

Friday, 14 June 2019

(10.30 am)

**SIR BRIAN LANGSTAFF:** Our first witness this morning is

Mr M, is it?

**MS RICHARDS:** It is, sir.

**SIR BRIAN LANGSTAFF:** This is the first witness in Leeds who has asked for anonymity, which will mean that nothing may be said or published which will disclose or is likely to disclose his identity, and in such cases I make what is called a restriction order, that is a legal order which enforces his right to anonymity. If anyone breaks it, they will be committing a contempt of court and could be sent to prison.

It is a serious order. For that reason I will set it out, as I always do, in full. Those of you who have been following the Inquiry on its live stream or have been at other hearings when I have made such an order will know what is coming. Those of you who don't, nonetheless you will hear what I have to say.

The order is as follows. The name and address of witness W1291, that's Mr M to you and me, and any other identifying information, such as the witness' image or a description of their appearance, cannot be disclosed or published in any form unless express

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**MR M, affirmed**

**Questioned by MS RICHARDS**

**Q.** You have severe haemophilia A.

**A.** Yes.

**Q.** As did your older brother, who we will just refer to, if that's okay, as your brother.

**A.** Yes.

**Q.** And you were both treated at Leeds Haemophilia Centre, St James's University Hospital here in Leeds?

**A.** Amongst other centres, Yes.

**Q.** Was that the main treatment centre?

**A.** When we were young and the one that we attended the most as a duo, so to speak. We subsequently went our different directions.

**Q.** About 1992 your care transferred to St Thomas' Hospital in London?

**A.** Yes. His followed there shortly afterwards as a result of my experience but we didn't stay there.

**Q.** Now, you were treated with cryoprecipitate and then with Factor VIII products, a range of different Factor VIII products over a number of years?

**A.** Yes. From the mid-60s until the present day.

**Q.** How did Dr Swinburne, who was the consultant immunologist whose care you were under at the Leeds Haemophilia Centre for some time, how did Dr Swinburne

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permission is given by me or by the Solicitor to the Inquiry acting on my behalf. Witness W1291 must be referred to only as Mr M.

This order remains in force for the duration of the Inquiry and at all times thereafter unless otherwise ordered, and I may vary or revoke this order by making a further order during the course of the Inquiry. Indeed, in one case in Northern Ireland that has already happened, because the witness concerned requested, after having given his evidence and considered it, that he wished his anonymity to be lifted and to be known by the name by which he would be known by others more generally.

So that's the order. It follows, please, that if you do have any mobile phones with you and are taking photographs for whatever reason in and around the hotel, would you please just take care that you don't inadvertently photograph him. The press are aware of the order. They won't be taking any such photographs, or if you do take photographs of him, make sure you ask his permission first and abide by whatever it is that he says, but what you must not do is disclose to any other person anything which might identify him.

Mr M.

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often refer to Factor VIII?

**A.** Jungle juice. That was her -- I guess with kids. I don't know if she told the adults that. She said, "Oh, you have come for some more jungle juice [redacted]."

**Q.** Can we stop the live transmission?

**SIR BRIAN LANGSTAFF:** You must not mention your name, must you.

**A.** I must not. She would say, "W1291, you are having some more jungle juice, are you". I should have known.

**SIR BRIAN LANGSTAFF:** That will do.

**MS RICHARDS:** Are we ready to start again? So Dr Swinburne would say things like, "Have you come for your jungle juice"?

**A.** Mm-hm.

**Q.** And you would have treatment to start with at the centre, but then a time came when you started having the Factor VIII treatment at home.

What can you tell us about that?

**A.** Yes. That started in the early '70s, perhaps '72, '73. We had to be trained to administer it ourselves intravenously. Another witness mentioned, I think it was only yesterday, about his training. We trained on oranges so why he had to train on himself, I don't

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1 know. That seemed bizarre to me but, yes, we used to  
2 inject oranges, because apparently the flesh of  
3 an orange is very similar to the flesh of a human  
4 being. So I guess we weren't using the real stuff on  
5 the oranges. So once we could inject an orange  
6 safely, we were allowed to do it ourselves at home.

7 **Q.** You have described in your statement that your parents  
8 were given a deep freeze --

9 **A.** Yes.

10 **Q.** -- at home.

11 **A.** Yes. We were given it, yes. It was a gift from the  
12 local authority.

13 **Q.** When you first got the Factor VIII products that were  
14 being used at home, which you understand were  
15 UK-sourced products, what did they look like?

16 **A.** I think so. I mean, in those days clearly there  
17 wasn't -- one did not take as much interest in the  
18 pedigree, the provenance of what we were taking, but  
19 I think if only we would probably have noticed if it  
20 was from America, because that would have been kind of  
21 glamorous, you know, in those days so, no, I think it  
22 was pretty boring such in a little brown box. It  
23 wasn't -- you know, it was very ordinary.

24 **Q.** But you described in your statement that at some point  
25 towards the late '70s the boxes changed.

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1 I always thought that was a clever one. Factorate,  
2 that probably causes a lot of confusion now. We used  
3 to refer to it as Factor VIII. Then they started  
4 spelling it F-A-C-T-O-R-A-T-E. Obviously now there is  
5 confusion whether you are talking about the actual  
6 product or whether you are talking about the brand,  
7 but yes. There were lots of these companies.

8 **Q.** We can see some of the ranges of products you used  
9 from a document you produced to the Inquiry.

10 Paul, it is 1291002, please. It is the next  
11 page.

12 We can see -- this is just for the period 1983  
13 onwards rather than the early period. We can see  
14 there Armour and the product you were just describing,  
15 Factorate?

16 **A.** I had forgotten some of these names.

17 **Q.** Cutter Koate, Alpha Profilate?

18 **A.** Brings back memories.

19 **Q.** Do you recall anything being said to you about the  
20 cost of these products?

21 **A.** Oh yeah. When it first appeared as cryoprecipitate  
22 there wasn't a lot of talk about the cost  
23 implications. We got the impression, certainly in the  
24 early days, it seemed to be actually being  
25 manufactured in the hospital in St James's. Whether

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1 **A.** Oh, it all began to change, yes. I mean, it was  
2 changing technically from needing to be kept in  
3 a freezer to being kept in a fridge and that was  
4 around the same time that it began to be branded,  
5 a branded product, and it became far more -- you know,  
6 glossy boxes with instructions and flaps.

7 It was a proper little kit and, yes, but

8 I remember a whole variety of different brands,  
9 because again it was something never we took a lot of  
10 interest in. You were just given it, took it away and  
11 used it.

12 Asked who made it, the word Baxter used to come  
13 up a lot. I remember that, because they used to make  
14 the syringes. All that kind of stuff used to come  
15 separately originally. So you would be given a set of  
16 syringes, a set of butterfly needles, a set of swabs  
17 and you would kind of have to get -- you would create  
18 the kit yourself.

19 So you used to notice who manufactured all the  
20 different bits of the kit but, as I say, mid '70s it  
21 began to change and it all began to come as  
22 a pre-packed item with everything in it, all very  
23 cleverly constructed, like a camping kit, where  
24 everything was in there in a minor little corner.  
25 Yes, they were branded, but Baxter, Armour, Factorate.

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1 or not that is the case I don't know. Whether it was  
2 just something -- an impression they gave to kind of  
3 reassure you I don't know, but it used to sort of come  
4 up the stairs from some other part of the hospital in  
5 big frozen bottles and then you would watch it go --  
6 some of the guys here will probably know. You watched  
7 it go into the heat, like a little foot bath. They  
8 would stand the bottles in it and you would watch it  
9 slowly defrost. I used to watch it go into the  
10 centrifuge and be spun out of the plasma, so it can't  
11 have been coming from very far away.

12 Then bit by bit by bit eventually it was coming  
13 from thousands of miles away. We just thought this  
14 was, you know, the wonders of modern technology. We  
15 weren't particularly concerned about it I don't think.

16 **Q.** Was anything specifically said that you recall about  
17 how much this was costing?

18 **A.** Yes. As time went by it became more and more of  
19 an issue and again, as previous witnesses have said,  
20 we were encouraged to return supplies when we were on  
21 home treatment if they were nearing their expiry date  
22 simply because clearly, as we understood it, in the  
23 hospital they had regular use of it, so they could use  
24 it up very quickly on in-patients, but if you left it  
25 too late, even that became impractical.

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1 We were told that we had to do that because the  
 2 stuff was so valuable and it wasn't to be wasted,  
 3 because it cost a lot of money. That began to change  
 4 over the '70s whereas, you know, it seemed as if the  
 5 stuff was now much more readily available, and no-one  
 6 seemed too worried about the cost. So the amounts  
 7 that you were given to take away, there was no  
 8 longer -- it you used to feel as if it was a little  
 9 bit rationed in the early days. "How many do you  
 10 need? Are you sure you need that many? How many  
 11 injections are you having? How regularly are you  
 12 having bleeds", and kind of a little calculation would  
 13 go on as to how many you could take home with you.  
 14 Later it was just being given to you wholesale.  
 15 Seemed like going to Costco, go round with the  
 16 trolley, pile it all in, take it home. No-one cared.  
 17 **Q.** Was anything said to you or, when you were younger, to  
 18 your parents about any risks of infection associated  
 19 with the factor products?  
 20 **A.** No.  
 21 **Q.** Was there ever any discussions with either your  
 22 parents or as you grew into your teens and young  
 23 adulthood with you about differences between different  
 24 products or any choices between different products?  
 25 **A.** No, they were all much of a muchness. We never had

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1 you bleed once, unless they keep you in they are  
 2 probably going to need to see you again, so not to  
 3 have to go through that just that practical rigmarole  
 4 of ringing for an ambulance just in itself was a boon.  
 5 Plus you were getting your treatment quicker and  
 6 with haemophilia the speed with which you are treated  
 7 is very important to the progression of whatever bleed  
 8 or injury you are suffering. So in terms of  
 9 controlling the collateral damage of a bleed in terms  
 10 of actual ongoing joint damage, that was reduced by  
 11 the fact that you were getting your treatment. If it  
 12 happened at home, you could be treated within  
 13 15 minutes of the injury.  
 14 That had a big impact on pain, because for most  
 15 haemophiliacs the pain is about the swelling, so as  
 16 your bleed expands, if it is not a laceration, if it  
 17 is internal or a bruise, it is the pressure it puts on  
 18 the tissue around the bleed that causes the pain and  
 19 the pain, again, as the guys in the room will know, we  
 20 were brought up with pain. We know a lot about pain.  
 21 If you could treat yourself, you could almost  
 22 literally see the bruise going back down. Remember  
 23 that, guys?  
 24 You could see it getting better, which is  
 25 amazing. So where you thought, "Oh, it is going to

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1 a choice. You know, it wasn't like a menu. You just  
 2 got what you were given. We never asked why it had  
 3 changed. It was just you took it away. You didn't  
 4 know it had changed until you got home and opened the  
 5 bag anyway. You wouldn't know what you had.  
 6 **Q.** Now, you said in your statement this:  
 7 "We trusted the doctors and it was all about  
 8 improvement. The message was that things were getting  
 9 better. The Nirvana was there would be a cure. The  
 10 new boxes of product and kit were smaller and more  
 11 convenient leaving more room in our freezer for my  
 12 mother to use. My brother and I thought our lives  
 13 were getting better, not shorter."  
 14 **A.** Yeah. I read that again this morning. Everybody  
 15 here, I am sure, of my generation will feel the same  
 16 thing. These were all very positive steps. You know,  
 17 what had been complicated, what had been inconvenient,  
 18 what had -- you know, it had impact on your normal  
 19 life in the sense you didn't have to -- I lived  
 20 20 miles away from St James's. We had a car, but that  
 21 was my father's, so he went to work in it, so if I had  
 22 a bleed during the day, it was an ambulance.  
 23 So, you know, you could go through a period  
 24 where you had to go to hospital three or four times in  
 25 a week, because these things are repetitive. So if

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1 take me 2 or 3 hours to get to hospital. Then they  
 2 are going to have to check me in and give me  
 3 an injection", all that time you are in more and more  
 4 pain and your injury is getting worse and worse and  
 5 worse, so if you could do it in 20 minutes at home, no  
 6 pain, no collateral damage. It's a great improvement  
 7 in your life.  
 8 **Q.** Now, you have recounted in your statement your mum  
 9 being told that there was a programme on television  
 10 that might be of interest?  
 11 **A.** Yes, weird.  
 12 **Q.** Or significance --  
 13 **A.** Yes.  
 14 **Q.** -- to the family. You sat down and watched it. What  
 15 can you remember about that?  
 16 **A.** The circumstances surrounding this -- why we were  
 17 alerted to watch it are pretty woolly. I don't think  
 18 they are that important, but for some reason we were  
 19 tipped off to watch this TV programme. I have I think  
 20 it was World in Action, which people may remember from  
 21 that period. We watched it. It was about  
 22 half-an-hour programme. Half of it had gone. We were  
 23 all looking at each, "Why are we watching this?" We  
 24 couldn't connect the relevance to why anybody had  
 25 said, "Watch this TV programme".

