 9 treatment for rheumatoid arthritis, they test for HCV
 10 now. But that was after they'd started me on
 11 treatment; so they didn't test me. They didn't think,
 12 "Oh, why has this woman got all these conditions? We
 13 can't find out why".
 14 I was put on a ward in the early 2000s through
 15 rheumatology for a whole week to see if they could
 16 find out what was wrong with me and all they -- well,
 17 they came up with a diagnosis of fibromyalgia with the
 18 thought there might be something else. But, no, even
 19 through thyroid cancer, on the immune suppressant,
 20 4-weekly tests, nobody ever found out until they
 21 thought I had got blood cancer as haematology will
 22 screen for everything.
 23 I mean, I was at the hospital, yes, my notes
 24 were that thick (*indicated*), endless tests, endless
 25 medications: all the time, never tested.

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1 Q. Your other particular concern is why you were given
2 the transfusion and you've said that you were never
3 told why you needed it?
4 A. I wasn't at the time.
5 Q. There's also no record of the transfusion in your
6 medical records, is there?
7 A. There isn't.
8 Q. When you applied to The Skipton Fund you requested
9 your medical records.
10 A. That's correct.
11 Q. Can you tell us a little bit more about what happened
12 then.
13 A. Well, I had trouble asking for them and they seemed to
14 delay in sending them. When I did receive them,
15 there's some notes. I was actually admitted on to the
16 ward on 19 May. There's a page of notes for the 19th,
17 the 20th, the 21st, the 22nd, then it goes to the
18 24th, the 25th, all the way up to the 29th when I was
19 discharged having given birth.
20 The 23rd was missing. There's no notes for the
21 transfusion. There's no notes for the ultrasound.
22 There are no notes at all for that date, nothing, you
23 know, not temperature, not foetal, there's nothing.
24 So I questioned them on this and said, you know, "This
25 is -- not only have you not got the bit I know I need,

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1 box to say that you didn't have anaemia?
2 A. That's correct, which is a surprise because I was
3 anaemic from a child. I've always been anaemic and
4 I'm still anaemic now. I was anaemic before I was
5 admitted but, miraculously, I suddenly became
6 non-anaemic through the time I was there and then ever
7 since I've been anaemic with transfusion level anaemia
8 with the other three pregnancies I had. So it was
9 just like somebody decided to wipe that day, my
10 transfusion, my anaemia, for whatever reason.
11 Q. You've said that that's what worries you most, that
12 they have hidden the fact of the transfusion?
13 A. They have hidden the fact because part of me is should
14 I have had the transfusion? Did I need it? It may
15 have been for anaemia, it probably was -- you know,
16 they would have found I was anaemic anyway. But
17 obviously since looking at things and learning, it's
18 like was I -- and because of the arguments when I was
19 at the ultrasound, you know, I personally think was
20 I given the transfusion on -- was I infected on
21 purpose?
22 Q. You've said in your statement that the whole situation
23 around the notes and the lack of the records makes you
24 question whether you were deliberately infected
25 because you were young and healthy and you say maybe

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1 but where is all the supporting notes, all the nurses'
2 notes", and it was a very lengthy process which ended
3 up with me putting in a complaint which was ignored.
4 I sent in a letter recorded delivery to the
5 hospital saying, "This is my complaint. I need you to
6 find these notes", to which they said they hadn't
7 received it, even though it was signed as their mail
8 room.
9 I actually went up to the hospital in person,
10 went to the reception desk and asked them to bring
11 somebody down from the office to hand them my
12 complaint letter and all a sudden they instantly found
13 everything, except for the notes.
14 It took, all in all, about ten months from
15 initial request for them to supply me with notes that
16 they said they'd got and a letter to say that they
17 thought that, due to the timescale and the building
18 moves, that any letters from that time, except for the
19 ones that I got either side of that, had been
20 destroyed or lost and they've never come up with the
21 day of the 23rd.
22 Q. So there's no record of 23 May?
23 A. No.
24 Q. Also you have noted in your statement that the
25 discharge letter from your admission has a tick in the

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1 they wanted to see what would happen.
2 A. That's correct. That still stands today because
3 I have some across through support groups other women
4 who were exactly the same age because I was 19, I was
5 young, and they were 19 and they were given
6 a transfusion for anaemia and there just seems to be
7 a few cases and it's why did they do it? Why was
8 there not notes there on that day? Why has nobody
9 ever followed me up? Why did they leave me for
10 30 years, and why does there seem to be such
11 a cover-up over it?
12 If it just been, you know, a regular, "Well, we
13 gave to have a transfusion. We admit you had
14 a transfusion and unfortunately people got infections
15 from them", but it seems to have been deliberately
16 hidden.
17 Q. You are worried that there continues to be a cover up
18 because of something that happened when you attended
19 the hospital in April of this year?
20 A. That's correct, yes.
21 Q. Tell us what happened.
22 A. Well, I'm always at the hospital, I'm always having
23 appointments and, as Andy said before, my notes are
24 quite thick, from obviously regular -- so I notice
25 them coming when the receptionist gets them out. So

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I went and sat in an appointment and I saw them lift the notes and the receptionist went ... and she looked concerned and I thought, "Oh no, here we go again. There's going to be a delay. Have they put my stickers with the wrong address", but she put it under the trolley to the side and she called the clinic nurse and she looked in them and she looked a bit concerned, and I was sort of, "Oh no, I'm going to be in for a real delay and what's concerning about my notes", because having seen rheumatology four weeks before and there was no problem with my notes what's happened now.

There was a really long delay in the clinic during which I had a hearing test and when I was finally called in the doctor said that my notes had been -- although they were in a real mess, they had been messed with and that he couldn't find my previous clinic letters, test results, to compare the tests I'd had that day with the previous clinic so could I tell him about what had happened between the last clinic and when I was attending.

I did actually have an oncology follow-up letter from a clinic ten days before with me printed to show him because they cover some of the same things with some blood tests and stuff so I didn't have to have

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- Q. They have denied that that is what was said by the doctor?
- A. Yes.
- Q. And denied that the notes had been accessed by anyone inappropriately.
- What's your response to that?
- A. I say that they -- that it is a further cover-up because the notes were in a terrible mess, the doctor did say that to me, I could see that they were a mess, and the fact that they used the word "inappropriately" means that somebody had looked at them but they had presumably thought it was appropriate to look through them, but they haven't given me any reason as to why they were in a mess. I mean, there is no answer to that at all. They've just, you know, got back to the solicitor and I've seen that letter and it doesn't explain it.
- Q. I want to move on from that.
- A. That's fine.
- Q. You had been diagnosed with hepatitis C in the autumn of 2016?
- A. Yes.
- Q. And in January 2017 you were told you would be put forward for treatment with Epclusa?
- A. That's right.

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them done again, so I showed him that, which he copied some notes down.

- Q. Can you remember a little more clearly what you recall the doctor saying about the notes.
- A. He said that it looked like somebody had messed them up and that he couldn't, therefore, find -- and if he tried to look through it could take maybe half-an-hour to an hour or whatever. You know, he thought it would take too long to even look through them all because they were in such a mess. It looked like somebody had messed them up. "I don't know what somebody's been doing with these", is what he said.
- Q. You're worried that someone's gone through your notes because you're giving evidence to the Inquiry?
- A. Yes, because it wasn't -- nobody was aware that I was going to be giving evidence before, at my rheumatology appointment my notes were fine, and since then, you know, all of a sudden, my notes are a mess, they're not in order, there's pages hanging out which there weren't at the previous appointment and there's no reason for anybody to have done anything with those notes between one appointment and the next.
- Q. You are represented by solicitors and the solicitor's contacted the trust?
- A. Yes.

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- Q. You then had to wait to start that treatment until August in 2017?
- A. Yes.
- Q. Why did you have to wait?
- A. I was told I would have to wait until the NHS funding was available. I was told it was done on a month to month basis, that who could have their treatment funded that month and that you wouldn't know who it was going to be until they'd had the meeting that month and decided who was going to get the treatment, so that if somebody suddenly became a really bad case -- you know, it was you didn't know when you were going to get treatment. The nurse said that she was retiring in five years' time and I may have had the treatment funded by then.
- Q. You feel you shouldn't have waited for treatment.
- A. No, I didn't see why on earth I should wait for the treatment, especially as I'd found out that it was the NHS that had actually given me the infection and caused so many medical problems associated with that and the fact I needed the treatment, they should have just made it available there and then.
- Q. While you waited for the treatment to start, did you have any support?
- A. No. I had no support. Literally, there was just --

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1 I was just left on my own. It was just like I was
 2 abandoned to sort of be on your own, there's no
 3 advice, there's no counselling, there's no help.
 4 "You've got this and you might die before we get the
 5 treatment". I mean, that's how I felt. I thought
 6 I was going to die waiting for the treatment, because
 7 they seemed to have said, "You're really ill. You
 8 need this but we're not going to do it until they say
 9 it's going to be funded", and I waited until I got
 10 about a week's notice for the treatment and it was
 11 just like "yes".

12 Q. What would have helped while you had that seven-month
 13 wait -- obviously, not having the wait -- but if you
 14 had to have the wait, what would have helped?

15 A. Well, I thought actually right from -- I think anybody
 16 finding out they've got an infection and especially in
 17 the way that anybody's had infection via, you know,
 18 the NHS, basically, that you should have counselling
 19 straight away.

20 I mean, I went through cancer and I had, you
 21 know, I got sat down, told the diagnosis, I got told
 22 what the treatment was going to be, the whole
 23 treatment package, you get support lines, you've got
 24 somebody there to -- you know, the leaflets,
 25 everything, and I was well looked after when I had my

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1 trust in somebody which I found really hard since
 2 finding out everything, and she just ... like,
 3 "I can't cope with this", and she actually, I had to
 4 go back and be referred to somebody else because she
 5 literally couldn't cope. She didn't understand the
 6 situation and she couldn't help me.

7 Q. So that period of counselling came to an end?

8 A. It came to an end rather abruptly, yes.

9 Q. Eventually you were referred for some sessions for
 10 cognitive behavioural therapy and eye movement
 11 desensitisation and reprocessing treatment?

12 A. That's right, yes.

13 Q. You have said that that therapy came to an end for
 14 reasons that we will come to.

15 A. Yes.

16 Q. But you've said that the fact that the number of
 17 sessions was limited to 10 to 12 was in itself
 18 difficult.

19 A. It is, because if you get therapy and you need to keep
 20 talk through something that's also not just been so
 21 traumatic but, you know, it's ongoing and you need to
 22 take the time to do it, to be told at the start,
 23 "Well, you've only got 10 to 12 sessions to actually
 24 be cured of your psychological problems, your
 25 depression, your anxiety, all this has got to be done

95

1 cancer.

2 This just abandoned me to the fears I had, the
 3 illness -- you know, the complete lack of knowledge,
 4 almost like they wanted me to go away and they wished
 5 they hadn't found me.

6 I think there should have been counselling.
 7 I actually asked in February, the one year, I went to
 8 my GP, a different GP because I won't see him anymore,
 9 if I could have counselling because I felt that I'd
 10 gone into shock when I got diagnosed. I felt I wasn't
 11 coping. I thought I needed help and they said they
 12 would put me forward to it.

13 I finally got, 12 months later, I got the offer
 14 of talking therapy. I went to the appointment.
 15 A young woman sat there, and she asked -- well, no,
 16 first I got a call saying would I go to a group
 17 therapy session and I was like, no, no, no way am
 18 I sitting in a room explaining why I'm like I am. So
 19 then I had an appointment to see somebody singly and
 20 I went in the room and she listened to me, everything
 21 that happened, and she was getting a bit sort of ...
 22 while I was talking and then she says, "I'm getting
 23 really stressed just listening to you", which just
 24 gave me no hope or, you know, of any help. I mean,
 25 I just felt I've just opened my heart, given some

94

1 because we only get funding for 10 to 12 sessions",
 2 it's like adding extra pressure to something that's
 3 awful already.

4 Q. While you were on the treatment with Eplusa can you
 5 tell us how you were?

6 A. Well, I was hoping to actually have no side effects
 7 because it was, you know, all I'd heard was it's
 8 really good, you take it for 12 weeks, you'll be fine,
 9 but I wasn't. I don't know whether it was just
 10 unlucky or whether it's the association of the
 11 multiple drugs I'm on and it reacted with those.

12 I was very sick. I was very tired. I had
 13 headaches. I couldn't sleep. I was shaky. I got
 14 hearing loss worse than I had before and I became
 15 desperately in a dark place that I'd never felt.
 16 I mean, I'd been depressed but this was just
 17 horrendous and it scared me.

