

1

Friday, 10 May 2019

- 1
2 (9.59 am)
3 **SIR BRIAN LANGSTAFF:** I'm told that our first witness
4 would like to be known as Andy.
5 **MS RICHARDS:** That's right, sir. Andrew Evans -- Andy.
6 **ANDREW EVANS, affirmed**
7 **Questioned by MS RICHARDS**
8 Q. Andy, there's a copy of your witness statement on the
9 desk if you need to refer to it, but I'm not going to
10 ask you to look at it but it's there if you need it as
11 a prompt.
12 **A. Thank you.**
13 Q. You were diagnosed with severe haemophilia A in early
14 1978 when you were a baby.
15 **A. That's right, yes.**
16 Q. And you were under the care for many years after that
17 of Dr Hill at the Birmingham Children's Hospital.
18 **A. Correct.**
19 Q. And I understand from the documents you have provided
20 to us that you were initially treated with
21 cryoprecipitate but then you were regularly treated
22 with Factor VIII products?
23 **A. Yes, correct, initially Bio Products Laboratory stock**
24 **but then later on American Armour products.**
25 Q. Do you know if your parents were ever given any

3

- 1 Q. Now, you have explained in your statement that you
2 were tested or your bloods were tested for hepatitis B
3 on numerous occasions from 1979 onwards and there was
4 a positive finding in relation to hepatitis B in 1981.
5 **A. That's what my notes show, yes.**
6 Q. You have also referred to there being a whole range of
7 tests undertaken in 1981, by way of example.
8 Could we have up on screen please, Paul,
9 1213002.
10 This is one of the documents you've produced
11 along with your statement, Andy, it shows a range of
12 different tests being undertaken in 1981?
13 **A. Yes.**
14 Q. Do you know what, if any, information was given to
15 your parents about the need for such tests?
16 **A. I've never been told by my parents that I've been**
17 **tested around those dates for anything other than**
18 **haemophilia clotting levels; so they may be -- my mum,**
19 **my Dad's passed away, but my Mum may be able to**
20 **provide more information but I don't think that she**
21 **knew about these tests either.**
22 Q. You have set out at least a belief or a suspicion in
23 your witness statement that it may be that tests were
24 being undertaken for purposes of research.
25 **A. Yes. Yeah, I'm -- from what we've since discovered,**

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- 1 information or advice or warnings about any risk of
2 infection associated with the use of those products?
3 **A. Not from official sources, no -- not from any of the**
4 **staff or doctors at the hospital.**
5 Q. You were taught to self-administer the products at an
6 astonishingly young age. Can you tell us about that.
7 **A. Yes. It used to take five or six people to hold me**
8 **down to have my injections. I would kick and scream**
9 **that much I don't think anybody likes having a sharp**
10 **metal rod poked into their skin, especially when**
11 **they're a toddler, and one day they were having**
12 **a particularly difficult time in getting a vein and so**
13 **I said, "Well, I'll have a go", and I took the needle**
14 **from them and I think they thought it was just a good**
15 **way of persuading me to engage with the process and**
16 **maybe let somebody do it a bit later on but**
17 **immediately I got a vein and everybody was very**
18 **astonished. I was three years and ten months at that**
19 **time.**
20 Q. Is it right you largely self-administered after that?
21 **A. Yes. Yeah, I mean, I tried to self-administer as much**
22 **as I could. If, for example, I couldn't, for example,**
23 **if I got a bleed in one of my arms or I had a nose**
24 **bleed that needed to be pinched or some other reason**
25 **then my Mum would do it but if I could, I would, yes.**

4

- 1 **it seemed that there was fairly common knowledge of at**
2 **least hepatitis viruses in the blood and so it would**
3 **be my suspicion that this kind of test was for that**
4 **purpose.**
5 Q. Now, you understand from subsequent conversations that
6 you've had with your parents that your father became
7 aware of a potential risk associated with the use of
8 Factor VIII products when reading a New Scientist
9 article?
10 **A. Correct, yes.**
11 Q. We have managed to track down the New Scientist
12 article that we think your father had read.
13 It's 1213005 please, Paul.
14 It is the bottom of the page.
15 "AIDS: transfusion patients may be at risk", if
16 we could have that highlighted.
17 If we just look at this, Andy, and see what it
18 was that your Dad had read:
19 "American scientists are scouring the country
20 for the first case of the bizarre new disease acquired
21 immunodeficiency syndrome, AIDS, in patients who have
22 undergone major surgery. The hunt for the cause of
23 the disease which was first diagnosed among male
24 homosexuals has now labelled as a prime suspect some
25 unknown blood borne virus. In just one year the list

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

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

21 **A. Yes.**

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

25 **A. Yes.**

7

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

4 **A. Correct, sir.**

5 **SIR BRIAN LANGSTAFF:** Thank you.