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1 It was all about some mystery disease in Haiti.  
 2 I knew about Papa Doc, things like that, the political  
 3 background of Haiti, but somewhere off in the  
 4 Caribbean. I said, "That's nothing to do with me".  
 5 Then there'd be drug users in New York City. Okay.  
 6 That's nothing to do with me. Then it would be gay  
 7 guys. Again, mostly in New York City it seemed.  
 8 Nothing to do with me. What's going on here?  
 9 Then about 15, 20 minutes in the programme it  
 10 suddenly led to haemophiliacs. Haemophiliacs in  
 11 America and then haemophiliacs in the UK and it was  
 12 kind of like -- it was a life-changing moment on the  
 13 TV in your living room, you know, with people all of  
 14 whom had some kind of, this modern word, stakeholder  
 15 in this matter. You know, we were shocked. We were  
 16 bewildered. It didn't seem real.  
 17 Q. You have described what you said was a strange or  
 18 surreal thought that went through your mind then and  
 19 again later on at various significant stages, that all  
 20 the groups of people started with the disease started  
 21 with the letter H, heroin addicts, homosexual,  
 22 Haitians, haemophiliacs.  
 23 A. Yes.  
 24 Q. You have said in your statement that the revelations  
 25 from that programme led you and your brother to start

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1 on. You know, the underlying message was, "Don't let  
 2 this affect your treatment or your behaviour".  
 3 Q. Did anything change in terms of the treatment that was  
 4 offered to you?  
 5 A. No, no. As I say, the line was no, nothing should  
 6 change. Nothing needs to change. You are safe.  
 7 Q. There came a point where you were aware of what was  
 8 being said in the media or starting to be said in the  
 9 media about this illness where you decided to stop  
 10 having treatment for a period of time.  
 11 A. I did, yes, in about -- this would be about 1983/4  
 12 through probably about 18 months I didn't have  
 13 treatment, because I was -- it just seemed to be --  
 14 I was, am, a severe haemophiliac. I do have bleeds,  
 15 but I was just on that cusp of the generation where  
 16 I was born in 1960. I was a lot healthier than my  
 17 brother, who was born in 1951, because of the  
 18 treatment.  
 19 So I kind of stored up sort of the benefits of  
 20 it from my earlier years and that allowed me to kind  
 21 of surf on my current well-being. I didn't have any  
 22 kind of chronic injuries. So my attitude was, "I will  
 23 see how this goes now without treatment. Yes, I will  
 24 have bleeds. Yes, I will have pain", but I was pretty  
 25 healthy, pretty strong. Everything worked. So

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1 to question your doctors, Dr Swinburne and Dr Hardy,  
 2 at the Leeds Haemophilia Centre for answers?  
 3 A. Mm-hm.  
 4 Q. What was the response that you got?  
 5 A. Well, I imagine that we weren't the only people doing  
 6 that, you know. Clearly my own parents had been  
 7 tipped off to watch this programme somehow through the  
 8 wider community of local haemophiliacs. So we  
 9 wouldn't have been the only people going to the  
 10 hospital and asking about this and being troubled by  
 11 it, you know, really troubled by it.  
 12 So I guess, you know, the days subsequently  
 13 after that broadcast the hospital, you know, whether  
 14 or not it was unofficially in terms of, you know, just  
 15 getting together in a room and having a coffee or  
 16 whether or not it was officially done, I don't know.  
 17 I don't know how much advance notice the hospital may  
 18 have had of the broadcast, but it was clearly a damage  
 19 limitation exercise.  
 20 It was a matter of, "Calm down. It is all -- it  
 21 is a long way away. It is not a very -- it is a TV  
 22 programme. It is sensationalising something. It is  
 23 complicated. It is not as bad as it seems", all these  
 24 kind of palliative sort of assertions by the medics.  
 25 It was nothing really to worry about and just carry

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1 I decided yes, I'd make my own unilateral decision not  
 2 to take treatment. The hospital weren't very happy  
 3 about it, but it was my decision, not theirs.  
 4 My brother was in a different situation, because  
 5 he was physically damaged and his bleeds were of  
 6 a different nature to mine, so he carried on having  
 7 the home treatment.  
 8 Q. You and your brother became protective of your  
 9 parents. You tried to reassure them there was nothing  
 10 to worry about in terms of what was being reported?  
 11 A. Well, I have been thinking about this. Again, I have  
 12 read my statement this morning. I don't remember  
 13 discussing anything to do with what was called --  
 14 everybody called it AIDS in those days -- from that TV  
 15 programme ever again with my parents ever, for the  
 16 next -- I mean, my father died in 2001 and my mother  
 17 died in 2009 and I don't remember it ever being  
 18 mentioned. That's not to say there wasn't  
 19 an awareness of it, but it was never discussed.  
 20 Q. You started having tests at the hospital. The  
 21 hospital was testing for HIV and you were called into  
 22 a meeting with Dr Swinburne. What can you tell us  
 23 about the first meeting?  
 24 A. That's the individual meeting?  
 25 Q. Yes.

16



1 A. Yes. There were a series of meetings. I mean, we  
2 were going in for treatment on a regular basis, as  
3 well as having home treatment. So it wasn't a kind of  
4 always a formal meeting. It was just you happened to  
5 be going in for a reason and you would see one of the  
6 doctors, usually Dr Swinburne, but not always  
7 Dr Swinburne. You know, it would come up in  
8 conversation, you know. We would want to talk about  
9 it. The story was ever-developing in the media, so it  
10 wasn't so much that these were timetabled meetings,  
11 "You will come in and we will talk about AIDS". It  
12 was just something -- you know, we were continually  
13 wanting information.

14 We were noticing there was an evolution in the  
15 responses we were getting from the doctors, so it may  
16 be there as a meeting, but there were several  
17 conversations and bit by bit this attitude of, "You  
18 have nothing to worry about" changed to, "We can test  
19 you", which in itself is clearly a movement. Why  
20 would we be tested for something we don't need to  
21 worry about?

22 Then it became, "We can test you". The tests,  
23 you know, were unproven. They were experimental.  
24 There was a question of whether or not you could rely  
25 on the results of any of the tests, but over a period

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1 Q. Then there was a subsequent conversation with  
2 Dr Swinburne when she told you something different.  
3 What was that?  
4 A. She told us that the understanding of the test was  
5 wrong, the science of the testing was wrong and that  
6 actually a good result was a bad result. So where you  
7 were positive, yes, you had the antibodies. HIV as  
8 it -- I think we had begun to call it HIV by then --  
9 was this insidious infection that meant that unlike  
10 most others, a positive antibody was actually a bad  
11 result, so positive is bad. Negative is good, whereas  
12 months earlier it had been the reverse. So it was no  
13 longer "You are in the clear. You haven't got it".  
14 It is, "You have got it, but we still don't really  
15 know what it is".  
16 Q. You said that was when you think Dr Swinburne referred  
17 to the virus as HIV for the first time, you had your  
18 fifth H in your sequence of Hs?  
19 A. Yes, another H slotted in, yeah.  
20 Q. In terms of putting any dates to this, I will just  
21 take you to a couple of entries in your medical  
22 records.

23 Paul, if we could have up, please, 1291007,  
24 page 4.

25 We can see towards the bottom of the page, it is

19

1 of probably a year or two years the tests began --  
2 like the treatment got better, the tests got better,  
3 you know. The science was moving on, so you would be  
4 regularly tested with a different test.

5 You know, the thing that got me was one time we  
6 were tested and because we came out positive for HIV  
7 antibodies, that was a good thing. We were clear of  
8 the virus, because if you have antibodies, you can't  
9 be infected. It is like being vaccinated, so we were  
10 actually told this thing you never had to worry about  
11 it, now we can test you for it and then we were told,  
12 "Hey, you don't have to worry about it."

13 We said, "You told us never to worry about it  
14 anyway. Now you're telling us we don't have to worry  
15 about it because we haven't got it".

16 Q. You described one of these conversations with  
17 Dr Swinburne with you and your brother, saying:  
18 "She had good news for us. She said AIDS  
19 positive antibodies had been detected in our blood.  
20 We had been exposed to the virus and were now  
21 protected from it and we were immune to the virus.  
22 She told us we were going to be fine, we were clear of  
23 the virus and could relax."

24 A. Yes, relax from something we didn't have to worry  
25 about.

18

1 the yellow highlighted section, 21 January '85:  
2 "Discussion re AIDS, et cetera."

3 A. I wonder what the et cetera was. That would be good,  
4 wouldn't it.

5 Q. That's the extent of the recording there.

6 Then if we have the same reference but page 5,  
7 please, Paul.

8 We've got a test result there. I think the date  
9 is 16 February 1985. It doesn't come out very clearly  
10 on that and we see there the test result positive.

11 Then just one further document, Paul. It is  
12 1291008, page 4.

13 We can see here 23 January '85, "positive" in  
14 the column "anti HTLV-III", so it would appear that at  
15 some point in early 1985 those positive tests were  
16 undertaken.

17 A. Mm-hm.

18 Q. There was then -- at some point -- you put it as the  
19 summer of '86 in your statement -- a big meeting in  
20 the lecture theatre at the hospital?

21 A. Yes.

22 Q. What can you tell us about that?

23 A. Yes. That was a case where we actually were sort of  
24 summoned to a meeting. We didn't know what kind of  
25 meeting it would be until we got there, but it turned

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1 out to be a mass meeting and seemingly every patient  
2 and their immediate families of the St James's Centre,  
3 which was a major centre, therefore they had a lot of  
4 patients, had been called in all at one go. This  
5 never happened before. I had never seen this many  
6 other haemophiliacs in one go.

7 It was in a lecture theatre at St James's, a big  
8 tiered room. They were all down there on the dais  
9 where, you know, we would be lectured from. It was  
10 full to the brim. We were right at the back,  
11 literally standing room only.

12 They went through, basically -- I don't think  
13 they had -- it was the days before PowerPoint so there  
14 were no slides, but they went through kind of, you  
15 know, the recent history of this mysterious infection,  
16 you know. You have to remember that the S in AIDS  
17 stands for syndrome. You know, it wasn't even  
18 a disease then. It was witchcraft. It was as if this  
19 had come from the moon. You know, the astronauts had  
20 brought it back on a piece of lunar rock. Everybody  
21 from an ordinary patient with absolutely no technical  
22 knowledge whatsoever through to professors of virology  
23 knew as much about this as each other. So they tried,  
24 I guess, to give us a potted history, but clearly  
25 everybody who was there wanted to know "What does it

21

1 meeting, but I don't remember seeing any of that  
2 medical team ever again, and our centre was moved out  
3 of the building it had been in all my life as  
4 a patient, the pathology lab at St James's, and it was  
5 moved out on to a site outside of the main hospital  
6 called the Beckett Wing. You had to cross roads. It  
7 is a different building.

8 All the staff changed. We never said goodbye to  
9 any of these people who had been our like -- part of  
10 an extended family. It was like whooh, a guillotine  
11 came down.

12 Looking back now -- at the time it was just part  
13 of this bewildering part of your life, but looking  
14 back I have to ask myself, "Where did all these people  
15 go? Why were these decisions made? Why were we  
16 suddenly put out into a different part of the  
17 hospital?"

18 A new consultant came. He was called  
19 Dr McVerry, who I think had been at other hospitals  
20 before he got promoted to running Leeds. He just took  
21 over, you know. Fair enough. He should. He had got  
22 the job. He would take over. Everyone else just  
23 disappeared. All these people I had known all my life  
24 just disappeared, no explanation, nothing.

25 Yeah, I asked him, you know, "All this science,

23

1 mean for me, us?"

2 The conclusion of the meeting was -- and  
3 I remember it quite clearly -- was that, "We can't be  
4 certain what it means for every individual. There  
5 will be a spectrum of outcomes from, sadly, death or  
6 mild symptoms of flu and you may find -- we have no  
7 way of predicting which ones of you in this room will  
8 get which outcome".

9 That in itself -- I mean, that was wrong,  
10 because most of the people in that room are dead now.  
11 I don't know many as got flu and I have never been  
12 ill, so on that spectrum they didn't mention my  
13 experience. They didn't say, "You may not suffer  
14 anything from this virus", so they were still wrong.

15 Q. You have described in your statement then perhaps  
16 a couple of years later with a replacement consultant  
17 and a conversation you had in which you were being  
18 given information in scientific terms about the virus,  
19 and you said:

20 "To better understand what the doctor was saying  
21 I asked him if HIV was going to be fatal."

22 What was the answer?

23 A. "Yes". That was another curious thing. After that  
24 meeting in the lecture theatre, I don't remember --  
25 I mean, there may have been one or two instances of

22

1 what does it mean for me?" Then there was no talk  
2 about flu then. It was like, "Well, you are going to  
3 die".

4 "Is there anything? Is there any ...?"

5 "No, there is no treatment. There is no  
6 likelihood of a cure. It is a complete mystery. It  
7 has bewildered medical science. How long have you  
8 got? Maybe two years, maybe not."