18 And then it cleared a bit, and the next day, and
 19 I realised that it was sort of two to three hours
 20 after I had taken the tablet this just wave of
 21 overwhelming awfulness that you just -- it takes you
 22 to a different place. It's like you have been taken
 23 out of yourself and there's just this scared shell
 24 that can't actually see life straight anymore.
 25 It's -- like you're in a fish bowl. Life doesn't seem

96

1 real.
2 It was horrible. I felt out of control and it
3 went on and it went on and I started getting dizzy
4 and I felt more down and -- from being able to cope in
5 a way, I hate to refer to Andy but he said you learn
6 to deal with the thing, and I dealt with the cancer,
7 I'd stayed confident, looked after my kids. It really
8 knocked me sideways and I haven't been the same since,
9 since that.
10 I mean, I was having the tests while I was
11 having it as well and I'd heard great things about
12 people's numbers dropping. Mine took to after 12
13 weeks to drop, so I was scared it wasn't going to work
14 and actually the nurse didn't think it was going to
15 work, but the test four weeks after I'd finished
16 showed it had actually cleared, which was a bonus.
17 But I've never felt the same since having it.
18 Q. Your hair turned a different colour as well?
19 A. Yes, I had -- if you imagine that I'd been ill, I
20 couldn't be the fit, healthy, happy person already,
21 then having gone down to 6 stone, I was skeletal and
22 I felt horrible. The one thing I had left was
23 waist-length hair, a lot of it.
24 The treatment, it started changing colour as it
25 was growing out and each month my hairdresser said

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1 did, that sounds like it's belittling it because it's
2 a big thing to get rid of it, but that's it, it's done
3 that. It hasn't changed my life. It hasn't changed
4 my health. It hasn't given me that I'm okay now.
5 Q. Mrs D, I'm conscious we've been talking for a little
6 bit more than half-an-hour. Do you want to take
7 a break at this point?
8 A. No, I'm fine. I'll carry on. I'll just keep crying
9 in my tissue.
10 Q. As you say, you've cleared the virus.
11 A. Yes.
12 Q. And you have now been discharged from the liver team?
13 A. Yes.
14 Q. But that in itself is making you anxious. Can you
15 explain why?
16 A. Because it was, "You've cleared it, goodbye". I was
17 told I'd got, you know, F3 nearly F4, you know, I'd
18 got severe fibrosis, it was obvious, it was nearly
19 cirrhosis, and I am on a lot of other things and
20 there's no follow up. There was no, well, you know,
21 I mean, I've already had cancer. I'm on immune
22 suppressants which makes you more likely of cancer and
23 having had hepatitis C there's another high risk of
24 liver cancer and I hoped or I think I should be
25 checked every six months or so to catch something

99

1 it's like looking at the rings on a tree, the
2 time-lines, it went yellow, it went a funny colour and
3 it all started breaking off and falling out.
4 I ended up with just horrible stubble and I know
5 it sounds stupid because everything, everybody goes
6 through in the illness, but that's just hit me so
7 hard. It was just the last little bit of you, it was
8 me, it was just that last bit of nothing to do with
9 the illness. I'd still got my hair, stupid and vain,
10 but it was just that one thing that kept me going.
11 Q. You said in your statement:
12 "My hair was the last thing I had and that
13 destroyed my self-confidence."
14 A. I just didn't feel like a woman anymore. I didn't
15 feel like a person. I was just this ill, skeletal
16 thing that ... you know.
17 Q. You have continued to feel really quite unwell, even
18 after the treatment?
19 A. Yes, I have not felt well since. I just felt -- I've
20 never felt well. I haven't felt well since 1987 but
21 I've been through everything else and gone through
22 everything else and I've just felt worse and worse and
23 worse, and I was so hoping the treatment would make me
24 better.
25 All it did was get rid of the hep c -- all it

98

1 early.
2 You know, it was 30 years before they found
3 that. I'd like them to catch something like that
4 a bit quicker but it's not the case. It's, "No,
5 you've cleared it, you no longer need" -- from
6 a mental okay, for just the knowledge that every six
7 months they could check there's nothing else going to
8 rear its ugly head would be at least helpful but they
9 don't want to do that.
10 Q. Since your diagnosis, your rheumatology team has
11 changed?
12 A. Yes, it has.
13 Q. As has your oncology team?
14 A. Yes.
15 Q. And you think that is because of your hepatitis
16 diagnosis?
17 A. I do. I found a change in an awful lot of people as
18 soon as I got that diagnosis. I wouldn't see the
19 consultant I'd been seeing for ten years. I'd
20 suddenly have to see somebody else.
21 The four-weekly blood tests which became almost
22 like a community day because you would go and you'd
23 see the same people, you would see the same
24 phlebotomists, they would be chatty. They stopped
25 being chatty. Where I have to have my blood tests

100

1 it's lots of little cubicles with curtains, and they
2 always leave all the curtains open, so it's like five
3 or six people having blood tests and, of course, it
4 said special precautions on every test after that, so
5 they'd get the gloves, and then you'd see other people
6 looking and you are thinking they're going, "They're
7 getting gloves for that person. They've got
8 something".

9 But it was the reaction from everybody. It's
10 like the doctors suddenly didn't want to see me. I do
11 not know whether it was suddenly, perhaps they felt
12 guilty they hadn't found it or they, you know, they
13 knew somewhere in my notes that it had said they
14 hadn't told me. They didn't want to do anything with
15 it.

16 The rheumatologist stopped seeing me, who had
17 been seeing me for years, yet he saw me a month or so
18 ago and said, the appointment before the last one, and
19 he said, "Oh, I saw that you're infection was from
20 a transfusion", and he mentioned that and I was just
21 like, "Yes, it was yet", yet he saw me then and he
22 hadn't seen me for years.

23 My oncology team was the same, all of a sudden
24 the person who's been seeing me didn't want to see me
25 anymore. It made me feel dirty. It made me feel like

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1 school as my kids. They thought that I should leave
2 or hurry up and die. But I scanned down and the worst
3 bit said -- and I don't want anybody else in the room
4 to be upset by this.

5 Q. I'm happy to read it if it is too upsetting for you.

6 A. Yes, if you would please.

7 Q. "They said that people like us should be taken into
8 a field and shot and then our bodies burned like
9 a cull of cows and badgers."

10 A. Which is kind of pretty difficult to take about your
11 son. It wasn't just for myself, it was for my kids.
12 I mean, they were saying it about my kids as well.

13 Q. You shredded the letter and got in touch with the
14 police.

15 A. I wanted it destroyed, yes.

16 Q. Sadly, things didn't end there, did they?

17 A. No, it didn't. I mean, I did phone the police and
18 actually I spoke to a woman police officer who said
19 that she'd actually experienced -- she'd been a police
20 officer in the '80s when she'd experienced stigma with
21 the HIV and AIDS people, so she was concerned that
22 this might escalate but hoped it wouldn't.

23 Then we had dead pigeons, dead rats, dead mice,
24 dead squirrels thrown at the front door, on the drive.
25 My son's -- my son is disabled and we have

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1 I was in the way in their clinic, like they suddenly
2 wanted to shuffle me off like into the cloakroom or
3 something, you know, "Somebody else go and see that
4 person because they got that", and that's how I felt.

5 Q. You have also had a very serious issue with your now
6 ex-neighbours?

7 A. Yes, I have. Well, I think it's the ex-neighbours,
8 you know, because I never found out who it was --
9 which is the reason I get emotional because I know
10 it's coming.

11 I obviously got in touch with the EIBSS and I,
12 you know, got letters. One of my letters didn't
13 arrive. I didn't know it was sent out but it hadn't
14 arrived. The only reason I know it didn't arrive was
15 because I got -- I had a letter come through the door
16 through the post with my name on it, opened it up. At
17 the top of the letter it had got my name and my
18 payment beneficiary ID number for better -- I don't
19 know what else you'd call it.

20 Q. The EIBSS reference number I think you called it.

21 A. That's it, yes. And somebody'd written they didn't
22 want dirty bloody people like us in their community.
23 They didn't want to be in the doctor's with me, they
24 didn't want to be sitting on the bus next to us, they
25 didn't want their kids to have to go to the same

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1 a wheelchair access ramp and somebody'd sprayed tomato
2 ketchup across it "people die" and just doing it like
3 blood and dirty blood and words running down the back.
4 You'd never knew what to go out to.

5 Q. It went on for quite some time, didn't it?

6 A. It did go on for some time. I mean, I had security
7 cameras up where I lived. You couldn't see but you
8 could just see the stuff being thrown on to the drive.
9 I mean, the cameras stopped the van being sprayed but
10 you couldn't see who. You could just see these dead
11 things being thrown at the house.

12 Q. You and the family were terrified that perhaps
13 something worse would happen, that the house would be
14 burnt down?

15 A. We did. It just made it very clear that it was, like,
16 leave or die. And I was petrified. I mean, I had to
17 make my children aware that there was a threat. I had
18 to say "don't go outside the door" because I didn't
19 want them to have to see these things we had to clear
20 up. My children became desperately, desperately
21 miserable. They stopped seeing all their friends,
22 they had to go under CAMS, the mental health service,
23 but then they didn't trust to tell them just how bad
24 it was or what was going on in case, in their minds,
25 maybe they might not want -- you know, they might

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1 think the same things of them, to the point that my
 2 one son wouldn't go to college anymore. My other son
 3 was at school. He wouldn't go to school. He's meant
 4 to be doing his GCSEs now. He hasn't been to school
 5 in months. It destroyed him. He didn't want to live
 6 anymore. He didn't trust anybody. He said if this is
 7 what life is like and how people are in the world,
 8 what's the point?

9 **Q.** After about five months you were able to move?

10 **A.** Yes.

11 **Q.** Move house?

12 **A.** Yes. We had to wait for the council. Because of the
 13 financial position that my husband and I had been put
 14 in through the illness, we had to rent from social
 15 housing. So we had to wait for them to find somewhere
 16 and agree it and for us to move.

17 **Q.** But since you've moved house, it's obviously got an
 18 ongoing impact, as you've said, on you and your
 19 family.

20 **A.** Yes.

21 **Q.** But more recently you've again had issues with letters
 22 from the EIBSS.

23 **A.** Yes. I mean, I did complain to the Royal Mail at the
 24 time when the one letter -- because it was obvious
 25 that the one letter had gone missing because it had

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1 **Q.** And then last month another letter has gone missing?

2 **A.** Another letter, yes. I mean, I really, really ripped
 3 into the Royal Mail over it because it was a new
 4 address and I was, like, oh my god, my kid's are going
 5 to be -- somebody's going to find out where we are
 6 again, the whole thing's going to start again, and
 7 they said 100 per cent it was all going to be sorted
 8 and everything. And then a letter didn't arrive.

9 My thoughts personally is that whoever's opening
 10 them and causing this problem has gone "I can't send
 11 it in a damage bag because it's going to be
 12 investigated, I'll just hold on to it and it will
 13 never get there". I mean, and they said you will have
 14 to wait -- even though they knew all the trouble with
 15 the, like, six or seven letters that I'd had a problem
 16 with and it is only from this place, no other post
 17 goes missing. They said I'd got to wait 15 working
 18 days to say it was missing, so I had to wait that and
 19 then I had to phone up again, which is quite stressful
 20 and traumatic having to phone up again and again and
 21 try and sort this out.

22 **Q.** You say you have asked the EIBSS to send things in
 23 plain envelopes but you don't think that can be have
 24 been happening because of the most recent letter going
 25 missing.

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1 got my EIBSS number on which showed that they'd --
 2 somebody had read it.

3 I again didn't have EIBSS letters arrive and the
 4 two that did arrive arrived in damaged bags that had
 5 been opened, very obviously been opened, and glued
 6 back down to the fact that it actually glued the
 7 letter to the envelope so it ripped when I opened it.

8 And I'm constantly in touch with the Royal Mail.
 9 I'm in touch with the police. They say it's down to
 10 the Royal Mail. But it's really concerning because it
 11 happened at the previous address. I've moved and the
 12 same thing is happening at a completely different
 13 address, but it's all the letters from the same place.
 14 Now, I got in touch with EIBSS and said "It says NHS
 15 BSSA there on the back of my envelope, please send it
 16 in a plain envelope" which I thought would be a very
 17 simple solution so that if anybody in the postal
 18 system -- because by then I was thinking it's got to
 19 be somebody in the postal system because it's
 20 happening time after time. I thought it would be
 21 a really simple option and that didn't happen as far
 22 as I know.

23 **Q.** You've had two letters arrive in plastic bags which
 24 have been opened?

25 **A.** Yes.

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1 **A.** Yes.

2 **Q.** What have you asked them to do now?

3 **A.** I've now had to actually ask them to send me
 4 everything by email which most people would think is
 5 an easy thing but because I have photosensitivity due
 6 to the autoimmune conditions which I believe have been
 7 triggered by the hep c I can't go in front of computer
 8 screens and everything. I am very light sensitive.
 9 I have to wear 50 plus factor, so I don't go on
 10 computers. I only have a phone. So accessing these,
 11 which I don't think my husband or kids should have to
 12 do, is now making it difficult for me to do that.
 13 I don't have that facility or to print them off or
 14 anything.

15 **Q.** All of those incidents have had a very significant
 16 impact on your family, as have your infections?

17 **A.** Yes.

18 **Q.** In your statement you've put it like this:
 19 "It's put pressure on all of us. It's caused
 20 stress in my relationship with my husband. It's put
 21 stress on my children. I have lost friends and there
 22 are family members that I no longer see. We don't
 23 have a social life. We don't see anyone. I've hated
 24 myself for years. This in itself has had an impact.
 25 If the kids want to do something I am too ill, too

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1 tired, or can't afford it. I haven't been the wife,
2 the Mum, the sister or the daughter that I could have
3 been. All of these things have been taken from me and
4 from my family."