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

9 **A. Yes, that is right.**

10 Q. We can see, if we have up on screen please, Paul,
11 1213003, there's reference there, the document itself
12 is not dated or not legibly dated, but we have
13 reference there:

14 "HTLV-3 antibody positive, date of specimen
15 1983."

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

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

6

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

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

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

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

25 **A. Correct, yes.**

8

1 **yes.**

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

4 **A. No.**

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

7 **A. Yes.**

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

10 **A. Correct, yes.**

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

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

22 **But from what I understand, there was no**
23 **briefing about what it meant for me or my prognosis or**
24 **my life from then on, other than the fact that it**
25 **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 --

13

- 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**

15

- 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?**

17

- 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**

19

- 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**

18

- 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

21

- 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

23

- 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**

22

- 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.

24

- 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**

25

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

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

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

27

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

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

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

25 A. Yes.

26

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

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

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

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

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

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

3 A. Correct, yes.

4 Q. We get a snapshot of hospital admissions from the
5 transfer summary that you've produced as part of your
6 evidence which shows that, for example, just between
7 July 1994 and the date of the transfer summary in late
8 '96 you had been admitted to hospital 24 times.

9 A. Yes.

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

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

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

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

29

1 quite quickly.
 2 So they had to do something else. They had to
 3 give me some other kind of prophylaxis against PCP and
 4 the first one that they tried was called dapsons.
 5 I think that was the anti-leprotic drug, so it was an
 6 anti-leprosy drug but I forget now why they took me
 7 off it. I think I was having a reaction to that as
 8 well. I couldn't tolerate it.
 9 The next one they tried was Thalidomide. Again,
 10 I don't think -- maybe that one didn't work properly.
 11 From what I'd heard about it, it was supposed to be an
 12 anti-emetic and, of course, we know about the foetal
 13 development issues with it, but it was still quite
 14 a good anti-emetic and, apparently, it was supposed to
 15 guard against PCP as well but for whatever reason it
 16 didn't with me.
 17 So the third and final attempt at guarding
 18 against PCP was a drug called pentamidine.
 19 Pentamidine was taken by nebuliser, which means that
 20 you put the liquid into a device. It turns it into
 21 a gas and you breathe it in, so the procedure was that
 22 I would take salbutamol first which would open up the
 23 pores in the lungs, I would have that for half-an-hour
 24 by nebuliser and then I would take pentamidine for the
 25 next maybe half-an-hour to an hour, something like

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1 my mobility and so that was a bit of a body blow to
 2 have that taken away as well.
 3 Q. Can I ask you about something you say in your
 4 statement, talking about the wheelchair. You said
 5 this:
 6 "It was one of the things that the bothered me
 7 most because although I knew I wouldn't survive my
 8 illness, the wheelchair took away my mobility and any
 9 independence."
 10 I wanted to ask you about a phrase, "I knew
 11 I wouldn't survive my illness".
 12 A. Yes.
 13 Q. You believed then, based on everything that was
 14 happening to you, that you were going to die?
 15 A. Yeah. If I hadn't made the conscious thought that
 16 that was the case, then somehow subconsciously I knew
 17 it. I was under no illusion how ill I was. It didn't
 18 stop me from having a fighting spirit and wanting to
 19 get better but that was the reality that was facing
 20 me, yes.
 21 Q. Your parents were told on more than one occasion that
 22 your next infection would in all likelihood be your
 23 last?
 24 A. Correct, yes, yeah.
 25 Q. There was -- after your transfer to the Queen

30

1 that. But the problem with pentamidine is that it's
 2 extremely toxic. I had to be put into a separate room
 3 within the hospital. The nebuliser had to be
 4 exhausted out of a window because the drug was so
 5 toxic. Bearing in mind that I'm breathing this
 6 directly in and then the room had to be kept vacated
 7 for about four or five hours after I'd finished the
 8 treatment as well.
 9 It wasn't a nice experience. It was -- it made
 10 my nose bleed. It made me shake. It made me cough,
 11 but at least it was only once a month and so I managed
 12 that for several months, yeah.
 13 Q. One of the things that bothered you most during all
 14 this time was when, because of your mobility problems,
 15 you had to use a wheelchair for quite a prolonged
 16 period of time.
 17 A. Yes. I tried to make my way around on my feet as much
 18 as I could but because of the hip problems, it was
 19 very difficult to go long distances and so -- I mean,
 20 I'd been used to being in a wheelchair for the
 21 haemophilia, but it was only for a period of two or
 22 three days at a time when I went to school, but at
 23 this point it was almost a necessity that I would have
 24 to be in it for any kind of long journey. Despite
 25 everything, despite the haemophilia, I've always had