9 From that point in my life to even now I live  
10 with a two-year like an operative period in my life,  
11 so at any given time I have always assumed I may have  
12 up to two years to live, but you may -- you don't know  
13 where you are in that cycle, so two years was always  
14 the maximum. I would never look ahead beyond two  
15 years and I still operate on that basis now.

16 Q. You have described in your statement you went from  
17 that conversation to a business meeting and you  
18 remember staring out of the window at the meeting.  
19 You couldn't remember afterwards what had gone on.

20 A. Yes.

21 Q. You then went and talked to your brother and he was  
22 given similar information.

23 A. Yes. I mean, it was one of the few times we were kind  
24 of formally asked to attend separately, because it was  
25 more convenient for us usually to go to the hospital

24

1 together but this time we had to be individual. You  
 2 had to be given this verdict one to one, man to man.  
 3 Q. Do you think you were given sufficient information and  
 4 advice about your condition and how to manage it and  
 5 about the risks of infecting others?  
 6 A. Well, no, that kept changing. I mean, I don't want  
 7 to -- it is difficult -- you know, it is easy to sit  
 8 here and to criticise with hindsight the advice you  
 9 were given.  
 10 It was a moving -- it was a fast moving picture  
 11 in that time. So I think -- I give people the benefit  
 12 of the doubt, because I can't remember when it became  
 13 clear what was dangerous to do and what wasn't  
 14 dangerous to do, what were the likely outcomes of  
 15 infection.  
 16 There is this crazy thing about misunderstanding  
 17 of the test. I mean, that is absurd, isn't it.  
 18 I mean, something as serious as this and you are told  
 19 the wrong way round of the outcome of the test, but  
 20 this was the nature of this syndrome. It was  
 21 mysterious, so whether or not I was given the right  
 22 advice I don't know.  
 23 In many ways what could he tell me to do? He  
 24 told me there was no cure. There was no treatment.  
 25 There was nothing to do to extend my life. There was

25

1 I mean, I have got a glass of water here.  
 2 I don't want anybody else to drink from this glass,  
 3 but how do I achieve that without drawing attention to  
 4 the fact that I don't want anybody to drink from that  
 5 glass and that if they do, if it just happens and they  
 6 do, do I just say, "Oh, well, actually I did my best.  
 7 I tried, but I will just let it go now", or do I make  
 8 a really crazy fuss about it and tell them to go and  
 9 get an HIV test. That's how I have lived my life for  
 10 35 years, not knowing how infectious I am, but  
 11 assuming I am pretty damn infectious.  
 12 Q. It was a few years later that you discovered you had  
 13 also been infected with hepatitis C. What can you  
 14 remember about that?  
 15 A. I don't remember exactly when -- I don't know if it is  
 16 in the records, but I couldn't tell you hand on heart  
 17 sat here when I found out I was infected with  
 18 hepatitis C.  
 19 Q. What you have said in your statement is you don't  
 20 recall a specific discussion about hepatitis C. There  
 21 is a handwritten note in your medical records that  
 22 someone was told about hep C in August '91 but you  
 23 know you weren't told whilst you were at Leeds  
 24 Haemophilia Centre. You found out only after you had  
 25 transferred to St Thomas's and been referred to King's

27

1 nothing -- he had no idea how it would kill me. It  
 2 was just going to kill me, so what is he going to do?  
 3 Nothing. What am I going to ask him to do? Nothing.  
 4 In terms of not infecting other people I don't  
 5 know how aware the doctors were of what was infectious  
 6 and what wasn't infectious. Clearly my blood was  
 7 pretty dangerous stuff. We realised that but it was  
 8 over a matter of time, quite quickly, though, that you  
 9 discovered that it was virtually every bodily fluid  
 10 you carried around with you and that was quite  
 11 disturbing.  
 12 Not many -- you don't bleed on people as  
 13 a matter of course, you know. It happens, but it is  
 14 unlikely, but when it became sperm, then clearly, you  
 15 know, your sex life is going to be affected. When it  
 16 becomes saliva you think, "Oh, god. That's  
 17 a difficult one". Then when it becomes -- and I said  
 18 this in my statement, and, you know, it is pretty  
 19 melodramatic, it was your tears. You couldn't cry on  
 20 anybody. You know, you were -- people went round in  
 21 these space suits to try and -- when they were having  
 22 to treat you. You felt as if you were living -- you  
 23 were carrying this bubble around with you that you  
 24 couldn't risk anyone else coming inside. So you had  
 25 this invisible space suit on.

26

1 College hospital?  
 2 A. Hepatitis had been around, sort of a word bandied  
 3 around the community, you know, another one of those  
 4 horrible buzz words, for a long time. So you were  
 5 conscious that there was some connection between being  
 6 a haemophiliac and having some sort of relationship  
 7 with hepatitis.  
 8 In the original days it wouldn't have been C,  
 9 because clearly it didn't exist. It did, but nobody  
 10 knew it existed. They called it different things. So  
 11 it were just hepatitis, but it also went by other  
 12 euphemisms, jaundice, glandular fever, but really  
 13 I think they are all hepatitis. Again, maybe there is  
 14 someone in the room can correct me. I think they are  
 15 all variations of the same thing, but there were no --  
 16 you have got to remember, if you have been told you  
 17 have got HIV and you are going to die in the next two  
 18 years, to be honest, you don't give a monkey's about  
 19 having hepatitis.  
 20 I used to go -- I remember when I moved to  
 21 St Thomas' from Leeds in the early '90s I can  
 22 remember, in my memory, in a corridor, a doctor going  
 23 by me and saying "oh, [redacted]".  
 24 Q. Can you stop the transcript live transmission? We  
 25 will just wait for a few moments and then start again.

28



1 So without mentioning names ...?

2 A. He said, "Oh, you, oi". I was going in one direction

3 to see someone else. He was going in another

4 direction about his own business. It just clearly

5 occurred to him. "Do you know your hep C status?" It

6 is a curious thing to ask someone that in a corridor,

7 isn't it, really? You normally say "Good morning".

8 "Hello, do you know your hep C status?"

9 "No, I don't".

10 "We must get that tested some time", then he

11 went away. He carried on in that direction and

12 I carried on in that direction. I don't remember it

13 coming up again for a long time. It was just

14 something someone was going to get around to some day.

15 I didn't care. I wasn't bothered. I was going to die

16 of HIV. What interest was it for me? As far as I was

17 concerned it was something he wanted to know to put on

18 my record. It was of no consequence to me.

19 Q. You also received a letter in September 2004 about

20 being at possible risk of vCJD. What was your

21 response, if you can recall, about that?

22 A. I was surprised. It is not the kind of correspondence

23 you expect, but I was philosophical about that.

24 I mean, again, it is my statement.

25 Being the kind of person who had once said, "No,

29

1 been caused by or exacerbated by those infections.

2 A. Okay. Let's do the hep C first: I had no idea I had

3 hep C, so I have no kind of history of being able to

4 say "I used to feel tired and I didn't know why it

5 was" or whatever it was or all the stories people have

6 had of feeling ill from not knowing or having been

7 exposed to hep C.

8 Hep C became a problem in my life when I went on

9 to the interferon treatment for it. Yes, that was

10 unpleasant. You know, there were the usual sort of

11 side effects: nausea, mood swings, lack of energy,

12 lack of interest in life, and also the concern as

13 to -- you were always told it probably wouldn't work.

14 This was the thing, so do you really want this

15 treatment, because it might not work. It probably

16 won't work. It doesn't work in both cases, but it did

17 work in mine.

18 So I had about nine months of three injections

19 a day and you had to -- you put one in your thigh, one

20 in your stomach and one in your shoulder and you had

21 to remember which order you had done it in and then

22 you went down the other side of your body, your

23 shoulder, your stomach and in your thigh, so it was

24 a bit of a rigmarole to go through but it was easier

25 than an intravenous injection because you just banged

31

1 I am not going to have home treatment because I think

2 it's a risky thing to do", I was someone who decided

3 to stop eating beef even though John Gummer told us it

4 was safe. I didn't believe him. I have no idea how

5 I came up not to trust the official guidance, but

6 I decided not to trust the official guidance in the

7 late 1980s and I stopped eating beef.

8 I got married in 1990 and we had -- it is

9 Yorkshire. We had roast beef and Yorkshire puddings

10 as the wedding breakfast. I didn't have the -- I was

11 the only person in the room, 200 people. I had

12 chicken, because I wouldn't eat roast beef because of

13 CJD.

14 So to then found out I had got it anyway, you

15 know, it was just the final irony, you know. I could

16 have had that beef, because they had given me it

17 anyway as just a bonus. Again, I still was convinced

18 I was going to die of HIV in 2004, so CJD didn't look

19 nice on the telly but HIV didn't look nice on the

20 telly, so ... I am still here now. It is 16 years

21 later nearly. I haven't got CJD.

22 Q. You have described in your statement the physical and

23 psychological effects of being infected with HIV and

24 HCV. Can I just ask you first of all to describe some

25 of the physical effects of conditions that may have

30

1 it in. It was pretty straightforward.

2 I can remember doing it in a friend's car

3 driving round Raleigh in North Carolina. It was

4 3 o'clock in the afternoon and I needed my injection.

5 I had shorts on. I pulled up my shorts, went in the

6 glove compartment, banged it in my leg. He wondered

7 what the hell I was doing. But there you go, it was

8 what I had to do, so it was a strange thing to do, but

9 there you go. I cleared the virus. My liver is still

10 damaged but I cleared the virus. Hep C, it is just --

11 you know, it is just a bit more damage on the way

12 through life.

13 HIV to me is the more significant problem, but

14 again, like the hepatitis, I have been blessed in

15 terms of HIV. I am completely, touch wood, today

16 asymptomatic of any of the conditions that go with

17 HIV.

18 Q. You describe in your statement having had lots of

19 opportunistic infections. Those are ones that have

20 cleared, come and gone.

21 A. Yes, but -- I don't know if they are to do with the

22 HIV or not, you know. Yes, if you look at my medical

23 records, I have had shingles, I have had -- I have got

24 this anaphylactic shock reaction now to various

25 insects and other sorts of allergies.

32

1 These are all things that have come upon me, but  
2 my own suspicion, and it is an informed suspicion, is  
3 that most of these problems I have have been caused by  
4 the medication I take for HIV. I was perfectly well  
5 until I started taking AZT, which now has the  
6 reputation of the kind of stuff that -- DDT that you  
7 spray on crops, you know. I think it is virtually  
8 a banned substance, but I took that for five years  
9 I think from the mid-1990s and it was after that,  
10 after I started the medication, that I started being  
11 ill, so I don't think it's HIV that's made me ill. It  
12 is the cure for HIV that's made me ill.

13 Q. You suffer a lot of pain.

14 A. Mm-hm.

15 Q. Particularly in your hands and feet?

16 A. Particularly my feet and my legs, yes. It is called  
17 peripheral neuropathy, which is a bit of a mouthful,  
18 PN for short. It is very, very painful. Also, it is  
19 a very difficult condition to describe, because  
20 definitively it is a lack of feeling. It is a loss of  
21 sensation that actually comes with pain, which is  
22 a sensation. It is very difficult to describe what it  
23 feels like.

24 Diabetics get it apparently, but most people can  
25 be treated for it through I think it is called

33

1 bedpan, which I don't, it means every 90 minutes  
2 I know, even though I have got everything I need  
3 around me I need for the day, I am still going to have  
4 to go to the bathroom and it hurts. Walking hurts so,  
5 you know, it's difficult.

6 Even when your feet are up, I need a constant  
7 distraction. If I am not distracted, I am in pain and  
8 if I am frustrated and that sounds -- you know, it can  
9 be anything. It can be like trying to find the right  
10 channel on the TV. It can be deciding what time to  
11 leave the house. It can be little decisions like that  
12 just get you in that state, it sets off a chain  
13 reaction where your feet and lower limbs throb and it  
14 is all because -- it is just part of normal life that  
15 affects you in this way, whereas you become in extreme  
16 pain just from the little bit of stress. You know,  
17 it's not stress, stress. It's not job stress. It is  
18 just like "Should I open the window? Shouldn't I open  
19 the window?" Oh, oh, oh, oh. It has given me  
20 a reason to think. That makes me hurt and I can't do  
21 anything about it.

22 Q. You have described in your statement the psychological  
23 effects of, in particular, the knowledge of the HIV  
24 infection. You have had a number of what you have  
25 described as breakdowns.

35

1 ibuprofen[sic] or a close pronunciation of that word  
2 but I can't take that. Haemophiliacs can't take that,  
3 because it affects the clotting status. So I have  
4 tried -- I have been recommended all sorts of  
5 different painkillers, but none of them work.

6 The only thing that has any effect whatsoever is  
7 something called dihydrocodeine. For one, it is  
8 addictive; two, it has immediate effect of you trip  
9 a bit on it, so it is not very convenient to take,  
10 because you have to know you are going -- you will do  
11 nothing that day and you are not going to speak to  
12 anybody that day, because you are not in a fit state  
13 to communicate with them, but that does have some  
14 effect, because, basically, you are out of it, but it  
15 is very -- it is now -- you know, it definitely has  
16 changed my life. I am now virtually, you know,  
17 immobile because of peripheral neuropathy.