5 A. Yes. I mean, it's to the point that it's caused such
6 distress I've had to bring my brother with me.
7 I mean, my husband is incredibly supportive but
8 because my children are so traumatised they won't
9 leave the house, he's had to stay at home with my
10 children and I've had to come here, so I've grabbed my
11 brother at the last moment and said, "You'll have to
12 come. I can't do this on my own". I don't go
13 anywhere on my own anymore, in case the stigma, in
14 case, you know, I have panic attacks.

15 Q. I want to move on to talk a little bit more about the
16 financial assistance. We've talked about the letters?

17 A. Yes, that's fine.

18 Q. But just in terms of the processes, as soon as you
19 were diagnosed with hepatitis C you registered with
20 The Skipton Fund?

21 A. Yes, because my hepatitis C nurse actually suggested
22 it. She actually told me about it. Because she
23 said -- she spoke to me, she said, "No, you got this
24 through this. They should pay out", so I applied for
25 the notes.

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1 I mean, yes, and with the uplift of payments and
2 things it is going to make it easier on myself and my
3 children and it's, you know, I'm grateful that's going
4 to help because I've been pushed on to a life of
5 benefits. My husband had to give up work to look
6 after me, so it's really ruined us financially.

7 I started off as a shelf stacker and I ended up as
8 a key holder of a national store. I was working for
9 one of the large nationals, I was trainee management.
10 I'd take over. I could do the whole job. I should
11 have been on an incredibly good wage. My husband was
12 working. All gone and now we're just -- so this
13 little uplift will help but we haven't got a house.
14 We haven't been able to buy a house because of it.

15 Again, the same as Andy said, you don't know if
16 it's going to carry on, you don't know whether it's
17 going to stop and there is that thing where anybody
18 else who's just been diagnosed, somebody who is
19 diagnosed, why should we have gone out without the
20 payments from back then, just because nobody found us
21 and told us we'd got this illness because we're
22 infected years, you know, 30 years ago. Why should
23 I only have like 12 months' payments?

24 Q. You also applied for funding for a specialist bed
25 because of the joint and muscle pain you suffer from.

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1 One problem I have with it is that you apply to
2 the Skipton or EIBSS and then you have to wait to get
3 all the information out of your medical professionals.
4 You have got to try to get the notes, the proof, then
5 you have to get the form signed. I mean, I sent it
6 in. They asked for more information. It got sent
7 back. Finally, I got it all sent in and it got
8 approved but this was well over a year and so, I mean,
9 they did agree in the end and the same with the SCN,
10 they agreed that so I get that, but the fact is why
11 doesn't somebody get paid from when they register.
12 Why doesn't somebody pay it if you're infected, and
13 it's from that -- why don't you actually get back paid
14 from when the scheme starts for everybody, because
15 everybody's been infected and it's not my fault or
16 anybody else's fault if I don't get diagnosed for
17 30 years instead of 20 years. Why did I not get
18 payments from then?

19 But even when I've got diagnosed they go, "Yes,
20 it's true. We're not going to backdate it to when you
21 registered. We're only going to pay you from when you
22 could actually get all the notes and the information
23 out of everybody", which was incredibly difficult,
24 which causes more stress, more time and everything
25 else.

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1 A. Yes.

2 Q. And that was turned down.

3 A. It was, yes.

4 Q. What your observations about that?

5 A. I phoned them up and I explained the problems that I'd
6 got and they said, "Yes, you can apply". The one big
7 problem I have is the inconsistency of the information
8 you get from them because you'll speak to one person,
9 they'll say one thing, and the next time they'll
10 say -- they said I need a letter from the doctor.
11 I went to the GP and they said, yes, they'd write
12 a letter supporting saying I suffered from these
13 conditions and they thought that a specialist bed
14 would help me. That I'd been diagnosed hepatitis C,
15 I'd got all this, which I phoned them up I said,
16 "I got this letter", and they said, "That will be
17 fine", and it phoned up 30 days later saying,
18 "I haven't had a decision. Is it going to happen".
19 I'd had to go round getting quotes, because you have
20 to get quotes for the bed, and they said, no, it's not
21 good enough because she said they, can't -- haven't
22 actually said it's the hepatitis C that causes the
23 pain, and I said, "Oh right, okay, well it's difficult
24 to say that", and I went back to the doctor and she
25 says, "Well, no, hepatitis C itself doesn't cause the

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pain. It can cause conditions that cause pain", but she wouldn't directly say the hepatitis C caused pain, so even though I was having all those problems they constantly kept saying no, to the point I didn't bother going back, because there was no way my GP said, "We don't know enough about it really anyway to write these letters but we've said we support you", and they've turned round and said no.

I was going to ask for the support for the counselling because I thought I'm getting nowhere with the NHS. I could do with that money to help counselling, but when you've been -- you've gone with your begging bowl out and they've gone "No", you don't want to do it again. It's a horrible process to have to ask, and to go through a process when you get what you think is enough, you know, you have to go to the doctor and say, "Please, can you do this. Please, can I have a bed please, sir", and they go "No, actually, the wording's not right", so I haven't asked for the counselling or anything else and I don't think I would.

Q. You have just given up?

A. I've given up asking for anything like that.

Q. Mrs D, those are the questions I have for you. Before I ask Mr Lock whether there are points he wishes for

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house move, and they said that it was getting in the way of my treatment, because obviously my anxiety and everything just went up a level.

So it was like being beaten with another stick. It was like finally you have got some help and because of the infection and the stigma that stopped me even having that help and she stopped it, and then I, because I couldn't go, I had to -- the sessions had finished so I would have to go back to the GP and be referred all over again knowing that I could go back and see somebody who probably doesn't understand and I'd still be under the pressure to be fine after ten half hour sessions, which isn't going to happen.

MS FRASER BUTLIN: Thank you.

SIR BRIAN LANGSTAFF: Mrs D, thank you very much that despite all the reasons you have to feel anxious you've had the courage to come and tell us your story as you have. Thank you.

We'll take a break until 2.30.

(1.19 pm)

(Luncheon Adjournment)

(2.31 pm)

SIR BRIAN LANGSTAFF: Our next witness would I understand wish to be known as Colette.

MS RICHARDS: That's right, sir, Colette Wintle.

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me to raise is there anything else you would like to say?

A. No. I think I'd just, I'd actually just like to thank all the support groups and people who have been there for me because nobody in the NHS was. The only way I found anything out is by some of these wonderful people and people who aren't here as well who have help me to get through this, because there's been -- I was just abandoned by it, and I really do hope that one of the recommendations is, from this Inquiry, that there is the counselling and the support and the help there, and I mean proper counselling and support by people who fully understand how this affects people and that's put in place from day 1.

Q. I'm just going to turn my back.

A. That's fine. (Pause)

Q. Just one point Mr Lock asks me to raise, and that is that we spoke a little bit earlier about the cognitive behavioural therapy and the EMDR that you were having and started.

A. Yes.

Q. Why did that come to an end?

A. Because I was going through the -- it was just -- I'd just started that when we started getting all the death threats, I'd had the letter, the stress, the

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COLETTE WINTLE, affirmed

Questioned by MS RICHARDS

Q. Colette you're a symptomatic carrier of haemophilia A. Can you tell us what that means.

A. Well, females generally have in the past been understood to be carriers of the defective gene, Factor VIII, but in my family that has not been the case, that many of the women in my family have been symptomatic of the condition as well and there are other bleeding disorders that have come into play, that have been discovered later, as happened in my case, so I'm not just symptomatic of haemophilia A but I also have Factor XI deficiency as well.

Q. The Factor XI deficiency was diagnosed in the mid-90s?

A. Yes.

Q. In terms of being a symptomatic carrier of haemophilia A, can you tell us how that was diagnosed and how the symptoms, whether of that or that combined with the Factor XI bleeding disorder, have manifested themselves over the years.

A. I was diagnosed at the age of three. My mother was known to the professor of haematology who established the haemophilia centre in the Glasgow Royal, and when my mother started a family he asked that, you know, her children be brought in so that he could test.

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1 I am one of twins. I have a brother and an older
2 sister.
3 So in 1962, Professor Douglas as he was known
4 tested both my sister and myself, didn't expect to
5 find it in my brother and, of course, did not but we
6 were found to be carrying haemophilia A.

7 But the difference was that, as I was growing
8 up, I was much more like my mother in the way that
9 I demonstrated that symptomatic behaviour in terms of
10 bleeding pattern. So I bled every day from my nose
11 all the way into adulthood. I have spontaneous bleeds
12 into muscle and tissue, small joint bleeds. I still
13 do and have had some serious internal bleeds.

14 It's had a huge impact on my life. I can't
15 really remember a period of time where I've not been
16 going to hospital for something and it's involved the
17 bleeding aspect, yes.

18 Q. In your teens, by the time you got to the age of 16
19 you were severely anaemic. That affecting your
20 schooling.

21 A. Yes.

22 Q. And you continued to experience bleeds over the years?

23 A. Yes, that's right.

24 Q. You were first given factor products, Factor VIII
25 products, in 1976 when you were 17 years old?

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1 of a fight to get them, I discovered a slip of paper
2 demonstrating clearly that the intention from the
3 haematologist at the time was that I would be given
4 cryoprecipitate.

5 Someone put a line through that and put
6 Factor VIII but they didn't sign that letter to say
7 why they had chosen to change that course of
8 treatment.

9 Q. We can have a look at that document. It's 1056003,
10 please, Paul. If we could just have -- thank you.

11 "This patient is a" -- we've got the date
12 10 June 76:

13 "This patient is a haemophilia carrier and has
14 been given ..." and as you said "cryoprecipitate" is
15 crossed out and "Factor VIII concentrate" handwritten
16 over by the haematology staff.

17 "After-care: routine plus", and then again it's
18 crossed out and we have "Factor VIII" written over
19 that, "... the latter under the direction of the
20 haematology department", et cetera.

21 You've subsequently discovered the particular
22 factor products that you were given in 1976. What
23 were they?

24 A. Hemofil and I think Profilate was the other one.

25 Q. You have said you don't think your parents received

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1 A. Mm-hm.

2 Q. Can you tell us about the circumstances in which you
3 were given those products.

4 A. Yes. From a very young age, I think the age of three,
5 I suffered from chronic throat infections and my
6 mother's doctor in the early days did not want --
7 I should have had my tonsils out when I was small, and
8 because there was not -- you know, there was a risk.
9 He knew that there was a risk because my mother had,
10 you know, was a problem herself with the bleeding, and
11 they were terrified that I would have an issue, so it
12 was put off and put off and, eventually, I lost a lot
13 of schooling because I was constantly off with
14 tonsillitis and throat infections, et cetera, and sore
15 ears, et cetera.

16 So it was decided that they would take the
17 tonsils out. So I was still a minor in those days so,
18 obviously, it was my parents who would have been
19 talking to the doctors about it.

20 My parents were never counselled by the doctors
21 on what type of clotting products that they would use
22 if I bled so there was no informed consent on what
23 they would use, and it's interesting that laterally,
24 years after this has happened, and I sought to get my
25 records from the Glasgow trusts, which it was a hell

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1 proper counselling about the nature of the products?

2 A. Mmm.

3 Q. As far as you are aware were your parents told
4 anything at all about any risks of infection
5 associated with such products?

6 A. No, not at all. In fact, my mother expressed shock
7 years later after I discovered what I'd actually been
8 given. She said, "I had no idea. I assumed that what
9 you would be given was British products". The idea
10 that, you know, I was being injected with blood
11 products which we now know were 100 per cent risk of
12 hepatitis and the source from where they came, which
13 was disgusting, and it would have absolutely broken
14 the protocol of how we collected blood in this
15 country.

16 You know, why on earth would you go to the
17 United States where people, the wrong type of person
18 is attracted because they are paid for their blood,
19 when you have a system in the UK here where that --
20 it's a gift, you know. So, yes, it blows my mind that
21 any doctor, you know, would be happy to take that risk
22 and I'm afraid to say that I know that by 1976 it was
23 quite evident that the knowledge of that had been
24 there for some years of what those risks were but they
25 most certainly were not imparted to my parents and, of

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1 course, I was a minor so I had no opportunity of
 2 discussion at all.

3 **Q.** There was a comment a doctor made to your mother on
 4 the day you were discharged from hospital which has
 5 resonated over the years with you and, prior to her
 6 death, with your mother. What was that?

7 **A.** Yes. I'd had a pretty traumatic month of being in
 8 hospital. I lost a tremendous amount of blood.
 9 I haemorrhaged very, very badly -- very poor nursing,
 10 I have to say, post surgery. There was a nurse on the
 11 ward insisted that I swallow down large lumps of meat
 12 and they tore the clots away from the back of my
 13 throat and, well, I actually almost died. The priest
 14 was called and I was given the last rite's. I had the
 15 curtains drawn around me for a whole week because they
 16 were just expecting me to pass. I just couldn't stop
 17 haemorrhaging.