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1 Elizabeth Hospital, there was some change in your drug
 2 treatments for the HIV.
 3 A. Yes.
 4 Q. You were moved on to 3TC; is that right?
 5 A. Yes, also known as lamivudine.
 6 Q. You began to see some improvements?
 7 A. I did. I began to see that the -- I think I'd still
 8 got *Candida* by that point in my throat and that had
 9 started to clear up a little bit. I started to feel
 10 a little bit more well in myself but I think the
 11 double combination of the AZT and the 3TC didn't last
 12 that long because they had protease inhibitors coming
 13 on line at that point as well, the first of which was
 14 ritonavir, and so they put me on that fairly quickly
 15 afterwards as well.
 16 Q. There was an episodes in the late 1990s when you were
 17 at home and you had something that was almost like
 18 a stroke.
 19 A. Yes.
 20 Q. What can you recall about that?
 21 A. They'd just changed my combination therapy and I think
 22 they'd put me on to one called indinavir (Crixivan,
 23 I think it was called), and I had only been taking it
 24 a day, two days, something like that. My Mum had had
 25 a friend over so she was quite preoccupied. The

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

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

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

35

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

8 So, yes, it was an interesting time.

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

11 A. Yes.

12 Q. But you said this in your statement:

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

15 A. Yes, I believe -- yes, that's pretty much exactly it.
16 It was the time when you turned from being a child to
17 an adult. It was the time where you stop being at
18 school, go to university or get a job, and you're
19 supposed to do that alongside all of your peers. You
20 are supposed to get your life experience at that
21 point. It's where you leave the apron strings of your
22 parents and go and find your place in the world
23 alongside everybody else and that I hadn't done.

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

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

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

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

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

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

20 A. Yes.

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

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

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

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

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

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

23 Q. But you found that very isolating?

24 A. It was isolating. I'm not a person that can motivate
25 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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1 bring people in the same situation together.
 2 You know, we could compare stories, we could
 3 compare the treatments that we'd had, we could tell
 4 each other how we were feeling without judgment, and
 5 it just seemed to me that, because the
 6 Macfarlane Trust was for people with HIV only, that
 7 the wider community could really benefit from
 8 something like this and, you know, we bandied ideas
 9 about.

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

25 So Tainted Blood as a website came about and

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1 Q. It's Michelle.
 2 A. Yes.
 3 Q. I think you wanted to tell us just a little about
 4 Michelle's background and how the two of you came
 5 together.
 6 A. Yes. I was at the bereavement weekend for two
 7 reasons. I was there because I'd been bereaved from
 8 my then fiancée in the States, so I'd got the -- I was
 9 kind of part of the community but not through that,
 10 I was part removed because of the country separation,
 11 but I'd also been asked there to speak as a delegate
 12 on the campaign and Tainted Blood and she was there
 13 because sadly her brother, Andrew, had been in the
 14 same situation as me. He'd gotten HIV and hepatitis C
 15 when he was a boy. He died at the age of 24 in 1996.

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

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

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

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

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

25 A. Yes.

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1 a normal relationship, and it was amazing.

2 Q. You married in 2007?

3 A. Yes.

4 Q. And you've got three kids?

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

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

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

23 So Michelle had to under go egg harvesting, which
 24 meant lots of hormone drugs beforehand and a little
 25 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 I 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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1 left alone with them because I couldn't help them if
 2 they needed anything and, at one point, I seem to
 3 remember they put it down to migraine caused by the
 4 drugs but I completely lost my vision and had to be
 5 rushed into A&E. Luckily that came back fairly
 6 quickly but just such a scary, horrible life-altering
 7 time really and it had an impact not just on me but
 8 everybody around me.

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

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

13 A. Yes.

14 Q. But you've said about this treatment in 2013:
 15 "Taking those drugs caused me to feel the worst
 16 I have ever felt in my entire life."

17 A. Yes, I stand by that, yeah, because I think it was --
 18 a lot of it was down to the -- in the days of AIDS
 19 I could -- I actually got quite good at being ill, you
 20 know, it was almost my thing. I could be ill.
 21 I could cope with it. I could get through this
 22 because I still had my mental faculties about me and
 23 I -- with the hepatitis C treatment that was removed.
 24 It was completely taken away from me. I had no
 25 control and it was horrifying. It was terrifying.

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

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

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

19 A. Yes.

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

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

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

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1 Q. The treatment did clear the hep c virus?

2 A. Yes, thank goodness.

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

5 A. Yes.

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

8 A. Yes.

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

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

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

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1 apart --

2 A. Yes.

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

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

7 A. Yes.

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

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

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

25 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 work around 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)

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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

	2	across [1] 65/25	69/14	anxious [2] 51/2 51/25
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