18 I spend most of my days -- I have a sedentary  
19 existence with a chair and a foot rest and I try and  
20 gather everything around me that I am going to need in  
21 that day. So, you know, phones, laptop, coffee, lots  
22 of coffee, cat, all the other things and I gather  
23 these around me for as long as I can take.

24 The problem is other of the meds affect your  
25 bladder, so unless I want to go to having some kind of

34

1 A. Mm-hm, three.

2 Q. How did the first come about?

3 A. The first was 2000/2001. It came to a head really  
4 where that was just around the time that we were  
5 trying for the second time to get IVF treatment for --  
6 to try for a baby. There was a -- there was a lot of  
7 real stress involved with that in terms of qualifying  
8 for it and then subsequently would it or wouldn't it  
9 be successful? So I was feeling pressure from that.

10 I was increasingly unhappy in my professional  
11 life. I worked with my brother. I had begun to feel  
12 as if we were kind of joined at the hip. It wasn't  
13 just enough we were brothers. We were in the same  
14 business. We had all the same diseases. We had all  
15 the same problems. We were trying to deal with them  
16 in our own way, but I felt we could -- it is  
17 impossible -- if you imagine if you are two brothers  
18 living in the same area, working in the same business,  
19 we are clearly sharing the same family, the same  
20 friends, the same small community group, one cannot  
21 decide to have one attitude towards their health  
22 status and the other another one, because as far as  
23 the world around you are concerned, you are the same.

24 So if one of you comes out as HIV positive, as  
25 a haemophiliac, as this, as that, then everybody is

36

going to assume the other one is too. It is completely unrealistic to lead a separate life and therefore to have a separate identity. So we were sharing like a compromise and it had to be that we kind of had to agree to the most -- the one that had the most extreme demands in terms of lifestyle, the other one must conform to, so he was far more sensitive about it than I was.

There were other aspects of our relationship in terms of the business we ran and the way we lived our lives that -- he was older than me, and he brought me up. I felt as if I had lost my individuality and I couldn't express myself in so many different ways, not just my health, but clearly that was a major factor.

I was feeling oppressed, frustrated, under a lot of pressure in terms of my marital arrangement with planning for a baby. It was crazy, because one of the things I was trying to be was sane because I had to present myself to ethics committees and things as someone who could be given IVF treatment, you know, worth the investment, and I am thinking to myself, "I am going mad here and I can't let on I am going mad, because if I breakdown, they are not going to give my wife IVF treatment". You know, it was counter

37

fairest thing I can do on balance, and I have had to look at pros and cons of this, is to say, "No, I don't have the right to own my own status because of what it could do to others".

That is a pretty big thing to go through life still carrying, you know, in this supposedly far more understanding world of 2019 where -- there are double standards around HIV. There are a lot of people now who say, "Oh, that was that awful disease but it is all okay now. They are fine, those HIV people because it's treatable. There are drugs. You can get it. It doesn't matter. It is like having, you know, the measles or influenza or something. You can live with it".

If that's the case, why is it that people can still seriously make a case to me that they don't want other people to know I have got it because it will affect them? It is a double standard. It is still a stigmatised disease. It is still a dangerous disease. Yes, people get it now. You know, they have treatment for it and the treatments are good, but when you got it in 1985 or whenever it was, you know, there's a difference between being diagnosed with it and getting it for a start. I don't know when I got it. It might have been 1979. It might have been

39

productive, because I went more and more insane as a result of not wanting to go insane.

**Q.** One of the factors you have described in your statement is this sense of feeling trapped in the business you were running with your brother because you couldn't just go get a job somewhere else, because you would have to reveal your HIV status?

**A.** Yes.

**Q.** Or you felt you would?

**A.** I imagined I would. It wasn't something I wanted to experiment with, you know. One imagines that, you know, this is what you will have to do. Again, the stigma around AIDS still, I mean, it still is -- I am sat here as Mr M and I have made a couple of boo boos around being Mr M already this morning.

I am not being -- I have not selected to be an anonymous witness today for my own sake. I don't care, but it's because to protect others who I love and I hope love me that I have, you know -- against my own preference, I am anonymous.

Now think about that. Why is that? Why here in 2019. I am 58 years old, 59 next month, and I am afraid to own my own identity because there is still a real possibility that this will have serious negative impacts on other people and, therefore, the

38

1982. I don't know. It is a long, long time ago.

Then it wasn't something that -- there was no treatment for it. There was no prognosis other than death, and the effects that are created by the treatment that my generation of HIV positive people have gone through are ongoing. We now live with the effects of bad medication and of poor prescription and of people rushing to find answers and experimenting on you with their medication.

Fortunately now, you know, I believe most HIV patients, if they are unlikely enough to get it these days, they take one tablet a day. I don't. I take 13 tablets a day for a combination of all the things I now have wrong with me and I will continue, as far as I know, I will continue doing that for the rest of my life.

**Q.** Can I just take you back to the 1980s and ask you a little more about the stigma and the impact, because clearly that still resonates with you now.

**A.** Mm-hm.

**Q.** You have said this in your statement:

"In the late '80s, early 90s, HIV/AIDS was all over the media, in the papers, on Eastenders and the Government tombstone advert on billboards. You couldn't escape it."

40



1 A. No.  
 2 Q. "I lived with the constant fear of death and of being  
 3 outed. Those known to be infected were ostracised.  
 4 HIV was like the plague."  
 5 A. Yes. I can't say better now. That is what it was  
 6 like. It was terrifying. It was coming at you from  
 7 so many different directions. There was a major  
 8 public health campaign that was all about terrifying  
 9 the rest of the population about how shocking, how  
 10 dastardly this infection was and not to risk getting  
 11 it.  
 12 But if you have already got it, you know, again,  
 13 you will just be frightened about what you have got to  
 14 be frightened about. I had already got it.  
 15 I couldn't change my lifestyle to avoid it. I wasn't  
 16 ignorant about AIDS. I was certainly no more ignorant  
 17 than anybody else was about AIDS.  
 18 So it was like constantly during the day just  
 19 driving around, putting on the radio, watching TV,  
 20 picking up a newspaper, you were being bombarded with  
 21 a message that told you what you had was horrible,  
 22 incurable and going to kill you.  
 23 Also it made it a topic of conversation.  
 24 People, you know, were being encouraged to communicate  
 25 this and educate themselves and their friends, so they

41

1 Q. 2005 you had a second breakdown.  
 2 A. Mm-hm.  
 3 Q. You describe that in your statement as a bigger one,  
 4 a worse one.  
 5 A. It was, yes. I guess if you imagine the last one was  
 6 2010, so this was like the midpoint. The 2000s was  
 7 clearly a bad decade for me, so this was the middle  
 8 trough. I had been off my meds from I think I managed  
 9 two and a half years without my meds, because what  
 10 happened was again in the hospital I was at St Thomas'  
 11 by this time -- for the first few years HIV treatment  
 12 was sourced in the haemophilia department. So you  
 13 were being cared for by the same doctors who looked  
 14 after your haemophilia.  
 15 That changed in about 2001/2002 where the HIV  
 16 treatment was transferred within the hospital to  
 17 a different department, which was the one that looked  
 18 after sexually transmitted diseases where there was  
 19 more of an expertise that had been developed around  
 20 HIV, through kind of -- I mean, this was in London.  
 21 It was particularly focused there on London's  
 22 gay community, so we went from going to the  
 23 haemophilia department. We would then go across the  
 24 hospital to this different department, which was in  
 25 itself a bit weird, because the other department was

43

1 were talking about it and you are amongst all those  
 2 people talking about it and carrying this secret  
 3 around. "I have got it". You are not going to tell  
 4 anybody you have got it, are you, because the best --  
 5 I mean, there weren't even -- it was all in the news.  
 6 You couldn't even get buried if you died of it.  
 7 Undertakers refused to bury the bodies. They used to  
 8 have to come round from the Public Health Department  
 9 and pick you up in a plastic bag and cremate you.  
 10 Who would want to volunteer that information to  
 11 anybody? So it was a massive secret. My brother and  
 12 I, we had a policy. We had a public facing business  
 13 to run. Our lives would have been economically and  
 14 emotionally devastated by a revelation of our status  
 15 because we lived our lives like secret agents, massive  
 16 secrets.  
 17 Q. In 2001 when you had your first breakdown --  
 18 A. Mm-hm.  
 19 Q. -- you were only able to access treatment through  
 20 paying for it privately.  
 21 A. Psychological treatment, yes. There was no NHS  
 22 treatment for kind of psychology or psychiatry, so it  
 23 cost me a small fortune to get any kind of treatment,  
 24 but I was fortunate. I had the means to do it. It  
 25 didn't feel fair, but it's what you do.

42

1 like a gay night club. So you would go down there and  
 2 there was thumping disco music and completely  
 3 different decor and completely different patients, you  
 4 know. So it was a bit weird to go in this department,  
 5 but they clearly had a far more advanced understanding  
 6 of HIV, because they had hundreds of patients  
 7 presenting with it.  
 8 So I met the doctor for the first time. You  
 9 know, we did a quick history. All very good. Then  
 10 I am on my way to the door and he says -- I don't know  
 11 why doctors do this. They seem to have a habit. We  
 12 have heard it over and over again. People ask you the  
 13 last question on the way to the door. I don't know  
 14 what it is. I was on my feet on the way to the door.  
 15 He said -- for some reason I mentioned, "Yeah, I have  
 16 got this weird sensation, I don't know how to describe  
 17 it, in the soles of my feet", and he said, "Oh, come  
 18 back. Sit down".  
 19 He was clearly alerted to something. My socks  
 20 are off and all that kind of thing and sticking pins  
 21 in the soles of your feet. He said, "You are  
 22 developing neuropathy".  
 23 "Oh, why?"  
 24 "Because of the drug you are on, the AZT.  
 25 I can't see why you are on it anyway, so we will just

44

1 discontinue it". So I had been taking this for four  
2 or five years by this time and he, a specialist in the  
3 treatment, said he had no idea why I was taking it,  
4 but it had already wrecked another part of my  
5 physiology, so they stopped my meds, because as far as  
6 this specialist clinic was concerned I wasn't --  
7 I didn't fit the profile to be on meds at that point.

8 So the meds were stopped. I went off them for  
9 two and a half years. I would go for regular  
10 check-ups, but bit by bit my T cells and my CD4 count  
11 began to react to the fact that I was no longer --  
12 I wasn't being medicated.

13 You are supposed to have -- the ideal situation  
14 is to have an undetectable viral load, which is  
15 I think something to do with the T cells, and  
16 a manageable CD4 count. Now, my viral load went from  
17 undetectable. It peaked at 35,000, which, you know,  
18 again, it is a matter of scale but clearly 0 to 35000,  
19 there's a long way in between, so it is a bit serious.  
20 My CD4 count, which is supposed to be about 400 to 600  
21 dropped to less than 10. So according to the  
22 biochemistry I was seriously ill, but I was fine.  
23 I didn't have any issues, but they decided that  
24 I should be back on meds, but I didn't want to go back  
25 on meds.

45

1 A. Mm-hm.  
2 Q. You had more treatment that you paid for privately.  
3 A. I had to pay for it again, same psychiatrist.  
4 Q. Then you went back to work. You felt like Humpty  
5 Dumpty put back together again and sent back to the  
6 same life.  
7 A. Yes. Seemingly the test for whether or not I was  
8 better was whether I was able to go back to work,  
9 which is not what I wanted to do. Weird, you know,  
10 "You are okay now. You can go back to work".  
11 "Argh. I don't want to go back there."  
12 "No, no, no, you are fine. Go back to work."  
13 So I went back to work.  
14 Q. What happened to your brother in 2010?  
15 A. He died. He was ill in about the May time. Nobody  
16 was quite sure what was wrong with him but they  
17 decided that he had pneumonia, so he went to hospital  
18 for a few days, pneumonia. All a bit worried because  
19 pneumonia is one of those diseases you associate with  
20 the onset of AIDS, full blown AIDS. What does that  
21 mean? Full blown AIDS. What a horrible description.  
22 You don't get full blown anything else, do you? Full  
23 blown cancer. You get full blown AIDS.  
24 So we thought, "Yes, this ain't good. He's got  
25 pneumonia". Then he was cleared of pneumonia. Came

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1 So part of the breakdown I had was the pressure  
2 I felt I was under and my family were under, because  
3 my doctor was saying to my wife, "You know, he is  
4 killing himself not taking these meds". I was in  
5 a bad situation of a dilemma. Do I go back to the  
6 meds that had made me so ill? It wasn't just the  
7 peripheral neuropathy. I had had -- the correct, the  
8 pronunciation -- lipodystrophy. What they do is one  
9 of them sheds you of all the fat in your body, so you  
10 basically shrink. I had had that and I had also had  
11 the reverse that makes you bigger and then  
12 I compromise now with something in between, so I have  
13 a mixture of both.