18 I did recover and on the day that I was
 19 discharged the doctor came to see my mother and he
 20 said to my mother, "Well, I'm glad that Colette's
 21 finally recovered and she's going home but your
 22 daughter will never be the same again".

23 That for me, knowing what I know now, was quite
 24 a significant thing to say. My mother sadly didn't
 25 question it, but those were the days of the doctor's

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1 again was my levels of energy. I would describe it as
 2 almost permanent malaise and as a young woman, 17 and
 3 growing into, you know, future adulthood, it's a time
 4 of your life when you expect to be full of energy and,
 5 you know, bouncing around.

6 I used to sleep for hours. I remember one
 7 occasion I think I slept solidly for 24 hours. My
 8 mother kept coming in to try and get me awake and
 9 I just would drift off again. I was exhausted all the
 10 time.

11 **Q.** By 1982, you'd moved to Kent and you were either about
 12 to start or had started training as a nurse.

13 **A.** Yes.

14 **Q.** You were treated in Kent, in Tunbridge Wells, again
 15 with blood products, factor products. What can you
 16 recall about that? What was the intervention and what
 17 happened?

18 **A.** I had developed quite, you know, marked pain in my
 19 back and I had terrible sciatica down one side of my
 20 body and they identified I had scoliosis but also
 21 I must have had a trapped nerve and it was decided
 22 that the course of action to get me sort of back into
 23 my training was to do a spinal manipulation under
 24 general anaesthetic.

25 The cover for that would be DDAVP. The advice,

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1 paternalistic attitude. You didn't question them.
 2 The white coat knew everything and you just didn't
 3 question. So my parents, my mother particularly
 4 because she was the one that was, you know, looking
 5 after me, my father was at work so he wouldn't come in
 6 and question, but my mother was very upset for years
 7 after that and regretted not questioning.

8 **Q.** You didn't receive any further blood products between
 9 1976 and 1982 following the treatment you have just
 10 described, although you did have bleeding episodes
 11 during that time?

12 **A.** Yes, I did. I actually at one point bled for several
 13 days from a duodenal ulcer. I did suffer, well, as
 14 I said I never stopped having daily nose bleeds and
 15 they could stretch up to several hours but I was never
 16 offered any treatment or encouraged to come in and
 17 have treatment.

18 **Q.** In that period those five or six years before we get
 19 to what happened in 1982, what, if anything, do you
 20 recall about how you were feeling and your physical
 21 health generally?

22 **A.** Well, it took me a long time to recover from all that
 23 blood loss and, you know, physically drained. I had
 24 dropped down to six and a half stone. It took me
 25 a very long time, but one thing that never was right

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1 as I understand it from letters that, you know, I've
 2 now seen laterally, to my GP and I think Dr Townsend,
 3 who was the orthopaedic surgeon who was doing the job,
 4 would be that he would liaise with Dr Taylor at
 5 Penbury Hospital, which was the nearest hospital, and
 6 although I think I had at that point I was registered
 7 at the Royal Free but they were sending the advice
 8 down to the local hospital, and it was quite clear in
 9 that letter that I was supposed to be given safe --
 10 well, what I know now would be a safer blood product.

11 **Q.** What blood products were you in fact given in the
 12 course of this surgery in 1982?

13 **A.** I was given Factor VIII.

14 **Q.** You've subsequently ascertained and we will come on
 15 later to subsequent meetings you had with the doctor
 16 in question, but you've subsequently ascertained that
 17 it was probably Factor VIII products from
 18 a pharmaceutical company called Immuno?

19 **A.** Yes.

20 **Q.** On this occasion in 1982 were you advised now as an
 21 adult or informed about any risks of infection or
 22 given any -- involved in any discussions --

23 **A.** No.

24 **Q.** -- with the doctor about different products?

25 **A.** No. In fact, what actually happened was, as often

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1 happens with mild haemophiliacs because they are not
2 treated prophylactically, they don't have bottles in
3 front of them with warnings or labels or anything.
4 What you are presented with is the syringe with the
5 already made-up product ready to inject into your arm.
6 So there's nothing, you know, to say that there's any
7 risk there, so there was nothing evident for me, and
8 most certainly there was no discussion. You simply
9 turned up and said this is your clotting products, and
10 they were injected and that was it.

11 **Q.** Now, after you had had those products in 1982, in the
12 period 1982-1983 you began to feel very unwell and you
13 went to see the GP or, indeed, more than one GP.

14 **A.** Yes.

15 **Q.** What kind of illness were you or symptoms were you
16 experiencing and what reactions did you get from the
17 GPs?

18 **A.** I was starting to lose weight rapidly. My colour was
19 odd. I felt highly nauseous. Just smelling food made
20 me feel sick. I had no energy. I just generally felt
21 really, really bad and that's why I consulted with the
22 GP.

23 I was, at that point I was working in a surgical
24 ward and I was struggling to get through the day and
25 so I knew that there was something not right. So

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1 **A.** Yes. This particular day I had been left to draw up
2 various injections and drugs for the next drug round
3 that was going to happen in the afternoon. Sister had
4 gone off the ward and left me to do that and I can
5 remember, it was an old fashioned hospital and I can
6 remember the old china sinks they had, hanging over it
7 thinking, "Oh God, I'm just not going to get through
8 this. I don't know how I'm going to keep going but
9 I have to do this".

10 Just at the point where I was standing doing
11 that, across the doorway came a lovely chap. He's now
12 an eminent liver surgeon at King's, but he was
13 a registrar in those days, called Nigel Heaton, lovely
14 chap, he came past and then he walked backwards and he
15 looked at me, and he said, "Colette, can I have
16 a word? Come here". Anyway, I went and spoke to him
17 and he said, "Just turn around and look at me". He
18 said, "Do you know you're jaundiced? How do you
19 feel?" I said, "I've been feeling terrible". He
20 said, "Why haven't you been to a doctor?" I said, "I
21 have. Three times I have consulted with a GP". He
22 shook just his head and he said, without knowing it,
23 "I think you've got hepatitis". He said, "You look
24 dreadful. You are jaundiced".

25 So he said, "Look, stop what you are doing."

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1 I consulted with two GPs and their attitude was,
2 "I think you might be just imagining the symptoms of
3 some of your patients that you are nursing", a pretty
4 appalling thing to say.

5 No, I wasn't imagining. The physical
6 evidence -- also I was saying to them, "Well, look, my
7 urine's really dark, you know, that's not right and
8 I just feel terrible and I feel sick. I want to be
9 sick all the time". No investigations, no follow-up,
10 nothing.

11 On this one particular day I just simply
12 couldn't get up and go to work and my sister said,
13 "I'm going to call the GP out", so she called the GP
14 out and he did the same thing. Completely dismissive,
15 didn't ask about any history or, you know, why this
16 might be happening and just said, "Oh, you know, she's
17 fine. She can go back to work. There's nothing wrong
18 with her".

19 **Q.** Now, you did go back to work --

20 **A.** Yes.

21 **Q.** -- as a nurse.

22 **A.** Mm-hm.

23 **Q.** There came a point in 1983 when you were diagnosed
24 with hepatitis B but not by your GP or via the GP
25 route. Can you tell us how that diagnosis came about.

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1 I said, "Oh, I'll get into terrible trouble", because
2 the sister that I worked for, she was an old tartar of
3 an Irish sister. You didn't dare cross her and not do
4 your job because she'd be on you. He said, "I'll deal
5 with her. You go off and do what you know to do". He
6 said, "You know how to test the bilirubin in your
7 urine". He said, "Do that, meet me on the other ward
8 next door, a female surgical, and I will take a sample
9 of your blood but I won't sent it locally. I will
10 sent it off to London", and he did. And he said, "Get
11 your" -- because we used to wear the nurse's cape in
12 those days, "Get your cape and go home". He said,
13 "You should not be on this ward, you're not well, and
14 don't come back until I tell you".

15 I said, "Okay", so I went home and told my
16 sister and she said, "Oh my Lord", she said, "I knew
17 there was something wrong with you". Okay, so we
18 waited a week and he phoned me at home and said, "I'm
19 sorry to tell you, Colette, but", he said, "you have
20 got hepatitis B and you can't come back to work".

21 So I then had to phone up and discuss this with
22 my training tutor and as soon as the hospital found
23 out they couldn't wait to get rid of me, and I asked
24 about, "If I get over this and I'm well enough, can
25 I come back and finish my training", and I was told,

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1 "No".

2 **Q.** Can you recall what, if any, treatment you received

3 for the hepatitis B at that point in time?

4 **A.** None.

5 **Q.** What impact did that attack of hepatitis B have on you

6 at the time? Obviously, you weren't able or weren't

7 permitted to go back to work. How else generally do

8 you recall feeling?

9 **A.** Desperately ill for a long time. In fact, I was ill

10 with that hepatitis for a further two years and

11 I didn't -- I wasn't able to return to work until 1985

12 and I was reliant on my sister keeping me living with

13 her and looking after me, and she was a young Mum and

14 struggling herself because she actually had also been

15 infected the same year, earlier that year, after her

16 first baby was born.

17 So there you had two of us infected from the

18 same hospital by the same doctor and neither of us had

19 any follow up.

20 **Q.** Now, I'm going to ask you to look at a letter. Can we

21 have up on screen please 1056010.

22 You will see, Colette, this is a letter dated

23 22 February 1984 and it's from the Royal Free from

24 Professor Kernoff, consultant haematologist, to your

25 GP and it's about you and your sister; is that right?

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1 **A.** Yes.

2 **Q.** If we just look at it, it refers to a phone

3 conversation on 20 February of that year and then it

4 says this:

5 "Because of the risk of hepatitis after

6 transfusion of Factor VIII concentrate being very high

7 in infrequently-treated patients, we try to minimise

8 blood product exposure when treatment is needed to

9 prevent or stop bleeding."

10 Just pausing there, Colette, were you ever told

11 at the time, 1993-1984, that there was a very high

12 risk of hepatitis for infrequently-treated patients

13 such as yourself if Factor VIII products were used?

14 **A.** No, never, and this makes it all the more horrific

15 because exactly a year later the Royal Free reinfected

16 me with hepatitis C.

17 **Q.** We will come on to that. The letter continues:

18 "DDAVP injection has proved to be very useful in

19 this respect ..." and goes on to explain why and then

20 in the last sentence of that paragraph:

21 "If DDAVP fails or a major elective procedure is

22 to be undertaken, we would prefer cryoprecipitate to

23 Factor VIII concentrate, because the former is

24 prepared from the plasma of many less donors."

25 **SIR BRIAN LANGSTAFF:** The other thing which it notes is

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1 **A.** Mm-hm.

2 **Q.** When did you first see this letter?

3 **A.** This morning.

4 **Q.** You've asked for your medical records over the years

5 on a number of occasions --

6 **A.** Mm-hm.

7 **Q.** -- from the Royal Free; is that right?

8 **A.** Yes. I actually had to write not once but three times

9 to the Chief Executive to complain because they would

10 send out parts of my records. Interestingly, and most

11 haemophiliacs will connect with this, general records

12 are kept in a separate part of the hospital but the

13 blood treatment records are kept in the haemophilia

14 centres, so they are separated, so they have complete

15 control over them. So when I requested my full

16 records I was getting them in portions, bits here and

17 bits there.

18 That letter -- that's the first time I've seen

19 that is today. I've never seen that before but that

20 makes it all the worse, that first sentence there,

21 because as I read it it's quite obvious they were

22 aware of the risks of using commercial products.

23 **Q.** Just for the sake of clarity, this is a letter

24 supplied to the inquiry by the Royal Free and shown by

25 the Inquiry to you.

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1 that you have what it describes only mildly depressed

2 Factor VIII levels.

3 **A.** Interesting because my Factor VIII levels started off

4 in single figures as a child. At the point that they

5 were talking about mildly depressed it might have been

6 23 per cent and it's gradually come up over the years.

7 It still floats below 50 but, of course, also I had

8 Factor XI that hadn't been diagnosed at that point

9 which didn't help so it made things worse when I had

10 a bleed. But, yes, they would often describe it as

11 mildly depressed. Of course they still held the

12 attitude in those days that I was just a carrier.

13 **MS RICHARDS:** Now, were you told anything at all at the

14 time about the availability of DDAVP?

15 **A.** I don't honestly recall. I was mildly aware of the

16 fact that the DDAVP was mentioned but there weren't

17 any discussions --

18 **Q.** Was there any --

19 **A.** -- that I can recall.

20 **Q.** -- discussion with you about there being this

21 hierarchy of treatment and for you or your sister

22 ideal was DDAVP, if that failed or there was to be

23 a major procedure, cryoprecipitate, and only if those

24 two were unavailable, effectively, Factor VIII? Was

25 that discussion ever held with you?

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- 1 A. No, because if it had been have been then I would have
2 been aware there was risks involved in this treatment
3 and I wasn't aware of the risks at that stage, no.
- 4 Q. If we then just look at the next paragraph there's
5 a reference to a number of the Professor's patients
6 with mild Factor VIII deficiency being treated by GPs
7 with DDAVP and that is suggested for the GP to
8 consider as a practical proposition.
- 9 Then if we go over the page please, Paul, we'll
10 see the second paragraph on that page, Colette, we'll
11 see the professor saying:
- 12 "If you have problems in obtaining supplies of
13 DDAVP, I should be willing to give you and your sister
14 a limited supply to keep at home."
- 15 Then there's reference to record sheets being
16 completed for the purpose of national data being
17 collected, the view being expressed there that we're
18 interested in assessing the blood product saving
19 impact of DDAVP.
- 20 Do you recall whether at this time, 1984, you or
21 your sister were given a supply of DDAVP at home?
- 22 A. No.
- 23 Q. No, you don't recall or, no, you weren't given?
- 24 A. No, we weren't given a supply, no.
- 25 Q. Were you given -- it seems unlikely if you weren't

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- 1 that was linked to the one I was working in. She
2 actually approached him on the ward twice and said,
3 "I need to speak with you", and he rebuffed her again
4 and actually told her off for being unprofessional in
5 approaching him, you know, whilst on the ward and
6 that, you know, "See me in my clinic", and she said,
7 "I've tried twice and I can't get an appointment with
8 you".
- 9 So the communication level was utterly
10 disgraceful and, you know, when I think about the way
11 she was treated the obstetrician when my sister was
12 rushed back into hospital after a massive haemorrhage
13 actually stood at the end of her bed and said, "people
14 like you shouldn't be allowed to have children".
- 15 So you can see the level of contempt that we're
16 talking about, so all this -- this letter would
17 suggest that there's great communication going on and
18 advice. No, that's not the case.
- 19 Q. So you have said none of this was imparted to you by
20 Dr Taylor?
- 21 A. No.
- 22 Q. It's a letter between the Royal Free, [redacted], and
23 your GP. Was any of this information shared with you
24 by your GP or by the Royal Free Hospital?
- 25 A. No, no.

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- 1 given the DDAVP, but was anything told to you about
2 record sheets or the collection of national data or
3 assessment of the impact of DDAVP?
- 4 A. No.
- 5 Q. Then if we have the last paragraph, please, Paul,
6 first sentence. It says this:
- 7 "If treatment with DDAVP is unsuccessful blood
8 product therapy may be indicated and I think it is
9 important again for you and your sister to appreciate
10 this."
- 11 Were there discussions with you about the
12 potential for future need for blood product therapy?
- 13 A. I mean, it seems quite incredible to me that, you
14 know, this advice and, you know, suggestion of
15 treatment, et cetera, and, you know, Dr Taylor would
16 be established with the local hospital and Dr Taylor,
17 Dr Taylor not only did he not impart to me when he was
18 busy injecting the commercial product into me, not
19 only did he not impart to me the risks of what he was
20 doing, but he also failed to tell my sister in the
21 earlier part of that year and, in fact, he refused to
22 see her in clinic.
- 23 She twice tried to get an appointment to see him
24 and she was rebuffed. She then approached him when
25 he -- because she was nursing in the other hospital

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- 1 Q. That's 1984. In 1985, you were given treatment again
2 for a third time with Factor VIII products.
- 3 A. Yes.
- 4 Q. Where was that treatment given?
- 5 A. The Royal Free.
- 6 Q. You were given treatment with Factor VIII made as you
7 understand it by Alpha Pharmaceuticals?
- 8 A. *(The witness nodded)*
- 9 Q. Were you given any options to have either
10 cryoprecipitate or DDAVP instead?
- 11 A. No.
- 12 Q. Were any of the matters set out in that letter
13 discussed with you by the Royal Free at the time you
14 were given this Factor VIII treatment in 1985?
- 15 A. No, no. And really it's quite appalling because they
16 reinfected me with non-A non-B, or hepatitis C as it's
17 now known. Not only did they infect me but they
18 didn't follow me up. They would have known using
19 commercial factor on me was high risk. They've laid
20 it out the year before, what's the safer option, so
21 they know, so they knew what they were doing when they
22 took that bottle all of the shelf.
- 23 I would suggest that they were using up old
24 stock as a lot of haemophiliacs had happen to them,
25 and that's what they did, they took that off the shelf

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1 knowing it was high risk and they used it on me, and
2 that particular batch is registered in the American
3 courts, because I went to America, you know, and it
4 was acknowledged in the American courts as a defective
5 batch.

6 Q. One of the particular concerns you have about the fact
7 you were given commercial Factor VIII products in 1985
8 was the state of knowledge by 1985 about, at the very
9 least, the risk of HIV.

10 A. Absolutely, and that's what horrified me because
11 I realised that, you know, they infected me with non-A
12 non-B, but it could have been HIV. I mean, for many
13 haemophiliacs they will know the pattern here. It's
14 like a Russian roulette every time you're treated.
15 HIV was the only thing I wasn't exposed to.

16 But I'm horrified that they did that to me in
17 '85 and retrospectively, you know, in the years of
18 campaigning and researching and so on, that I can say
19 because it's in the public domain and it's in
20 a published book called, "HIV the myth" Dr Charles
21 Rizza, who was Oxford Haemophilia Centre director
22 actually is in print saying, "By the mid-'70s and '80s
23 we knew all the products were infected". Why the hell
24 did they use them then for a further ten years? It
25 doesn't make sense.

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1 A. Yes.

2 Q. You said in your written evidence that there was
3 discussion on the issue of you having had hepatitis B?

4 A. Yes.

5 Q. An episode from which you had recovered from, and
6 there was some particular discussions about hepatitis
7 B and issues of immunisation. Is that right?

8 A. I hadn't -- what they'd found was that I, despite
9 having had it chronically for two and a half years,
10 I hadn't raised enough immunity to protect me from
11 getting it again, so they needed to vaccinate me, so
12 I had a series of three vaccinations so that, you
13 know, I could mount some form of level of protection
14 within my body.

15 Q. Was there any discussion with you at this meeting in
16 1987 with Dr Goldman and Keith and yourself about what
17 we now know as hepatitis C, what was then referred to
18 as non-A non-B hepatitis --

19 A. No.

20 Q. -- was there any discussion at all?

21 A. No and, retrospectively, looking back now, again, the
22 contemptuous attitude because they actually placed us
23 both, me particularly but placed us both in grave
24 danger because you are not allowed to go to live in
25 countries like Oman or the United Arab Emirates if you

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1 Q. Having been given those factor products in 1985, you
2 remained a patient at the Royal Free Hospital and in
3 June 1987 you married your first husband and in the
4 early spring time of that year, prior to your first
5 marriage, you and your husband Keith attended the
6 Haemophilia Centre at the Royal Free for some advice
7 and genetic counselling?

8 A. Yes.

9 Q. What had particularly prompted your attendance on that
10 occasionally and who did you see?

11 A. I'm pretty sure it was Eleanor Goldman and the prompt
12 was that we were getting married, we were going to
13 live abroad, management of my haemophilia and
14 naturally genetic counselling because we intended to
15 have children. So I felt it was important for Keith
16 to fully understand what the risks were if we had
17 children, a 50/50 risk of passing on the haemophilia
18 gene. Were I to need any haematological intervention
19 or care, you know, how we would go about setting up
20 advice from England so that whoever was, you know,
21 looking after me potentially when we moved would know
22 what they were doing and that was the main purpose of
23 going in. That's what was discussed.

24 Q. You and Keith were planning a move to Oman in the
25 Middle East?

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1 have hepatitis.

2 I don't know what the rules are now but in those
3 days you would never have been allowed entry into that
4 country and if you were discovered to have it and
5 hadn't declared it, it was a jailable offence, so
6 nobody in their right mind would put themselves in
7 that position in the first place.

8 So, obviously, if I had known I'd got chronic
9 non-A non-B we wouldn't have been moving abroad. So
10 I just can't believe that, you know, they must have
11 been aware of that. They must have known that you
12 couldn't -- you couldn't go abroad and live in
13 a country and not declare you'd got something like
14 that.

15 Q. Let us look at another document, Colette, 1056004.
16 This is a letter from the Royal Free again to a GP,
17 20 June 1985, and we'll see from the first paragraph
18 it refers to you having had bleeding episodes. It
19 refers to you having used Factor VIII concentrates and
20 then if we go to the second paragraph -- sorry, third
21 paragraph, please, could we highlight the first two
22 lines.

23 So 20 June 1985 your GP is being told by
24 a professor at the Royal Free Hospital:

25 "I agree that this lady has chronic non-A non-B

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1 hepatitis. This has presumably been transmitted from
 2 Factor VIII concentrates."
 3 Were you told in 1985 that you had chronic non-A
 4 non-B?
 5 **A.** No, and, actually, the first time I saw that letter
 6 was when I accessed under Freedom of Information my
 7 GP's files and records, and when I pulled that letter
 8 out I couldn't believe my eyes because they'd been
 9 communicating about a condition that I had not been
 10 informed of.
 11 **Q.** In terms of you first seeing this letter, that was
 12 a number of years later?
 13 **A.** Yes, quite a number of years later.
 14 **Q.** But in 1985 you were not told that the view was that
 15 you had chronic non-A non-B hepatitis?
 16 **A.** No.
 17 **Q.** And moving forward to the meeting in spring of 1987
 18 that you and the Royal Free --
 19 **SIR BRIAN LANGSTAFF:** Just before you move forward, can we
 20 have a look at the rest of that paragraph. Is it
 21 saying that there is potential infectivity to any
 22 child, baby in the womb, and that has simply not been
 23 mentioned to Colette?
 24 **MS RICHARDS:** Colette, if we look at this, and you can
 25 assist us with your understanding of the letter, it

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1 have explained?
 2 **A.** I went to live in Oman. What happened was that we
 3 went out to Oman. I was there for three months and
 4 then my husband was asked to go and establish
 5 a publishing house in the United Arab Emirates so
 6 I had to come back home and then a residency
 7 application had to be put in before I then went back
 8 out to the UAE.
 9 **Q.** You had expressly requested a medical letter to whom
 10 it might concern.
 11 **A.** Yes.
 12 **Q.** The purpose of which was if you became ill whilst
 13 away, you would show the letter to any doctor who was
 14 treating you; is that right?
 15 **A.** Mmm.
 16 **Q.** We should just look at that letter, Colette. It is
 17 1056005. We see it is 18 September 1987:
 18 "To whom it may concern."
 19 It's a letter signed by Dr Eleanor Goldman and
 20 we should just look at the second paragraph of the
 21 letter, please, Paul, if we could just highlight that
 22 second paragraph.
 23 You will see there, Colette, it refers to the
 24 events of 1976. It refers to treatment with
 25 Factor VIII, it says there in 1983, followed by an

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1 says -- it sets out the doctor's view that:
 2 "The non-A non-B hepatitis is only mild, suspect
 3 the prognosis is good, no contraindication to
 4 pregnancy. At the present time we do not know whether
 5 the virus will be transmitted to the neonate. The
 6 amount of non-A non-B virus in the blood is much lower
 7 than with the hepatitis B virus. For this reason the
 8 level of infectivity to the infant should be lower [it
 9 doesn't say non-existent]. I have not mentioned this
 10 aspect of the problem to her."
 11 **A.** Mmm. There you are.
 12 **Q.** Was there is ever any discussion of any of these
 13 concerns or issues with you?
 14 **A.** No.
 15 **MS RICHARDS:** Thank you, sir.
 16 That's 1985, and then moving forward to 1987
 17 when you were having this counselling session with
 18 your then future husband, Keith, and Dr Goldman, was
 19 the information that had been set out in this letter
 20 two years previously by the Royal Free shared with you
 21 at that stage in 1987?
 22 **A.** No, not at all.
 23 **Q.** As you have said you had a particular concern, you and
 24 Keith, about the fact that this wasn't disclosed
 25 because you were going to Oman for the reasons you

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1 acute attack of hepatitis B and then it says:
 2 "Liver function tests remained mildly abnormal
 3 afterwards, you remained had been negative since
 4 February 1984 when she came under the care of the
 5 Royal Free Hospital."
 6 Then it says this:
 7 "She had a further attack of hepatitis, probably
 8 non-A non-B, in 1985."
 9 Do you recall whether -- this letter was given
 10 to you at the time, I think, to take with you; is that
 11 right?
 12 **A.** Yes, it was a protective letter and really it was just
 13 to say she's had hepatitis B, recovered from it, and
 14 I didn't actually pick up on that particular bit
 15 because I didn't know what she was talking about.
 16 I should have questioned it but I didn't know what she
 17 was talking about. But the idea it was probably non-A
 18 non-B, well, blimey, they should have known because
 19 they knew they had given me an infected batch off
 20 their shelf and I think the reason they didn't explore
 21 that with me is because they would have to explain why
 22 they did that to me having the year previously set out
 23 what was the safest treatment.
 24 **Q.** So this was expressed as being you had had in the past
 25 this further attack of hepatitis in 1985, described as