14 So I had gone through this situation where  
15 I felt I had grown to the giant of a man. I had  
16 shrunk to a midget of a man. I had had the  
17 neuropathy. I had had one breakdown. I thought, "Do  
18 I want these meds? Other than what the meds have done  
19 to me, there was nothing wrong with me, and yet my  
20 biochemistry said I am killing myself", so ultimately  
21 I ended up having a breakdown and going back on the  
22 meds.

23 Q. You have said in your statement you were very unwell  
24 for about six months. You were diagnosed with  
25 depression and clinical anxiety.

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1 out of hospital. He still didn't seem right. He was  
2 still going back. To turn out anyway, cut a long  
3 story short, yes, had had pneumonia but the pneumonia  
4 was actually because he had liver cancer, so they  
5 discovered he had liver cancer. He didn't just have  
6 new liver cancer. He had had liver cancer seemingly  
7 for a long time. They started doing biopsies and all  
8 this kind of thing. It soon became clear about  
9 August, so this was May to August, he was actually  
10 riddled with cancer, which begs the question how had  
11 nobody noticed because he was -- he was end stage. So  
12 he had gone from being fine in May to end stage liver  
13 cancer in August.

14 You know, my first reaction was, "What about  
15 your ultrasounds? What about your fibroscans?" He  
16 had never had any. As I say, we went our separate  
17 ways treatment-wise. He wasn't at St Thomas' anymore.  
18 I don't know where he was. He had gone through  
19 a whole series of haemophilia centres. He was  
20 a difficult person, so he would fall out with doctors.  
21 There would be issues and he would move on like  
22 a gypsy from centre to centre, but he had -- I have  
23 a six monthly ultrasound and a 12 monthly fibroscan  
24 and I have been having for, what is it now, I must  
25 have been having these for 15 years at least, maybe

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1 longer. He wasn't and he got liver cancer.  
 2 He died in the November of 2010 and it was  
 3 a horrible, horrible death. I mean, I don't know what  
 4 a nice one is, but it was pretty damn grim.  
 5 **Q.** And after your brother's funeral you broke down again.  
 6 **A.** Yes. Not so much because of the -- you know, it  
 7 wasn't so much because of the funeral and because of  
 8 him dying. This was an awful year in my life. Again,  
 9 we were business partners. We weren't just brothers.  
 10 There were other issues in that business. It is like  
 11 the perfect storm situation arose. Lots of other  
 12 things that just happened to go off in 2010 went off  
 13 the same time as he got cancer. It all came to a head  
 14 with his funeral. I stayed at work until his funeral.  
 15 Everybody turned up at his funeral. I read the eulogy  
 16 and then I disappeared for six months, because it was  
 17 all too much.  
 18 Our relationship had been -- that's my brother  
 19 and my relationship had been impacted by that time.  
 20 Before I had been trying to get out of this business  
 21 by then for ten years. He wouldn't let me go, you  
 22 know, financially and emotionally. I would oscillate  
 23 between not wanting to leave him and feeling  
 24 desperately needing to leave him.  
 25 He had reacted to being HIV positive and all

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1 thought I was going to die, I would be the one,  
 2 because I was the one with the neuropathy. I was the  
 3 one with the shingles. I was the one with the three  
 4 breakdowns.  
 5 You know, if anybody was the one you would have  
 6 backed to go first or to go at all, it would be me,  
 7 and he had decided this and I had decided this  
 8 privately that it would be me so, yes, we talked about  
 9 the irony of the situation. Here I was still  
 10 ploughing on asymptomatic and here he is dying. It's  
 11 a funny conversation, isn't it.  
 12 **Q.** The business that you had run together after his death  
 13 you carried on with it for a while but it then was  
 14 wound up.  
 15 **A.** Yes. I mean, as I said, I stepped back from it for  
 16 six months. Again it became apparent that if things  
 17 were going to continue, then I ought to go back to it  
 18 against a lot of advice from psychologists that  
 19 I shouldn't go back to it, but I did and, you know,  
 20 I tried to become him again, because he is what had  
 21 been lost. So is it meant a change of approach,  
 22 because he was much more the kind of customer facing  
 23 part of our business. So I had to become that person  
 24 because it was easier to replace my more back office  
 25 role. You know, you can bring people in to do that,

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1 that goes with it in a different way. As I say, we  
 2 had different attitudes to owning that identity. It  
 3 had done terrible things, I feel, to his personality.  
 4 So although we saw each other every day, we were in  
 5 a way estranged.  
 6 **Q.** Before your brother died you had previously talked  
 7 together about --  
 8 **A.** Mm-hm.  
 9 **Q.** -- which of you would be the first to die and both of  
 10 you had always assumed it would be you.  
 11 **A.** We had one of those meetings, you know, where  
 12 everybody went away and left us on a Saturday  
 13 afternoon to talk about the situation after he had  
 14 been diagnosed with incurable cancer -- inoperable  
 15 cancer. There was nothing that could be done for him.  
 16 He was just sat in a chair slowly dying.  
 17 We had one of these heart to heart conversations  
 18 and it came up, you know. Clearly, you know, we had  
 19 talked about it. We could joke about HIV and our  
 20 situation amongst ourselves, just the two of us, so it  
 21 wasn't something that we had difficulty discussing.  
 22 We just both came to the conclusion, you know --  
 23 he believed he was indestructible, always had. From  
 24 that it became clear he had always thought I was going  
 25 to die, that I would be the one and I had always

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1 but the specific personality has to be the one that  
 2 meets the clients. So I had to adapt and become that  
 3 person, which was weird, because it was like becoming  
 4 him and people used to -- we had long standing clients  
 5 who had been with us all our business lives. They  
 6 would come in and say "oh, [redacted]."  
 7 **Q.** Can we stop the transmission, please, sir.  
 8 **A.** You are very good that, picking it out. I would never  
 9 notice.  
 10 **Q.** If we take a few moments and we will start it again:  
 11 carry on.  
 12 **A.** Yeah, people would actually sort of commend me and say  
 13 "Oh, it is just like dealing with your brother". I am  
 14 not sure I want that, but it was commercially  
 15 necessary.  
 16 **Q.** You then retrained as a teacher.  
 17 **A.** Mm-hm.  
 18 **Q.** And pursued that for a period of time, but you had to  
 19 give that up because of the pain levels meant you have  
 20 not been able to sustain it?  
 21 **A.** No. I can do an hour, which I now do as a personal  
 22 tutor, mostly on Skype. You know, that's easier to  
 23 do. I can manage that. I can have my feet up and my  
 24 laptop and teach but, no, wandering around the  
 25 corridors of a school now, you know, 60-hour week,

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1 I can't do that.

2 **Q.** You say you are once again in a position of not being

3 able to obtain life insurance or mortgages?

4 **A.** There has only been one time I have had real life

5 insurance. I got hundreds -- dozens of policies of

6 personal accident policies where there will be

7 a payout if I am on a bus and it crashes. I took all

8 those out, because they are the only kind of life

9 insurance I can get. So I have got lots of these

10 little £50 grand policies where if I am killed on

11 public transport, my family get money. So I spend

12 a lot of time on buses! I have been on three trains

13 that have caught fire, but I am still here so, yes,

14 life insurance, I finally got a situation where

15 I engineered a situation that our business was at its

16 peak in around about the early 2000s again, where

17 I realised that we now had enough people working for

18 us to have a group life insurance, which is not

19 individually medically underwritten. You just go

20 along and say, "I have got X number of people working

21 for me. This is their different rates. This is what

22 they get paid. We as a company will pay the premium

23 and you all get life insurance".

24 I thought to myself, "That's a real wheez".

25 Little does this insurance company know but they have

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1 those and even then it is difficult, you know.

2 They are always going on about how much it

3 costs, because they have to throw away all their

4 instruments. They cannot be resterilised after they

5 have been used on you. Even these community health

6 dentists still don't want you, you know. I am now on

7 to my third in the last -- less than ten years and,

8 you know, they come up with the most curious -- "We

9 have just discovered your postcode is not within our

10 area".

11 "I have been coming for ten years."

12 "Oh, no, no. We just found it. We are going to

13 move you to somewhere else". You are just bounced

14 around. They always say they are going to write and

15 they never do. You have to then go to your GP and

16 say, "Have you had a copy of a letter saying that

17 ...?"

18 Why it should be with dentistry. Thank God it

19 is not like this with haemophilia, you know, if you

20 were being bounced from centre to centre but as far as

21 your teeth go, it is -- they are always sticking

22 themselves. Twice I have had a dentist do a needle

23 stick with himself and, you know, then it is like the

24 nuclear warning going off in the surgery, for good

25 reason. I am sympathetic about the dentists, that it

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1 got two HIV positive haemophiliacs on this roster. We

2 had this cover. It was £150,000 I think it was and it

3 ended up paying out my brother and then when the

4 business went down, the life insurance went down. So

5 my wheez, you know -- I never -- my family never

6 benefited from.

7 **Q.** Can I just ask you about the impact that your

8 infection has had on accessing dental treatment?

9 **A.** It has had an awful impact on -- I don't know why it

10 is. There is something about -- it must be to do with

11 the structure of the NHS and when they decided in the

12 1940s or whenever it was that dentistry would be

13 somehow different to everything else you can have

14 wrong with you, but for some reason you mention to

15 dentists you have -- you have been exposed to CJD and

16 it is like you have told them you have got leprosy.

17 They don't want to know.

18 So I have been bounced from dentist to dentist.

19 It has never been -- I haven't had a high street

20 dentist since the 1980s. I always had a hospital or

21 what's culled a community health dentist, which is

22 a kind of special service where you go to if you

23 have -- usually it is people with serious learning

24 difficulties or they are in wheelchairs. They are

25 completely incapacitated. You have to go to one of

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1 happens to them, but I guess this is another reason

2 why they don't feel inclined, you know, to encourage

3 you to be on their roster. So, yes, dentistry is

4 a little part of your life on its own and it is

5 a recurrent serious problem of getting ongoing

6 treatment.

7 **Q.** Can I then ask you about your experiences with the

8 MacFarlane Trust and with EIBSS.

9 In terms of the MacFarlane Trust what's your

10 experience been of making applications to them?

11 **A.** It's never been easy. It has never been encouraged

12 but, yes, I mean, I have had benefits, so to speak,

13 from the MacFarlane Trust. I have had a loan,

14 an interest-free loan from them once, clearly I had to

15 repay.

16 I used to get hospital travel costs from them

17 and then ultimately, you know, in a common experience

18 with most people, towards the end of their existence

19 you would get regular quarterly payments from them and

20 there was some discretionary -- always very

21 complicated systems, you know, very bureaucratic

22 methodology of what you qualify for, what you don't

23 qualify for, lots of strange terminology around the

24 types of payment you got, different organisations,

25 because there was a Skipton Fund as well as the

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1 MacFarlane Trust and for some reason they were  
2 separate. So it was always very difficult to follow.  
3 It was difficult to know what you could apply for,  
4 what help was there. So I think, you know, most of us  
5 were pretty passive in terms of you got what you were  
6 given, kind of thing. That was the feeling I had  
7 about it.

8 Q. You have described in your statement in early 2018  
9 receiving an invitation from the MacFarlane Trust for  
10 grants to use the residue of available funds before  
11 the Trust was being wound up and said it was quite  
12 a rigmarole to obtain the quotes you would need.  
13 A. Yes. They came out towards the end of their existence  
14 and said, you know "we have got money", which I think  
15 is a surprise to a lot of us, because they had spent  
16 most of their existence saying they had no money.  
17 Towards the end they said, "We have got some money.  
18 We need to try to distribute it amongst the  
19 beneficiaries, so would you like to think about  
20 applying for" -- I don't know if there was a short  
21 list of things you could apply for but I suspect there  
22 was, but it was the same sort of difficulty. It  
23 wasn't easy, you know. They had various -- I think  
24 people have described it as jumping through hoops.  
25 Yes, there were lots and lots and hoops, leap

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1 Higgins Trust?  
2 A. Yes.  
3 Q. You had a telephone conversation with the Acting Chief  
4 Executive of the MacFarlane Trust?  
5 A. It is another one of these where you get a letter  
6 suddenly out of nowhere, a letter comes saying, "By  
7 the way, we are probably aware we are being wound up",  
8 or whatever, for our many failures. It didn't say  
9 that but that's what it should have said, "We are  
10 being wound up and we have just discovered we have  
11 650" -- they didn't say the amount. They said, "We  
12 have got a residue of funds and we need to do  
13 something with that. It's got to go somewhere, so we  
14 have decided to give it to the Terrence Higgins  
15 Trust".  
16 That was a double shock, one, that they had any  
17 money left and, two, that they were giving it to the  
18 Terrence Higgins Trust, so I was just curious. I am  
19 sat at home remember in my little corner with not  
20 a lot to do, no Skype lessons, so I thought I'll ring  
21 the MacFarlane Trust and ask them what's going on.  
22 So I -- it was really weird. Normally you ring  
23 these people and you can't speak to anybody and they  
24 do not want to tell you anything, but within about ten  
25 second of saying why I was ringing I was speaking to

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1 frogging. All sorts of things you had to go to do.  
2 Snakes and ladders. You would go up and then down.  
3 You know, you would go back and get a quote. Make  
4 sure no-one else can -- one of the provisions, the  
5 EIBSS still does it. Make sure you have exhausted all  
6 the other possible sources of assistance.  
7 What other sources of assistance are there? How  
8 do you exhaust sources of assistance? I don't know  
9 how to prove I have exhausted the sources of  
10 assistance that don't exist. So somehow you have to  
11 do it. Then you have to get two quotes for  
12 everything, which is bizarre, because who -- who wants  
13 to say to the builder, "Thanks for all your planning.  
14 Thanks for all your help, but now I have got to go out  
15 and see if I can get a cheaper quote to see if someone  
16 else can do it and send that off".

17 It is not the way you do your home improvements,  
18 continually messing people around, getting them to  
19 give quotes but they are never going to do the work  
20 for you just because you have got to get a quote.  
21 Anyway, that's another story. The bigger story is how  
22 much money they had left.

23 Q. You, when you ascertained that your understanding was  
24 the residue of money that they had left would be  
25 transferred from the MacFarlane Trust to the Terrence

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1 the Acting Chief Executive. "Oh, hello. Why have you  
2 come on the line?"

3 "I understand you want to talk to me about this  
4 Terrence Higgins Trust."

5 "Yeah, I do actually".

6 "Right, what would you like to know?"

7 "How much money have you got left?"

8 "Oh, \$£650,000."

9 "Really?"

10 "Yes."

11 "How much money did you distribute?"

12 "£450,000."

13 "That seems odd, so you have got more left than  
14 when you said you were desperate to distribute the  
15 money to the beneficiaries, you have got more left  
16 than you distributed."

17 "Yes."

18 "That's probably because you made it so  
19 difficult to qualify for a distribution."

20 "Oh, those are the rules. We have to abide by  
21 the rules".

22 "Is that why you are giving the money to the  
23 Terrence Higgins Trust?"

24 "Yes, we had a trustees' meeting and the  
25 decision was made to give the money to the Terrence

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1 Higgins Trust". I said, "Why?" He said, "The  
2 trustees discussed it."  
3 "Can I see the minutes?"  
4 "No, you can't."  
5 "okay, why?" She said, "The trustees have to  
6 follow the rules set down in the trust deed and it is  
7 all to do with the money having been earmarked to be  
8 for the care of people, in this case haemophiliacs  
9 living with the effects of HIV, and there aren't many  
10 places we could send the money to meet those criteria  
11 so we are sending it to the Terrence Higgins Trust".  
12 "Oh, okay. You can't share any other  
13 information with me?"  
14 "No, that's it. It is done, done deal."  
15 "When is it going to happen?"  
16 "It's already happened. We have already given  
17 the money."  
18 "Right, okay", so I left it that, but it irked  
19 me, all sorts of -- (a) that they had this amount of  
20 money left, because they only got 10 million in the  
21 first place. So this 6.5% of the money they had had  
22 for nearly 30 years they still had left. Most people  
23 in this room who had anything to do with MacFarlane  
24 will know that they were always, always pleading  
25 poverty. It was always going to run out. They never

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1 thing I remember at the time the Chief Executive, the  
2 lady on the phone, told me they are going to appoint  
3 a liaison officer. I thought that's a good idea  
4 because that will soon soak up the 450 grand in  
5 salary.  
6 Funnily enough, I have not heard a peep from the  
7 Terrence Higgins Trust since that letter saying the  
8 money had gone, that letter from the MacFarlane Trust  
9 saying the money had gone to the Terrence Higgins  
10 Trust. As far as I can see, no disrespect to the  
11 Terrence Higgins Trust who I know very little about,  
12 I am sure they do wonderful work, but they aren't  
13 doing anything for me. The MacFarlane Trust, to be  
14 honest, did B all for me.  
15 Q. EIBSS?  
16 A. They are doing B all for me as well.  
17 Q. You have had dealings with the EIBSS?  
18 A. Mm-hm.  
19 Q. What would you like to say about your experience  
20 there?  
21 A. Well, just -- I have been at it nearly two hours.  
22 I will shrink this down.  
23 I remember being told by the EIBSS, there was  
24 a circular went out saying, "No-one will be worse off  
25 under the new arrangement than the old arrangement.

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1 had any security of future income. It was always on  
2 a shoe string. We should always be so grateful for  
3 any penny we got because they had so few pennies and  
4 they had to share it out and it was so difficult to  
5 share it out and to find anybody who was really  
6 entitled to it, and yet all the time they had the  
7 money and they still failed to spend it all on us  
8 while they could. Even when they were desperate re  
9 supposedly trying to spend it on us by appealing to us  
10 to apply, they still failed to distribute it all, and  
11 then they made this unilateral decision, supposedly  
12 based on the legal framework that they had to live  
13 under, under their Trust deed.

14 I thought, "Sod it. I am going to get a copy of  
15 this trust deed". I did and there is nothing in that  
16 trust deed that relates to what this woman said to me  
17 on the phone about the restrictions upon them and what  
18 they had to do with the money.

19 In fact, they could change the trust deed at any  
20 time to do whatever they liked with it as long as they  
21 followed the trust law. They didn't do any of that.

22 Q. As a haemophiliac living with the effects of HIV have  
23 you had any communications from the Terrence Higgins  
24 Trust?

25 A. No. It was December that all that happened. The only

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1 Some people will be exactly the same but no-one will  
2 be worse off and vast majority of will you better  
3 off". Well, I am worse off. So that was another lie.  
4 There is this thing about -- again, it is all -- why  
5 it that is to be so complicated I don't know, because  
6 what we have got is not complicated. We are  
7 haemophiliacs with HIV, hep C and CJD.

8 Now, it is a lot but it is not complicated, is  
9 it? It is not difficult to get your head around, but  
10 you download their booklets and try and get your head  
11 round how to qualify and apply for any kind of  
12 assistance that you are supposed to be getting. This  
13 is assistance. This is the thing, it is supposed to  
14 be here to help you.

15 These organisations should have people coming  
16 out to visit us in our homes and saying, "What can we  
17 do for you? This is what we have got. Do you realise  
18 you can have this?" It is not like that at all. It  
19 is about, "Here is all our paperwork. Read it  
20 yourself. Find it on the Internet and work out if you  
21 think you might qualify and then we will put you  
22 through the mincer to see if you really do." That's  
23 how it operates, so eventually I went through all this  
24 new stuff and I realised I was losing my what they  
25 called the discretionary payment.

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1 Q. And what was the reason you were losing it?  
 2 A. Because my wife earns too much money.  
 3 Q. So it is the means testing of the household?  
 4 A. Means testing. What has my wife's income got to do  
 5 with the fact that I am again a haemophiliac, who is  
 6 HIV positive, who is hep C positive and CJD positive?  
 7 It's got nothing to do with my wife. Why should she  
 8 have less money -- what they are saying is, "Your wife  
 9 can pay the money that we would pay you. So go to her  
 10 and ask her for about £250 a month that we used to pay  
 11 you under the old scheme, because she earns too much  
 12 to give you it. So just get £250,000 a month from  
 13 her, will you?"

14 So if you think about this in practice, you  
 15 know -- I won't get into the nitty-gritty of my  
 16 marital financial arrangements -- but in practice  
 17 again it's a simple thing, isn't it? If it were all  
 18 cash, you'd go to your wife and say, "Oh, you know you  
 19 were having that spa treatment and that night out with  
 20 the girls and movie night? Well, you're not anymore,  
 21 because you have got to give me now £250 because  
 22 they're not giving me it. So you have to have  
 23 a lesser lifestyle to look after me, this guy who has  
 24 been a burden on you for the last 35 years of your  
 25 life".

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1 discretionary payment. It is in the booklet but there  
 2 is two types of discretionary payment. God knows why.

3 This one -- so I said -- I mean, they were  
 4 pestering me for two years to apply for this  
 5 discretionary payment that I didn't qualify for.  
 6 I told them on the phone "I have looked at your  
 7 booklet. I don't qualify for it."  
 8 "Oh, apply anyway", they said. They were really  
 9 touchy-feely on the phone. "We need to know how the  
 10 community is affected by our new rules. Would he want  
 11 your feedback". I said, "Okay. I am not going to  
 12 fill it in because I don't qualify. I am not going to  
 13 get a load of pay slips but I'll send it in". They  
 14 said, "Send us a covering letter. Explain your  
 15 circumstances. It has been very interesting talking  
 16 to you, Mr [redacted].

17 Q. Can we stop the transmission. Don't worry. We will  
 18 start it again in a moment.

19 Okay. We can carry on.

20 A. "Very interesting talking to you on the phone. Send  
 21 us a covering letter laying it all out for our  
 22 information." So I did, a month later I got a really  
 23 insulting letter back saying, "You do know you don't  
 24 qualify, don't you?"

25 "Funnily enough, yeah, I do."

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1 Now I am a bigger burden. I am a financial  
 2 burden. Why? Why is it? Then the EIBSS have the  
 3 nerve -- how they have the information I don't know  
 4 but they say, "Oh, by the way we have looked up. You  
 5 are now getting a special category mechanism payment,  
 6 aren't you?"

7 So you are actually, financially, you are  
 8 significantly better off than you were under the old  
 9 scheme when we kind of aggregated all your payments".  
 10 I said, "Yes, because I am a lot damn sicker than  
 11 I was to qualify for that special category mechanism  
 12 payment. It is not something you have just decided to  
 13 give me. I had to go through another load of hoops to  
 14 get that and you rejected that the first time". It is  
 15 just bizarre.

16 The thing is they all call it, you know,  
 17 assistance, entitlements, benefit. We all think it  
 18 should be compensation, but it is not compensation and  
 19 it should be compensation. It's been a tough 30-odd  
 20 years living with this. It is not our fault and we  
 21 are actually made to feel like beggars panhandling our  
 22 way through life and the way you are treated -- again,  
 23 right now I have just qualified for some -- for travel  
 24 costs to go to hospital. Now, I hadn't applied for  
 25 this before, because, again, it is another type of

66

1 That's when they got into all this, "We are  
 2 giving you all this, we will give you ..." The gist  
 3 of it was, "We are giving you all this extra money for  
 4 your special category measures because your liver is  
 5 annihilated. You should be damn grateful for that.  
 6 Your wife is making a lot of money so she should be  
 7 looking after you."

8 "Yeah, I used to make a lot of money. I don't  
 9 anymore."

10 "But you are not entitled to all these  
 11 payments", so I was right back to square one where  
 12 I had begun. "I am really glad I helped you with your  
 13 feedback exercise. I hope you learned a lot with my  
 14 covering letter."

15 So I was put off these discretionary payments.  
 16 Then it came to my attention that there was this other  
 17 type of one-off discretionary payment for other  
 18 variety of reasons. So I emailed them and said, "Are  
 19 these means tested as well?"

20 "No, these aren't means tested."

21 So consistent, you love it, don't you? "So  
 22 I might qualify for these?"

23 "Yes, if you have exhausted every other avenue  
 24 of assistance."

25 "I don't think anybody else will pay for me to

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1 go to St Thomas' for my hospital appointment".  
 2 But I was worried they were going to say, "You  
 3 shouldn't be going to St Thomas. You should be going  
 4 to some other hospital nearer you, so we are going to  
 5 stop that". I thought that's what they would do.  
 6 Going to St Thomas' is why I am alive and my  
 7 brother is not. As far as I am concerned, these  
 8 people cannot interfere with where I go for my  
 9 treatment because I am getting now good treatment.  
 10 I have faith, I have trust and I am alive, so I am  
 11 going to St Thomas'. It costs money but you can buy  
 12 advanced tickets, all this kind of stuff, so I try to  
 13 keep it to a manageable amount.  
 14 "Yes, you do qualify. You have exhausted all  
 15 the other avenues of existence. We will give up some  
 16 money. Send us your receipts for the last three  
 17 months." I said, "I have again going since you were  
 18 set up in like end of 2017". I am sure I can get --  
 19 they wanted me to get letters, of course, and stubs  
 20 from my train tickets.  
 21 I said I can probably get them back to 2017 if  
 22 you want. "Oh, there is no need to do that." I said,  
 23 "Why are you going to give me it anyway?" They said,  
 24 "No, you can only have three months."  
 25 "Why is that then?"