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1 probably non-A non-B.
 2 Did you pick up at all on the significance, if
 3 any, of the reference to non-A non-B?
 4 A. No.
 5 Q. Did you understand this to be communicating to you
 6 that, in fact, they thought you had chronic non-A
 7 non-B?
 8 A. No, no. If I had, then surely they would have been
 9 following me up and surely they would have referred me
 10 to a hepatologist but that didn't happen.
 11 Q. We've actually got a letter from your first husband
 12 for the purposes of the Inquiry. It is 1056009. It's
 13 the last three paragraphs on that page. Keith says,
 14 he confirms that:
 15 "At no time was it ever mentioned to us during
 16 our counselling sessions that Colette was infected
 17 with the hepatitis C virus."
 18 Pausing there, it was then known as non-A non-B
 19 but, again, for the avoidance of doubt, as
 20 I understand your evidence, it wasn't mentioned as
 21 non-A non-B either?
 22 A. No.
 23 Q. Then reference to, in the bottom of the page:
 24 "Had I/we been informed I would never have put
 25 Colette's life and freedom at risk by moving to the

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1 Q. Non-A non-B mentioned at all?
 2 A. Never mentioned.
 3 Q. Hepatitis C mentioned at all?
 4 A. Never mentioned.
 5 Q. When did you discover that you had been diagnosed with
 6 hepatitis C?
 7 A. Months after I got married to Steve. They called us
 8 into the clinic. We had had the session and they saw
 9 me two weeks before we got married in clinic at the
 10 Royal Free, and there was not one single mention of
 11 hepatitis C.
 12 They obviously -- as routine when you go to the
 13 centre they inevitably always take blood samples from
 14 you while you're in there and clearly they would have
 15 done that and probably -- well, doing what they
 16 normally do with them, you know, testing them, looking
 17 at your clotting levels. That's what I assumed that
 18 they were doing, was looking at my clotting levels,
 19 but it's evident that several months after that
 20 happened, several months after we were married, they
 21 called us back into the clinic to deliver the news
 22 that I'd got hepatitis C.
 23 Q. Steven has also given a statement to the Inquiry and
 24 in that he said:
 25 "At no point during this counselling session was

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1 United Arab Emirates", and over the page he explains
 2 why that would have been particularly problematic.
 3 Top of the next page please, Paul. Because
 4 having such a condition would have been exceptionally
 5 difficult to treat in the UAE and having it as an
 6 expatriate resident could have led to serious legal
 7 consequences.
 8 A. Yes, exactly.
 9 Q. In 1991 by which time you had met your current husband
 10 Steven, who sits beside you, and you were intending to
 11 get married in the course of 1991?
 12 A. Yes.
 13 Q. Is it right that at some point in the first half of
 14 1991 you and Steven had a counselling session at the
 15 Royal Free?
 16 A. Correct.
 17 Q. Was that again for similar purposes?
 18 A. Absolutely, yes.
 19 Q. With Dr Goldman again?
 20 A. Yes.
 21 Q. Was anything said to you in the course of that
 22 counselling session attended by you, Steven and
 23 Dr Goldman about chronic non-A non-B or chronic
 24 hepatitis C?
 25 A. Never mentioned.

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1 there any reference or mention of Colette's hepatitis
 2 status. Shockingly, it was several months after our
 3 marriage but in the same year, 1991, that we were
 4 informed by the Haemophilia Centre that Colette was
 5 positive for hepatitis C."
 6 So having been told finally in late 1991 that
 7 you had hepatitis C, what information was provided to
 8 you about that condition?
 9 A. It was tremendously played down. I was told not to
 10 worry about it at all. It was just like having bad
 11 flu really, and I remember thinking, well, this
 12 doesn't feel too, you know, good if it's flu because
 13 you know, the classic symptoms are, you know, bone
 14 ache, muscle ache, fatigue, all of that.
 15 Of course, when you put all that together it
 16 then starts to make sense and when you connect it back
 17 over the episodes and then when I think back even to
 18 '76, you know, when I didn't feel right even though
 19 I had supposedly recovered from that dreadful episode,
 20 it made sense, you know, that terrible fatigue.
 21 There's nothing quite like it.
 22 Yeah, it was quite devastating really, wasn't
 23 it, to find that out and also that, you know,
 24 laterally, the knowledge of what was in my records and
 25 what was known but it hadn't been imparted to me, to

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1 us, or the risks. It was just like, you know, "It's
2 okay, it's just a bad flu. You'll be right", not the
3 devastating consequences of what it was doing to my
4 liver and, obviously, you know, retrospectively
5 looking back, how long my body had been under attack
6 from hepatitis virus literally from the age of 17.

7 **Q.** Now, you underwent your first course of treatment for
8 hepatitis C in about 1995?

9 **A.** 1999.

10 **Q.** 1999. What was that treatment and what was it like?

11 **A.** Oh, it was ribavirin and interferon. I have never
12 felt so ill in all my life. It was like being here in
13 this world but not being here. It was quite surreal.
14 I was in curled up pain. I had pain all through my
15 spine, literally all through my body. My muscles were
16 aching. I would frequently pass out on the couch and
17 be out for several hours. I felt sick and, as we hear
18 quite regularly now, I had huge hair fall out.

19 I was fortunate to be blessed with a massive
20 head of hair and thank God I had some to lose it was
21 quite horrific because it came out in great big
22 clumps. So, you know, if had a bath it was floating
23 in the bath, if I was in bed I would wake up, it was
24 on the pillow, it was lying on the carpet, it was just
25 everywhere and most women will relate to this. You

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1 if you, you know, if you are going to do then you
2 retire me on health grounds. I'm not just walking
3 away from my job. It's not my fault that I'm sick",
4 but they said, "You can't continue as you are". I was
5 working with the district nursing team at the time.
6 It was, you know, night duty and we used to cover
7 something like 400 square miles, so it was quite
8 a demanding job and I just -- I had to retire that
9 year.

10 **Q.** In your written statement you talked about the
11 treatment in 1999:

12 "The side effects were many and too awful to
13 bear."

14 You have referred to the hair loss:

15 "... but also peripheral damage to the blood
16 vessels in my legs, numbing of the lower limbs, loss
17 of appetite and physical pain all over my body which
18 was indescribable."

19 **A.** Yes, and I still have to this day. It was
20 interesting, both the back of my legs, it was obvious
21 that the treatment had -- was damaging the blood
22 vessels, so all the peripheral blood vessels were all
23 ruptured. So I had sort of purpley red and black all
24 down the back of my calves, and I lost sensation in my
25 toes and my lower limbs, and that went on for quite

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1 know, your hair is very much your sense of being
2 feminine, you know, and making you feel nice about
3 yourself. When your hair drops out like that it's
4 horrible, really horrible.

5 There was one occasion I know that Steve was
6 terrified because he came home from work to find me
7 laid sprawled on the couch completely out of it and he
8 said he thought I'd died because my colour -- I was
9 sort of a strange colour, wasn't I, and he was
10 terrified. And I have to say that I could only manage
11 to do four and a half months of that treatment because
12 I was having to self-inject and take tablets and the
13 side effects of that were horrendous.

14 I couldn't taste my food, I wasn't particularly
15 hungry. The weight dropped off me and, yeah, just --
16 and the side effects of it, but the fatigue was
17 probably the worst and, of course, I was a young
18 mother. My daughter was starting school. I was
19 struggling to cope and the year prior to that, because
20 I had continued to try to work, but I had reached
21 a point where the hepatitis was affecting me so badly
22 and, ironically, I was nursing for the NHS in my last
23 role and I was forced to retire. I just couldn't
24 continue.

25 They wanted to get rid of me and I said, "Look,

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1 some time.

2 It took a long time to recover from that. That
3 rash stayed there for about two or three year.

4 **Q.** So that treatment you weren't able to complete.

5 **A.** No.

6 **Q.** It didn't clear the virus and you continued to
7 experience the physical and mental symptoms of
8 hepatitis C?

9 **A.** Yes.

10 **Q.** Now, you have talked in your witness statement about
11 a meeting that you had in 2002 with Dr Taylor who had
12 been the doctor in 1982 in Kent who had given you the
13 Factor VIII products.

14 **A.** Yes.

15 **Q.** One of the purposes of the meeting was you wanted to
16 get the batch numbers for the products.

17 **A.** Yes.

18 **Q.** What was, in your recollection, Dr Taylor's response?

19 **A.** Well, initially, I obviously had to sign a form
20 requesting my records, which I duly did, and I was
21 sent a small sheaf of general records where it
22 referred to, you know, the fact that I'd been in
23 hospital, I had had treatment and there was -- I think
24 there was even a recorded batch of normal saline but
25 no blood batch records of Factor VIII.

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So I contacted the hospital again and said these records are incomplete. Where are the blood records for my treatment in 1982, December '82? Well, there aren't any, and I said, "Well, that can't be right. There must be", because the thing is with the condition of haemophilia it's a life-long condition and, therefore, any treatment that you have had has to be kept for the reasons being that people get adverse clinical reaction to some treatments, they might develop prohibitors, so you keep those records. They have to be kept.

He said, "There are none. They've been destroyed", and I said, "Well, you should know that those particular records should never have been destroyed for the reason that I'm just telling you". So I insisted upon a meeting and I set out I think 12, a dozen questions in advance, and I sent that in the post and said, "I'm giving you an opportunity to answer these questions", because I was really concerned about his attitude. I didn't like his cavalier attitude anyway but I thought I'm going to have to confront him. So we set up a meeting and I took with me a lady from the Community Health Council, which was the last independent patient advocate and Steve came along with me.

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meeting with me and having a discussion about this or warning me before you gave me these blood products, 'By the way, there could be a risk here of hepatitis', and he sat there and he stared into the distance, "Ah well", he said, "it was a mere oversight. I forgot to tell you".

I said, "What, a life-threatening disease, filthy commercial blood products and you thought just an oversight, you forgot to tell me, you thought that was okay?" His attitude was, yeah, very cavalier, wasn't bothered in the slightest.

Q. You know, I think, that Dr Taylor's provided a statement to the Inquiry and there are some documents attached but you have not had very much opportunity in terms of time to look at those?

A. No.

Q. You want to be able to look at those and, if necessary, provide a written response?

A. Yes, yes, I do.

Q. The other thing that then came to your attention in 2004 was an issue about the risk of exposure to vCJD.

A. Hm mm.

Q. You had been treated in 1993 by, your statement says, a blood plasma batch made by BPL and you became aware later from news reports about BSE and CJD, you became

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He amazingly developed quite a lot of amnesia throughout that meeting. He didn't answer the questions as I'd asked them and he had had plenty of opportunity to, you know, think about it and give me a good response, and I had to force out of him where he was purchasing his products from and who was purchasing them and where the purchasing records were for those blood products, none of which he could provide.

Q. The answer in terms of where he was purchasing them from or where the hospital was purchasing them from was a company called Immuno. Your understanding is that they purchased or sourced their products from the States.

Now, did you have any conversation with Dr Taylor in the course of that meeting about what information he had or hadn't given you prior to the procedure?

A. Yes. I wanted to establish what his state of knowledge was with regards to the risks of commercial plasma, and he confirmed to me that he was very well aware of the risks involved. I thought, "Well, that's very interesting, so why was I not consulted on them?"

So I said to him, "Well, that's, okay, interesting because I don't recall at any stage you

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aware of those issues and you wanted to raise it with the Haemophilia Centre at the Royal Free?

A. Yes.

Q. What happened?

A. Well, I was very concerned when I saw -- I thought not another pathogen, you know, surely to God. So I phoned them up and I said, "Have I been exposed to new variant CJD", and I was met with a very dismissive attitude and told to stop worrying and fretting about it, no. The answer was no.

Well, 1993, just to say, I was actually in hospital for quite a protracted period of time. I was actually in for three months and I had three operations during that time to remove a tumour, and the surgeon made a mess of it each time but anyway it was, obviously, during this period of time that this product would have been used and then some years later, obviously, there was questions being raised in media reports that, you know, there was a possibility of this so that was why I was questioning and was told categorically, "No, you are fretting about nothing unnecessarily, so off you go".

Clearly that's not been recorded because there's no record in my notes but that conversation was had because I remember discussing it with my sister and

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1 saying, "I'm really terrified that here we go again,
2 this is something else", that, you know, and I said,
3 "Knowing my luck, I probably have been exposed to it".
4 **Q.** In 2004, November 2004 -- if we have up on screen
5 please, Paul, 1056006 -- you received this letter from
6 the Queen Elizabeth Hospital Birmingham where you had
7 moved and your care had been transferred there by this
8 time.
9 **A.** Yes.
10 **Q.** It says this:
11 "Dear Colette, following your recent out-patient
12 clinic appointment I wrote to Christine Lee with
13 regard to the variant CJD exposure situation and have
14 had a reply today from her. As per the instruction of
15 the patient reply sheet that you returned to them,
16 I am writing to let you know that you did receive UK
17 sourced Factor VIII concentrate between 1980-2001 and
18 that in 1993 you received a quantity of Factor 8Y from
19 a batch that had been contributed to by a donor who
20 subsequently went on to develop variant CJD."
21 Then there's a reference to the possibility of
22 arranging a date to discuss it further.
23 **A.** Yes.
24 **Q.** What was the impact on you of receiving that
25 communication?