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1 follow their guidance.  
 2 Their guidance doesn't allow them to help me.  
 3 They should be bending over backwards to help me, but  
 4 they are not. Every time I ring up or look into  
 5 getting something, I am afraid they will find  
 6 something and take something off me instead of giving  
 7 me something. Like I said, I was afraid that they  
 8 would say, "You shouldn't be going to St Thomas", but  
 9 I have got away with that. Listen to that expression,  
 10 I have got away with it. That's how I feel about  
 11 getting help, that it is something you get away with.  
 12 "Oh, wow, I have got away with this", but they got  
 13 away with my discretionary payment, one to them. It's  
 14 a battle. I am at war with these schemes and they are  
 15 at war with me. Bonkers.  
 16 It should be compensation. It should be sorted  
 17 out. We shouldn't be in this situation. It should be  
 18 a draw. The war should end. I don't know what it is  
 19 they're afraid of. None of us know what it is they're  
 20 afraid of, but somebody is holding out and we don't  
 21 know why. How deep it goes, who is being protected,  
 22 why they are being protected we don't know.  
 23 The conspiracy theories that surround this are  
 24 absolutely ridiculous, but the situation is so crazy  
 25 that you have to listen to the conspiracy theories and

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1 "That's the rules."  
 2 "Whose rules?"  
 3 "Civil Service rules."  
 4 "I am not a civil servant."  
 5 "Oh, but we abide by the civil service rules  
 6 like if you were claiming your expenses for a business  
 7 trip."  
 8 "I am not claiming expenses for a business trip.  
 9 I am claiming my expenses for being HIV positive, CJD  
 10 positive, hep C positive and (unclear)."  
 11 "You can't have them for more than three months.  
 12 Send us three months and we will give you three  
 13 months."  
 14 Why? Why don't they want -- can't they afford  
 15 it? It would be another £450. What was the reason?  
 16 Where is -- all they do is point to a document.  
 17 That's the reason. I say, "Yeah, but that's just  
 18 a document. You are the EIBSS. I don't fit into any  
 19 kind of document. I didn't sign up for any of these  
 20 diseases. This isn't a career choice for me. Why  
 21 have you got a set of rules that you impose on me?  
 22 Why can't I say 'My rule is I don't -- I shouldn't  
 23 have HIV. I shouldn't have CJD and I shouldn't have  
 24 hep C. You don't fit into my rules, so make me  
 25 better", but no, no, no, I can't do that. I have to

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1 give them some credence, because no-one else is  
 2 offering us any kind of explanation. Somebody told me  
 3 they thought it was because it was a biological weapon  
 4 that had gone wrong in the United States and it was  
 5 all to protect the CIA. Well, you think this is like  
 6 looking up horror stories on the Internet, isn't it,  
 7 but then you go home and you go and you sit and watch  
 8 a TV programme at night and you reflect and you think,  
 9 "Why wouldn't they tell us?" You find yourself in the  
 10 situation of giving credence to the crazy conspiracy  
 11 theories. Other people say it's the Clintons. Am  
 12 I allowed to say that? They say it's the Clintons,  
 13 because they had something going on in Arkansas when  
 14 he was governor of Arkansas selling prisoners' blood  
 15 and that there is a trail of death and assassinations.  
 16 Bizarre, but until this is sorted out people will feed  
 17 on these theories. It is probably something really,  
 18 really insignificant. It is probably somebody made  
 19 some crazy decision that they are embarrassed by. Who  
 20 knows, but until someone finds out or someone is  
 21 prepared to say, then this goes on. People are dying  
 22 while this goes on. Bonkers.  
 23 Q. I don't have any further questions for you. Is there  
 24 anything else you would like to say?  
 25 A. There's lots more, but I've already been here two

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1 hours. Has Mr Snowden got any questions for me?  
 2 **Q.** That's -- you've anticipated me. It looks like he  
 3 does.  
 4 **A.** Oh, lucky me!  
 5 **Q.** Just one further point and it arises from  
 6 an observation you make in your statement. You talk  
 7 about how when you present yourself at an NHS  
 8 facility, you have to recount your entire life story,  
 9 all your medications, all your infections, going  
 10 through the same questions and you had a suggestion --  
 11 **A.** I have got a suggestion, yes.  
 12 **Q.** -- as to how it could be better done.  
 13 **A.** Okay. Right. We'll all be aware of this, you know,  
 14 guys and girls in the room, the community. Oh, aren't  
 15 we fabulous? You go through these. You have to go  
 16 for new things, don't you? You know, you go for  
 17 a vaccination. You go for a blood test. Already you  
 18 have to be ready to tell these people, "I'm HIV  
 19 positive. Do you know that? I'm hep C positive and  
 20 I've been exposed to CJD", as they put another, third  
 21 layer of rubber gloves on -- yes-- and think, "How did  
 22 I get this job?" Usually these days, because, you  
 23 know, the way things are run, Phlebotomy Department at  
 24 the particular hospital I go to for regular sort of  
 25 non-virology, non-haematology blood tests it's two or

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1 to provide a central service for the ongoing care of  
 2 people like me, which we can approach in times of  
 3 need, confident that our records and special  
 4 requirements will be met in a professional, timely and  
 5 courteous manner."  
 6 **A.** Yes. We have special needs and we're a pretty unique  
 7 subset of people who have all these co-infections that  
 8 work inside -- the infections impact the other  
 9 infection, but as a group we are probably quite  
 10 homogenous. So there ought to be, you know -- to put  
 11 right one of the wrongs that was done to us by this  
 12 system the system should devise a custom-made care  
 13 package for us so that again, like I said about the  
 14 supposedly assistance schemes that don't come to you  
 15 and say, "What can we do for you in terms of financial  
 16 aid or practical help?", there should be one that  
 17 comes to us for medical help, because our needs are  
 18 complicated. You go into your GP. I have no idea  
 19 what they're talking about. You know, I have to look  
 20 stuff up on the Internet to see what's wrong with this  
 21 guy who has just wandered in. It shouldn't be like  
 22 this. We are a subset with a particular set of  
 23 infections, set of needs. There should be a system  
 24 whereby, even though we are geographically spread, the  
 25 modern world, modern technology should be able to deal

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1 three patients in the same cubicle. So I'm telling  
 2 everybody. I might as well tell the waiting room what  
 3 I've got. Then the next thing is, "Well, what meds  
 4 are you taking?" I take thirteen. How the hell do  
 5 I remember what meds I'm taking?  
 6 I was in hospital two months ago for a carpal  
 7 tunnel operation and they were pestering me -- this  
 8 was St Thomas', my hospital -- they were pestering me  
 9 on a regular basis to remember what meds I was taking.  
 10 They prescribe them. I was woken at 2 o'clock in the  
 11 morning the night before my operation because the  
 12 doctor was coming round to ask me what meds I was on,  
 13 my own hospital, because they said they wouldn't let  
 14 me take them in the hospital until I told them what  
 15 they were so they could approve them. I had taken  
 16 them hours ago. Sod this. I went to bed. They woke  
 17 me up at 2 o'clock to say, "What meds are you on?"  
 18 These days I forget I'm a haemophiliac by the  
 19 time I've told everybody what's wrong with me. It's  
 20 supposed to be a major illness. I should be aware of  
 21 it. I've forgotten I am that exhausted by remembering  
 22 everything else.  
 23 **Q.** You put it this way in your statement in terms of your  
 24 suggested solution:  
 25 "Surely it is not beyond the wit of the system

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1 with that whereby we are known, our histories are  
 2 known, our cross-over infections are known, and, you  
 3 know, we shouldn't be out on the high street trying to  
 4 find a dentist.  
 5 **Q.** Thank you. Sir?  
 6 **A.** Can I have that little word now that I was offered  
 7 before you asked Mr Snowden?  
 8 **Q.** Yes, of course you can.  
 9 **A.** Make it quick, because we are all hungry. Yes?  
 10 **SIR BRIAN LANGSTAFF:** Well, you have about half an hour  
 11 before we normally have lunch --  
 12 **A.** I won't take half an hour.  
 13 **SIR BRIAN LANGSTAFF:** -- but you needn't take it all.  
 14 **A.** No, I won't.  
 15 Let me begin by saying how grateful I am that  
 16 you are our judge. I met Sir Brian for the first  
 17 time -- he was sat next to me when we had those  
 18 preliminary hearings. I had no idea he was the judge.  
 19 I just thought he was another guy here for whatever  
 20 reason. Yes? So it was really weird when he then got  
 21 up and became the judge. Yes? I, like a lot of  
 22 people in this room I am sure, was very wary of this  
 23 whole principle of having this Inquiry, because we  
 24 have been fobbed off so often in the past. I remember  
 25 saying to Sir Brian you had a poison chalice to do

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1 this and, you know, within about an hour of it  
2 starting you probably wish you were somewhere else  
3 still retired. I am sure his opinion hasn't changed,  
4 but I came here -- clearly, something like this is run  
5 by a judge and you expect that judge to be  
6 an establishment figure. Sir Brian is that  
7 establishment figure but if you had to have  
8 an establishment figure, the patrician, then I think  
9 that's the patrician I think we would all would want.

10 He once told me the last time he was in Leeds  
11 was a murder trial. If I was ever tried for murder,  
12 I would like him to be my judge. Okay. So well done,  
13 Sir Brian. Thank you for hanging on with us. We are  
14 really pleased about that, but the fact is this is  
15 a public Inquiry. Here we are. The people have  
16 claimed all sorts of things on behalf of this public  
17 Inquiry. It is the biggest one ever and most UK-wide  
18 one ever. I don't want to dis other public enquiries,  
19 you know. Hillsborough, Grenfell, all of these other  
20 public enquiries, you know, I don't want to boast to  
21 be bigger than them, but it is a weird thing, and now  
22 to be sat here, as I anticipated I think somewhere in  
23 my statement, who would ever have thought they would  
24 be giving a witness statement and being a core  
25 participant in any kind of public Inquiry?

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1 Public enquiries, you know, we are familiar with  
2 them. They pop up on the news. I have said  
3 Hillsborough, Grenfell, all the others, but typically  
4 they are looking at something that has happened at  
5 a point in the past and it's frozen in time. This one  
6 is not frozen in time. So as far as the comparison  
7 with Hillsborough was going, it is as if that match it  
8 is still going on. As far as Grenfell is concerned,  
9 unfortunately, it is as if that fire is still burning.  
10 So while forever we are understandably forensically  
11 having to take the time it takes to get all the  
12 evidence that is necessary for this together, the  
13 suffering continues and, again, it sounds melodramatic  
14 and on YouTube now I probably look okay and a lot of  
15 people are worse off than me, but there is suffering.

16 While we are here I think someone is dying every  
17 four days, the infected, as we are called, of this  
18 Inquiry. That is different. It's a different sort of  
19 public inquiry. You know, again putting it on to  
20 Sir Brian, I am sure he feels that responsibility and  
21 I pity him that responsibility, because he has to do  
22 this right and we have to give him the time to do it  
23 right, and his team are doing wonderful work and all  
24 our lawyers are doing wonderful workings but people  
25 are dying.

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1 You know, in terms of the experience you expect  
2 to have in your life this is not one of those that you  
3 expect to happen to you. It is bizarre to be sat here  
4 in this public -- in a national UK public Inquiry.

5 When I was in my early teens, I thought the  
6 biggest tragedy in my life was there wasn't going to  
7 be a cure for haemophilia in time for me to be  
8 a professional footballer. That was it and in those  
9 days professional footballers only made about £100  
10 a week. It's not like now. That was a my dream to be  
11 a professional footballer.

12 Little did I know the extent of tragedy that was  
13 going to eclipse that idea of being a professional  
14 footballer. To now be here and to be, you know, right  
15 now, this very moment, because I have been the next  
16 person up for the last 18 hours, which has been  
17 a really weird feeling, and to be sat here sort of at  
18 the centre of this thing, oh, wow, you know. It is  
19 the sort of thing we've dreamt of this, haven't we,  
20 but to actually be here it is actually a bit of  
21 a nightmare to be here. Who wants to be here amongst  
22 this, to be the pinpoint, but here we are and, yes, as  
23 I said earlier, yes, we would like some answers, and  
24 if it is going to take a public inquiry to get those  
25 answers, then so be it.

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1 Years ago lots of people died and they are not  
2 here except perhaps in spirit. One thing that  
3 an Inquiry has got to somehow -- this week has been  
4 better not because it is in Leeds. I would be biased,  
5 but because I think the profile of some of the  
6 statements that have been heard this week have harked  
7 back to those early days and that's important, because  
8 that's when certainly the part of this Inquiry that  
9 I come from, the haemophilia part of this Inquiry,  
10 that's when our numbers were decimated. Those people  
11 that died then, they had no idea there was going to be  
12 a public inquiry in 2018/2019 about their suffering.  
13 They were just gone. It was an awful, awful time.

14 It's difficult to recapture the reality of that  
15 now and for all that people that come forward and we  
16 have all got this hep C and it is there, I don't want  
17 to belittle that, but compared to the traumatic  
18 circumstances of the mid 1980s, nothing now compares  
19 to what it was like to be that dangerous to everybody  
20 else and to be so alone with this syndrome.

21 I was going to be killed by a syndrome. I had  
22 not even got the dignity of a proper disease. Who  
23 wants to die from a syndrome, something that no-one  
24 understands? It was like science fiction to get HIV  
25 and it still is to some extent. Every time we are

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1 treated we are on the cutting edge of medical science.  
2 Every new drug that comes along we are guinea pigs  
3 for. It is important to remember that time and those  
4 people and how those people were lost to us.