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1 time and, of course, it occurred to me, well, what
2 guidelines are being given to different departments in
3 the hospital if they are faced with a patient like me
4 who's discovered that they've been exposed to new
5 variant CJD? What happens to the equipment? How is
6 it autoclaved? Is it thrown away? If I need an
7 endoscopy, will that equipment be reused or, you know,
8 for the purposes of trying to avoid infecting others
9 will it be thrown away?
10 I was talking to the doctor as he was, you know,
11 trying to stop my nose from bleeding and he said, "We
12 haven't got any such guidelines", and I said, "Well,
13 why not, because by then you should have had them".
14 He said, "They haven't been handed out to us". He
15 said, "I've got no idea what the protocol is here".
16 So, again, I'm having to push for answers and
17 ask the questions.
18 **Q.** You set out very clearly in your written statement and
19 you have set it out again in your oral evidence, your
20 understanding and belief that neither your parents
21 originally nor you were put in a position to give
22 informed consent to the use of blood products because
23 you weren't given the requisite information.
24 **A.** Mmm.
25 **Q.** You also say in your statement that you have found in

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1 **A.** I was horrified, absolutely horrified and bloody angry
2 because I asked them, "Tell me, have I been exposed",
3 and I was told no. I actually asked Jonathan Wilde to
4 contact Christine Lee because my gut was telling me
5 differently and when that answer came back, I was
6 furious because if you look at the time gap between
7 1993 and when I was actually informed, you know, it's
8 nearly -- it's ten years' gap.
9 But worse still I actually had, to get to the
10 nitty-gritty of exactly what had happened, I had to
11 write myself and I have a set of communications
12 between me and the CJD surveillance team in Edinburgh,
13 to actually get the batch number and find out about
14 the person who donated the blood, how long they were
15 ill with the disease and, you know, from the point
16 that they donated the blood to the point they were
17 diagnosed and then subsequently died. So that
18 information wasn't freely given to me. I had to go
19 seeking that information.
20 **Q.** Do you recall whether there were any further
21 discussions between you and whether it's Dr Wilde or
22 anybody else about those issues?
23 **A.** No, and in fact further to that I was still suffering
24 from quite severe nose bleeds and had to be treated.
25 I had to have my nose cauterised for the umpteenth

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1 your medical records evidence that at the Royal Free
2 you were tested without your knowledge or consent for
3 hepatitis G, and if we just have on screen 1056008,
4 that's a test result there recorded that -- you found
5 this in your records subsequently?
6 **A.** I found it in my records, no date attached -- well,
7 yes, 1995, but no reference to who ordered the test,
8 why they ordered it and certainly no discussion with
9 me as to why they were testing for hepatitis G. There
10 is nothing in my records to identify who was behind
11 that and why.
12 **Q.** As far as you are concerned you were not asked to give
13 that consent and did not give it?
14 **A.** No.
15 **Q.** Was the result, negative, one that was ever
16 communicated to you as far as you know?
17 **A.** No.
18 **Q.** In terms of issues about obtaining medical records you
19 have described the position in relation to the Royal
20 Free, you've described the position in relation to the
21 hospital in Kent and Dr Taylor?
22 **A.** Mm-hm.
23 **Q.** You also set out in your witness statement that you
24 had some difficulties obtaining your Scottish health
25 records from the Glasgow Royal Infirmary; is that

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1 right?

2 A. Yes, huge problems. Again, I had to write to the head

3 of the trusts and complain that the records were

4 incomplete. Where were the blood batch records?

5 I explained exact dates of when I was admitted, how

6 long I was in hospital for, all the address details

7 and my maiden name, hospital number, the exact dates

8 during which I believed I was treated and where were

9 those records?

10 They couldn't -- no, they don't exist. I said

11 that's -- "No, they will exist, I want them".

12 Effectively, what I had to do in the end and, again,

13 it was force, through my campaigning, I've done a lot

14 of stuff with the media and at that time I was working

15 with Sarah Smith who was working for, I think,

16 Channel 4 then and I had to threaten them with turning

17 up at the hospital gates with the cameras rolling and

18 I said, "Make no mistake, I will not miss and hit the

19 wall". I said, "You produce those records or I'm

20 going to embarrass this hospital so find them".

21 Low and behold they miraculously turned up.

22 Found on a microfiche somewhere outside of the

23 hospital and had been moved, but they existed where

24 I had been told, "Oh, they are 26 years old. You'll

25 never -- they don't exist". Well, they did, yes.

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1 time. I'm sure that Steve will maybe make a comment

2 about that but it must have been horrible for him

3 living with that fear, me living with the fear and, of

4 course, you know, the other thing that I didn't

5 mention was that, you know, I was suffering from

6 depression as well.

7 Q. I wanted to ask you about the effect on your mental

8 well-being.

9 A. Yes.

10 Q. You have talked about in your statement, about

11 everything having had a huge effect on your mental

12 well-being. It's caused you anger, it's caused you in

13 the past to contemplate suicide.

14 A. Yes.

15 Q. And you say in your statement that you almost carried

16 out that desperate act a few years ago but you

17 realised you would leave behind unresolved grief and

18 anger which would have been hellish for your family.

19 A. Yes, that's true. I had reached probably the lowest

20 I think I've ever been in my life. It's common when

21 you've got a chronic condition like this, they want to

22 put you on a variety of different tablets and I do

23 believe that the antidepressants that they put me on

24 at the time probably actually made my mental state

25 worse and on this particular evening I just --

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1 Q. Now, I would like to ask you some questions, Colette,

2 about the impact upon you and your family of your

3 infection with hepatitis C and consequent treatment

4 for that. In terms of your family circumstances, you

5 said you have got your husband, Steve, and you have

6 a daughter now in her 20s, and in your witness

7 statement you said:

8 "The impact of my chronic ill health has had

9 a very negative and damaging effect on our family

10 life."

11 Could you elaborate upon that.

12 A. Yes, for the majority of my daughter's younger years

13 I couldn't be the Mum that I needed to be for her.

14 I couldn't join in on family events because I was too

15 ill, invariably struggling to get out of bed every day

16 with fatigue and trying to cover it up from my

17 daughter as well because I didn't think it was fair

18 for a little person to have the worry of mummy not

19 being well and potentially mummy getting sick and

20 maybe mummy dying. Trying to be a wife to my husband

21 who had, you know, a blossoming career and he's trying

22 to keep hearth and home together.

23 He's terrified, you know, to leave me, can't

24 support me in the way he'd like to, but it stole time

25 from him too and he felt like a lone parent for a long

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1 I couldn't hack it anymore.

2 I was in my night clothes and I ran from the

3 house barefoot down a dark lane, because we live in

4 rural countryside. I ran down that lane, tears

5 streaming down my face -- I still think about it now.

6 I ran down there thinking how I need the courage to

7 just put myself in there. There was a series of quite

8 deep ponds that people go and fish and I ran through

9 that gate and headed for that pond and I was covered

10 in mud, it was wet, slippery, scratched by the bushes as

11 I was running past and getting nearer and nearer and

12 I got to the edge of the pond and I put my foot in the

13 water and thought, "Just get on with it, Colette.

14 Just do it now and then the pain will be over".

15 Whether it was a guardian angel or something

16 there's another little voice sitting here saying,

17 "Excuse me, what are you going to leave behind?

18 A little girl who doesn't fully understand, you know,

19 what's happened to Mum and a husband who has been

20 fantastic, supportive", he's been with me on this

21 journey and, believe me, from when I started

22 campaigning in '94 this man has walked across

23 Westminster bridge with banners, he's had T-shirts on

24 him, "hep c bloody murder", you name it. He's been to

25 debates with me, he's been to Westminster, the

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Department of Health. There isn't a place that Steve hasn't -- Downing Street, he's been with me all the way, and I couldn't do it.

So I pulled back. They realised that I'd disappeared and they were out looking for me and eventually I went back and I sat on the bench outside of the house and I just wept and ... yeah, they scooped me up, took me in, washed me off and said, "Come on, pull yourself together", which was hard, very hard.

Q. In terms of the physical impact of your infection, you have described powerfully in general terms the symptoms that you experience over the years. You told us about your 1999 treatment. You underwent a second course of treatment in 2015?

A. Yes.

Q. How was that?

A. Dreadful. Terrible pain, terrible -- I was very jaundiced for the first two months of the treatment. Skin was rashy and tingling. Again, the fatigue just wiping me out, and this time my hair started to fall out but uniformly rather than in clumps and actually it's only just stopped falling out.

I have a big head of hair to lose thankfully, and it looks like a normal head of hair to most people

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I would undergo a test which they do where they keep you awake, slightly sedated, and they cut your jugular, and insert a wire all the way down through the major vessels until they get to the liver. They scan you beforehand so they know where they want to go to look for cirrhotic material and that was quite an experience.

Being ex-medical, perhaps I got through it because I am fascinated by the workings of the human body, and so I decided that I would chat to the doctor who was doing it, a very lovely man Dr Olaf, who was exceptionally nice at keeping me calm because it is quite something to be awake and have somebody cut into your neck next to a major artery. He was horrified that I wasn't anywhere near sleepy and kept saying, "Can you stop asking me questions". But, yes, I had to go through that for them to actually decide this damage has gone to quite a level.

It was something, actually, that annoyed me about two years before I left Kent, I was not seen by anyone at the Royal Free. It's almost like they didn't want to see me. Yeah, perhaps because by then I was a seasoned campaigner and had plenty to say and I suspect it would be uncomfortable for them for me to ask why they infected me in their department in '85

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but to me that's quarter of what I had but it's only just stopped coming out four and a half years later. I was only on it for.

STEVE: It was going to be four months, wasn't it?

A. Yes --

STEVE: They said it needed to be six months.

A. Yes, they needed six months instead of four months to try and clear the virus.

MS RICHARDS: And the virus did clear in relation to that second course of treatment.

A. They say it's cleared. I'm not totally convinced that you really do get rid of hepatitis C. It's a very clever virus and it can hide and the fact that they haven't got a test that can show it's well below zero, even subzero, I think my level came down to something like 12, but I'm still feeling the effects and I thought, maybe naively, I thought that, well, if I do this, because Dr Mutama, who's my hepatologist, was concerned that because of the length of time that I have been diagnosed with cirrhosis (which was 2004, by the way), that it was highly likely that I would be at high risk of going into liver failure and I'm still very high risk of getting cancer.

Actually, I haven't told you this but in 2004, to ascertain the level of damage, I was asked if

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maybe, you know, CJD, lying about it, you know -- and they did lie.

Q. Despite the treatment in 2005 having the effect that you've described, whether or not it's accurately described, as clearing the virus --

A. That was 2014.

Q. 2014, sorry -- you have continued to experience a range of physical symptoms?

A. Yes.

Q. You have described in your statement constant muscle and bone ache, chronic insomnia?

A. Yes.

Q. Pain?

A. Yes.

Q. You have a condition called costochondritis, which is inflammation of the cartilage connecting the ribs to the breast bone?

A. Yes.

Q. You have fibromyalgia?

A. Yes.

Q. Arthritis in your joints and very marked deterioration in the discs of your spine?

A. Yes.

Q. In terms of dental care, you have been able to access that -- is that right -- but through a specialist

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1 clinic at the Queen Elizabeth Hospital in Birmingham?

2 A. Yes, it's done in the hospital. They have a clinic

3 for haemophiliacs and they invite you in either

4 six-monthly, if you need it, or annually for general

5 care, dental care. So that luckily hasn't been an

6 issue.

7 But when I was living in Kent, I had -- yes,

8 I had to actively seek a dentist who was willing to

9 treat someone with chronic hepatitis and, obviously,

10 I didn't know about the CJD exposure until I moved to

11 the Midlands. But I'm sure that a lot of

12 haemophiliacs have experience, and I've heard them say

13 they have experienced this problem, yes, getting

14 dental care.

15 Q. You have talked about in your statement how the

16 conditions, the infections that you've had or have,

17 have led in terms of treatment to you having to be

18 operated on last to being regarded as a dirty case to

19 there being a lack of knowledge on the part of the NHS

20 staff who treat you often about the history of how

21 these infections have come about. But you also said

22 this. You're asked or you have been asked on several

23 occasions by NHS staff if your infections were due to

24 lifestyle choices, such as drug abuse or alcoholism;

25 is that right?

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1 explain, you know, and you're almost on the defence

2 all the time and anticipating every time you go into

3 hospital and you're faced with medical staff what

4 they're going to surmise of how you came to be in this

5 predicament.

6 But I'm a great believer in education and I've

7 spent my entire life since my knowledge of hepatitis

8 came about trying to make sure that the stigma that

9 people have suffered (and actually it still does

10 exist) that they wouldn't have an excuse if I told

11 them and explained to them how it came about.

12 Education's a great thing because it empowers people

13 and you're far more likely to not just educate them

14 but create in them an understanding and an empathy

15 that maybe wouldn't be there because they wouldn't

16 know about what's happened to people like me with

17 a bleeding disorder who don't expect throughout their

18 lifetime to be infected with multiple viruses over

19 decades. It's just something people don't expect to

20 hear. I mean, it's like a horror story really when

21 you unfold it as to how things evolved over the last

22 three decades and how I came to be in this

23 predicament.

24 Q. One of the other things you've said in your statement

25 is having had to, as you've explained, take early

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1 A. Correct, yes. That was said to me. I actually had to

2 transfer my haematological care from Birmingham. I'm

3 quite angry about this. But I presented on two

4 occasions with an active bleed and was refused

5 treatment and I was deeply, deeply unhappy about that

6 but I think, possibly because I'd had an exchange with

7 Dr Wilde and he knew that I was an active campaigner

8 and quite vocal on my criticisms of Government, the

9 NHS, the doctors that treated their haemophilic

10 patients in such a way of putting them at high risk,

11 and I felt compromised.

12 So I was forced to go to St Thomas', which is

13 quite a distance to travel. But on this particular

14 occasion, I had to go and have a pre-operative

15 check-up before having a procedure done. This lady

16 was a trained sister and I recall sitting down and the

17 first thing out of her mouth was, "So your chronic

18 hepatitis C: is this down to your lifestyle choice of

19 alcohol or drugs?" I was horrified.

20 It's been said to me when I am -- I mean, I have

21 regular six-monthly scans. Now, most of the staff

22 have obviously got to know me thankfully now but in

23 the early days, you know, you could see straight away

24 what was going through their mind "why's she got

25 cirrhosis of the liver?" You're constantly having to

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1 retirement in 1998 and been unable to return to the

2 workplace, you often find yourself having to explain

3 and justify the fact that you're unable to work and

4 have to reveal very private information to friends or

5 people you might meet in social circumstances and

6 elsewhere?

7 A. Yes, that's right, and there have been many occasions

8 where my husband's job involves quite a lot of

9 corporate, sort of, entertainment and as his wife, you

10 know, I go along to support him and, you know, help

11 him with customers and so on, and invariably the

12 conversation will naturally come round to, "So what do

13 you do?" I have to say, "Well, I don't work" and they

14 say, "Oh, very nice". And I'll say, "No, you don't

15 understand. It's not out of choice. I don't work

16 because I can't work" and they look in amazement.

17 Well, I suppose part of the problem is this

18 facade because you learn over time if you paint your

19 face and put a smile on your face, then to all intents

20 and purposes I look normal and I guess we all want to

21 look normal, don't we? We all want to be accepted by

22 others and don't want to feel we're different. It's

23 embarrassing at times to say, "No, I don't. I had to

24 retire when I was, you know, 38 years of age and

25 I wouldn't work again" and then have to go into the

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detail. Then I feel guilty because on occasion Steve would say, "Could you just not talk about it" and then you -- What am I going to say then? Why don't I work? Because I'm a lazy so and so? No, I'm not going to say that. Yes, you do have to justify it.

I told a funny story earlier. My daughter -- you know, kids at school, you know how they talk, "What does your mummy do? What does your daddy do?" and so on and Rebecca didn't find out really what the issues were with me until her early teens. But invariably, you know, kids come and have a sleepover and whatever and would say, "What does your Mummy do for a living? What does she work at?" and she would say, "Mum just does dishes at home". Just does dishes at home.

But Mummy meantime is out there campaigning, trying to raise the profile of this damnable disaster, and she's coming home and saying, "Well, what's that camera doing in the garden, Mum?" or "Why are you going to the local radio station? Is that you in the paper. Eventually, it started to unfold but, yes, it's been pretty tough having to reveal those private aspects of my life and tell the story of, you know, what has happened to me physically and what the ultimate prognosis is going to be. And believe me,

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and you're physically and mentally not up to it, you know, it's very, very hard to deal with.

Q. In 2010, when you met the Health Minister, you were told that the Government would be willing to offer counselling or psychological support to be made available to victims but you've said that the funding was such a small amount of money, it wouldn't have been adequate to meet the needs of the community --

A. Yes.

Q. -- and it was going to have to be through the trusts and funds?

A. Yes. I raised it with Ann Milton and actually more directly with Rowena Jeacock, who was the head of the Blood Policy Team, and asked her -- this is quite late in the day 2010 but, you know, knowing that so many haemophiliacs, you know, would be suffering with depression and PTSD -- and I asked how much money, you know, had been set aside at all because they had announced that they would provide money for counselling. The sum that was told to me was 300,000 had been set aside for an entire community of patients.

I said, "Well, that's not going to stretch anywhere near enough". I said, "If someone was to apply for it", I said "how do they get it?" "Well,

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I mean, having nursed people who have died from liver cancer, it is quite a horrible way to die.

I have regular nightmares. I don't sleep. Maybe if I get an hour or two's decent sleep a night that might be it. The rest of it's just surface sleeping. My body's in constant flight and fright. I suffer night sweats all the time. I'm sure a lot of the haemophiliacs will tap into that one. So yes, it's pretty horrible to have that.

There's no getting away from this. You wake up with it in the morning, you go to bed with it at night, and it's sitting there with you all the time, yeah.

Q. In 2010 as part of your campaigning, you met with the then Health Minister about the availability or lack of availability of counselling and psychological support. Have counselling or psychological support ever been made available to you or to your family?

A. We had a short spell of counselling at the Royal Free but it was more related to the early years when I was finding it very difficult with Rebecca. Some people have expressed this already that it affects your brain, you're foggy-brained, you get angry, you get fidgety and very, very difficult and if you've got a young child, you know, who's having a difficult day

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they have to go through the Hep C Trust". So I said, "Okay".

And I said, "How many sessions would that actually allow them to have if they were able to secure that?" A maximum of six, I was told.

Well, I'm sorry but, you know, my experience in what's happened to me I know six sessions wouldn't help me one jot; so I don't know what they were thinking about. 300,000 is a drop in the ocean of what really is actually needed.

Q. In terms of the funds themselves, what's your experience, your direct experience, been of the application process and the information which the Skipton has required applicants such as yourself to provide?

A. An appalling process as people have described it and I've described it this way myself. You're made to feel like a beggar with a bowl. The method and way in which they ask people to apply, the level of intrusive information that they ask of people is a disgrace. They've also set out about a divisive process which has set many, you know, people against each other because one's getting a certain amount of money, the other one's getting another lot and it's clearly grossly unfair, demeaning and derisory the sums of

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1 money we're talking about here and the means testing
2 issue is utterly appalling.

3 I said at the outset that if -- and I know a lot
4 of these trusts just weren't meeting the needs of
5 victims, just aren't, and even when they decided --
6 and I wasn't consulted and, you know, I still remain
7 angry about this, some of the longest-standing
8 campaigners were left out of a lot of meetings that
9 took place when, you know, we were looking at a change
10 in the financial reviews on these trust funds, and
11 I said at the beginning, you know, and I've said it
12 for several years that it's absolutely shocking that
13 the state is responsible for the multiple infections
14 of a very vulnerable patient group -- and, I'm sorry,
15 I'm just speaking as someone with haemophilia.

16 It seems to me an absolute disgrace that the
17 state can infect people in this way, spend three
18 decades covering it up, and insult us with these
19 pathetic sums of money which in no way could possibly
20 meet or represent the losses that people have suffered
21 and they are not enough even now for people to get by
22 on. They're the most basic levels.

23 I actually said something in the Department of
24 Health and it raised a few smirks round the room but
25 I asked directly in a meeting with Ann Milton and the

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1 done to me by the people who were supposed to be
2 caring for me."

3 That's the end of the questions I wanted to ask
4 you and you know, I think, that a number of the themes
5 you raise in your statement issues about the trust and
6 schemes and so on are matters that the Inquiry will
7 indeed be investigating in due course. But is there
8 anything else before I ask Mr Stein if there are any
9 further questions that you would like to say at this
10 stage?

11 A. Yes, I just set some thoughts out. If you'll bear
12 with me, I'll read them.

13 I'd just like to say that I do welcome this
14 Inquiry as a final opportunity to seek the real truth
15 behind the contaminated blood disaster and I hope the
16 final outcome will really deliver truth and justice
17 where there has been none; that there will be
18 recognition of the extreme pain, suffering and an
19 acknowledgement of people's financial losses, which
20 have hugely impacted on my life and that of my family
21 and many others; the damage that's been done to my
22 family life and the relationship with my child, which
23 has taken many years to repair and we're still trying
24 to get there; and it's my hope, Sir Brian, that you'll
25 re-look at Lord Peter Archer's recommendations that he

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1 Head of Blood Policy, "Who came up with the sum of
2 money that we're talking about?" That was back in,
3 I think 2011, I asked that question. "Who come up
4 with these sums of money?" And they couldn't answer
5 me.

6 I said, "Well, would you be satisfied in
7 receiving that if you'd had done to you what I've had
8 done to me? Would you be accepting that" I said,
9 "because whoever thought these up should be shot".
10 There was a smirk and a giggle around the room but
11 I actually meant it because it is deeply insulting,
12 really insulting, and cruel that people have been in
13 some cases pushed into financial penury. Some have
14 not been able to afford to buy their own homes.

15 My worry -- I mean, my husband here, you know,
16 he won't get a penny from the current trust fund or
17 the previous ones if I die because he would be means
18 tested; so he wouldn't get anything. I think that's
19 wrong and the only way you're going to properly help
20 people is to give them proper compensation. We don't
21 want begging bowl funds.

22 Q. Colette, you've said in your statement, in summary in
23 your statement, this:

24 "My life has not been what it is or what it
25 could or should have been because of what has been

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1 made in his independent report, which I was a witness
2 to, because I think they remain arguably a most
3 comprehensive set of recommendations and it would be
4 nice to see them implemented, as they should have been
5 at that time in 2009 when the report went out.

6 I think most of us feel -- you know, we want --
7 every infection that we've been exposed to should be
8 taken into consideration in those recommendations if
9 we're talking about compensation proper. You know
10 hepatitis B hasn't been considered here and certainly
11 there's no word of compensation for being exposed to
12 CJD. We're just talking at the moment about hep c and
13 HIV.

14 I want to see accountability for lies that have
15 been told by Government officials and that even when
16 those lies have been exposed, nothing's been done
17 about them. Those decisions have blocked justice for
18 haemophiliacs for quite some time and for people who
19 have been infected in other ways. I hope it does
20 become clear in summarising of this Inquiry that, you
21 know, as more people give evidence that this was not
22 a medical accident, it was largely avoidable.

23 And I want assurances too that, you know,
24 certainly from Government that long-standing
25 campaigners won't be blocked and left out of meetings,

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as we have been, because that's had a very serious impact. It's certainly not a democratic process if you exclude people, you know, that should be there and part of discussions because, obviously, it's affected the way that the new payment schemes and financial trusts were folded. I'm referring particularly to the Macfarlane Trust was set up under a legal framework and people signed to that and it was meant to be for life and widows were not meant to be means tested but that is happening and it's happening in the new scheme.

I want financial security for my husband if I die because, you know, this new announcement with EIBSS and victims are furious about means testing but, you know, as I said, under the current rules that Steve won't get a penny for the loss of my life and there's too many anomalies across the devolved governments which are shocking because if I'd remained living in Scotland for example, I would have been entitled to that scheme plus my husband would have got 75 per cent of that pay-out if I lost my life. That's not the case here.

Finally, I'd say that as a victim of the worst treatment disaster in the history of the NHS I want to say to every successive Government, past and present,

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and to the current Parliamentarians that you had, and still have the responsibility to ensure justice for every person who has been afflicted and bereaved by a life-threatening treatment supplied by the state. I think we're talking about, as far as I'm aware, over 2,500 haemophiliacs have lost their lives and those of us who are left still battling every day with the physical and mental damage of being infected with multiple viruses and having to fight for scraps of *ex gratia* payments.

You know, I want my pain and suffering recognised and it's so stressful because that delay in getting justice is compounded by the anger and the disgust that I feel for those who have been complicit in covering up this blood scandal.

I would say too finally that it's deeply, deeply upsetting to me that I have [redacted] in Dublin both of whom were paid out over 20 years ago by a government who, without any admission of liability, did accept that they had to recognise the pain and the hardship that were inflicted upon victims. So I would say one thing: why is my life worth so much less here in the United Kingdom than [redacted] in Eire? That's not right.

Q. Thank you, Colette. I am just going to turn my back

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and ask Mr Stein if there are further questions.

Nothing.

SIR BRIAN LANGSTAFF: I have nothing of my own to ask.

Just let me thank you for what you have said to us this afternoon and for being here to give your evidence and to tell us what you have.

A. Thank you.

SIR BRIAN LANGSTAFF: Thank you very much.

I omitted to but I should have thanked Steven as well.

We now take a break for the next week until the Tuesday after next when we reassemble in Belfast.

MS RICHARDS: Sir, that's right. We resume our hearings in Belfast on 21 May.

SIR BRIAN LANGSTAFF: We will not be back here in Fleetbank House until 4 June. If anyone wishes to follow the Belfast hearings, it will be for the four days beginning the 21st, after which there's another short break. Then they can do so following the live streaming if they are not there in person. They are, of course, very welcome to be there in person but I suspect that most of you will be following online and by getting the transcripts in due course. Thank you very much.

MS RICHARDS: Thank you, sir.

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(4.07 pm)

(The hearings adjourned until 21 May 2019)

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