5 As I say, it is a different -- I think it is  
6 a different kind of public inquiry and that the  
7 suffering is different because of that, because it is  
8 not frozen into time. We are none of us moving on,  
9 none of us putting distance between then and now.  
10 There is none of that, "time is a great healer".  
11 There is no healing. Time is just adding insult to  
12 injury for most of us.

13 So I applaud Sir Brian. I have his poster on my  
14 bedroom wall! I wish this work well and I know it is  
15 going to take more time but, you know, he has won us  
16 over. We want the Inquiry to continue, to continue in  
17 this way, but we are all still terrified in the middle  
18 of the night that it is all going to be another  
19 whitewash I am afraid because we don't know where --  
20 what is it really we are looking for? I don't know,  
21 some of us are here because we want compensating.  
22 Yes, we all want compensating. Some of us are here --  
23 are we going to get these answers? I don't know. Are  
24 we here -- is it a which hunt of medics? I hope not.  
25 Are we putting the NHS on trial? I hope not. I don't

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1 (12.39 pm)

2 (Luncheon adjournment)

3 (1.49 pm)

4 **SIR BRIAN LANGSTAFF:** Ms Richards, I think our next  
5 witness would wish to be known as Maggie.

6 **MS RICHARDS:** Yes.

7 **MARGARET MADDEN, sworn**

8 **Questioned by MS RICHARDS**

9 **A.** Hi.

10 **Q.** Maggie, you are here to talk about your son Daniel and  
11 your mother, who is also Margaret.

12 **A.** MarGaret Madden.

13 **Q.** Also you are going to say a little about your cousin,  
14 Ronald.

15 **A.** Yes.

16 **Q.** Your mother, unusually for a woman, herself had  
17 haemophilia A?

18 **A.** Yes.

19 **Q.** When you were in your teens you were tested to see if  
20 you were a carrier.

21 **A.** Yes, I was.

22 **Q.** And you were.

23 **A.** Yes.

24 **Q.** You had three sons. We are not going to name two of  
25 them, but your youngest son was Daniel?

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1 have a grudge against the NHS. The NHS has done  
2 wonders for me. It is just this little bit of it that  
3 has destroyed my life, but I don't think it is the  
4 NHS, but I don't know exactly what it is, but it must  
5 be something, because 35 years of resistance and  
6 silence cannot come from nothing. If you can find it,  
7 sir, please find it and let us know. That's all we  
8 ask. That's it. Thank you very much.

9 **MS RICHARDS:** Thank you.

10 **SIR BRIAN LANGSTAFF:** Well, thank you, Mr M. If we do  
11 find it, we shall say what it is, whatever it is and  
12 without any fear, favour, affection or ill will.

13 You asked who wanted to be here. We do, because  
14 we are a UK-wide Inquiry. It is our task and it's  
15 a task we mean to see through to the end and as  
16 quickly as reasonable thoroughness will permit for the  
17 reasons that you have just so eloquently put forward.  
18 Thank you for everything you have said and for being  
19 here today and for being our Mr M.

20 **A.** Thank you.

21 **SIR BRIAN LANGSTAFF:** We will take a break now and we will  
22 take a break until 1.50. I am sorry for those who  
23 feel they missed their morning coffee, but they may be  
24 able to make up with the cookies halfway through the  
25 afternoon. 1.50.

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1 **A.** Yes.

2 **Q.** And Daniel was born in 1971.

3 **A.** Yes.

4 **Q.** And he did indeed have haemophilia?

5 **A.** Yes. He was born with the haemophilia, yes.

6 **Q.** Would you speak a little closer. You are very softly  
7 spoken.

8 **A.** He was born with haemophilia. Is that better?

9 **Q.** Much better. Now for the first few years of Daniel's  
10 childhood he didn't experience many problems.

11 **A.** No.

12 **Q.** You have described in your statement how from about  
13 the age of 6 he began to have recurrent bleeds. Is  
14 that right?

15 **A.** That's right, yes.

16 **Q.** How did the haemophilia impact upon Daniel's life?

17 **A.** Well, it stopped him playing out. It stopped him  
18 being with his brothers. Stopped him from doing  
19 normal things that boys do, because he just could not  
20 do them because he would end up being black and blue,  
21 or he'd cut himself and bleed or bleed inwardly and  
22 his legs would be swollen. He had intravenous drips  
23 in them days.

24 **Q.** So he would start off with the drips. He was under  
25 the care of the Children's Hospital at Pendlebury.

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1 A. He was.  
 2 Q. He would have treatment with cryoprecipitate but then  
 3 a time came when he moved on to having Factor VIII  
 4 treatment?  
 5 A. Yes.  
 6 Q. You think that that was probably some time in the late  
 7 '70s?  
 8 A. Yes.  
 9 Q. But you are not precisely sure.  
 10 A. No. Everybody did it all at the same time more or  
 11 less, actually. We were all taught.  
 12 Q. You were taught how to administer it at home.  
 13 A. Yes.  
 14 Q. You said in your statements you jumped at the chance  
 15 because you thought that would make a more normal life  
 16 for Daniel and also make life easier for his brothers  
 17 because they would --  
 18 A. Yes, because every time Daniel had a bleed and went to  
 19 Pendlebury, the boys had to come out of school and go.  
 20 Q. You learned how to administer the Factor VIII to  
 21 Daniel, and also to your mother and, indeed, to your  
 22 cousin Ronald as well.  
 23 A. Yes.  
 24 Q. Now you have explained in your witness statement that  
 25 Daniel -- you put together from bits and pieces of

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1 A. No. We just thought it was a miracle really, because  
 2 at least the family could have some kind of, you know,  
 3 a proper life and you didn't have to go running  
 4 backwards and forwards to the hospitals and the  
 5 children could go to school. In fact, Daniel started  
 6 school as well.  
 7 Q. Daniel went to a range of different schools and moved  
 8 around a little. He went to a school called Weldon  
 9 Hall School for a while?  
 10 A. Yes, he did.  
 11 Q. Then he went to Summerhouse School?  
 12 A. Yes.  
 13 Q. There were nurses there at the school and they knew  
 14 about his haemophilia?  
 15 A. Yes.  
 16 Q. He really enjoyed it there. He would be given his  
 17 Factor VIII at the school.  
 18 A. That's right.  
 19 Q. Now into the early 1980s you started to be aware, to  
 20 notice that Daniel was suffering from a lot of colds  
 21 and sore throats?  
 22 A. Yes.  
 23 Q. What can you recall about that?  
 24 A. Well, I thought it was because he had started school  
 25 really. You know, you get all these kind of different

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1 medical records, he had a number of different  
 2 products. In 1978 you think he had a Factor VIII  
 3 product supplied by Armour Pharmaceuticals. In 1979  
 4 he was given Factor VIII on a number of occasions at  
 5 Newcastle Royal Victoria Infirmary. Is that right?  
 6 A. He was, yes. He had an operation on his knee.  
 7 Q. We can see if we have up on screen, please, Paul  
 8 1364002, we can just see there, Maggie, the date 1979  
 9 and we can see on the right-hand column a range of  
 10 occasions on which he was given Factor VIII.  
 11 Sometimes it is recorded he was given Hemofil?  
 12 A. Yes.  
 13 Q. Those occasions they were actually administered at the  
 14 hospital.  
 15 A. Yes.  
 16 Q. Now, you have described in your statement recalling  
 17 one occasion when you had to go back to Pendlebury  
 18 Children's Hospital and return the Factor VIII that  
 19 you had been given. Is that right?  
 20 A. Yes, that's right. Everybody did.  
 21 Q. Were you given the reason for that?  
 22 A. They just said it was something wrong with the labels,  
 23 so they gave us all different treatment.  
 24 Q. Were you ever told as Daniel's mum of any risks  
 25 associated with the use of the factor treatment?

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1 things, coughs, colds, runny noses. I just thought it  
 2 was that that was doing it but it was all -- he had no  
 3 sooner get rid of one than he would start with  
 4 something else.  
 5 Q. You have described that you noticed he was sleeping  
 6 more?  
 7 A. He was very tired, yes.  
 8 Q. And he started to lose weight?  
 9 A. Yes.  
 10 Q. But he was having check-ups at a local children's  
 11 haemophilia clinic and at school by the school nurse  
 12 and you were told there wasn't anything to worry  
 13 about.  
 14 A. That's right.  
 15 Q. You then explained in your statement about 1982 Daniel  
 16 had another operation on his knee and then he was  
 17 given Factor VIII again on that occasion.  
 18 A. That wasn't Pendlebury. That was Newcastle.  
 19 Q. That was Newcastle?  
 20 A. Yes.  
 21 Q. Now just tell us a little about what Daniel was like,  
 22 would you?  
 23 A. If he could climb it, he'd climb it. He was a typical  
 24 lad. He was always up to something. If his brothers  
 25 went somewhere he would hide until they walked past

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1 him and he would follow them wherever they were going.  
 2 He was really a boy even though he had problems and he  
 3 knew the consequences and he would be in agony, he  
 4 still wanted to be part of that. He was not one of  
 5 these little quiet boys, unfortunately. He was  
 6 a proper lad.  
 7 **Q.** Now, in about 1985, some time in 1985 when Daniel woke  
 8 up in the night, he was feeling very sick and you  
 9 noticed he had spots on his stomach and you called the  
 10 GP.  
 11 **A.** Yes.  
 12 **Q.** Can you tell us what happened.  
 13 **A.** The GP came, knocked on the door and I opened the  
 14 door. He just stood in the doorway, because it was  
 15 like a walk in house where you walked through the  
 16 front door and you were in the living room. He said  
 17 to Daniel, "Just lift up your pyjamas, son". He did.  
 18 He went, "Chickenpox. Calpol and calamine lotion".  
 19 That was it. He was gone.  
 20 **Q.** You described the doctor didn't come into the house.  
 21 **A.** No, didn't come in.  
 22 **Q.** Stood at the door. Was that unusual?  
 23 **A.** Yes, but in your mind you think it is because he's got  
 24 chickenpox and he is going to visit other people. So  
 25 you don't -- it clicks, but it doesn't click, if you

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1 doing like you do and nothing was happening, but the  
 2 sores had actually turned -- the spots had actually  
 3 turned into sores and this were round here (*indicated*)  
 4 on his stomach and they were weeping badly, but they  
 5 were bleeding.  
 6 So the first thing I did is like jump out of  
 7 bed, sort him out and then strip his bed and  
 8 everything and I thought, "How can they be chickenpox.  
 9 They can't still be here". So with that I went back  
 10 to Pendlebury Hospital and when I got there -- I had  
 11 to phone the ambulance because my husband was away and  
 12 I didn't have the car, so I had to phone the  
 13 ambulance. They come and took me to Pendlebury  
 14 Hospital.  
 15 They wouldn't let me in the hospital. They came  
 16 into the ambulance. The nurse came in with a mask on,  
 17 gloves on, gown, everything, and even the ambulance  
 18 men didn't understand why I couldn't go into the  
 19 Haemophilia Centre, you know. It is only chickenpox.  
 20 Do you know what I mean. They just said, "That's it.  
 21 Give him two bottles of Factor VIII every other day,  
 22 prophylactic treatment and carry on with your calamine  
 23 lotion and your Calpol".  
 24 **Q.** This was not the normal way you were treated when you  
 25 took Daniel to the Haemophilia Centre?

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1 know what I mean. You just think he don't want  
 2 chickenpox.  
 3 **Q.** You think now with the benefit of hindsight --  
 4 **A.** He knew.  
 5 **Q.** -- that that was shingles rather than chickenpox?  
 6 **A.** Yes.  
 7 **Q.** You think now again, putting two and two together,  
 8 that that doctor had some knowledge that Daniel, in  
 9 fact, had something rather more seriously wrong?  
 10 **A.** Yes.  
 11 **Q.** Daniel didn't get better and the spots were turning  
 12 into sores and they were bleeding.  
 13 **A.** They were going together. Instead of being individual  
 14 spots they was clumping together.  
 15 **Q.** You said in your statement he was being sick. He was  
 16 losing weight.  
 17 **A.** He was yellow. He didn't want to do anything. He was  
 18 just another kind of boy to what he always was.  
 19 **Q.** And then one of your other sons came running into the  
 20 room and called you because he said Daniel was  
 21 bleeding bad?  
 22 **A.** Yes.  
 23 **Q.** What was wrong?  
 24 **A.** The sores had started -- well, they were weeping  
 25 anyway. Obviously, I was using this calamine lotion

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1 **A.** No, no. I used to get him out of the ambulance or if  
 2 I had to carry him or the ambulance men would carry  
 3 him into the centre. We all just went into the  
 4 centre. Everything did it, just went into the centre,  
 5 but there was no way he was going in there. She  
 6 wouldn't let him in.  
 7 **Q.** There were two things unusual. You weren't being  
 8 allowed in. You were told they want you to stay in  
 9 the ambulance and the nurse came out to you and,  
 10 secondly, the nurse was wearing gloves and a mask and  
 11 gowned up?  
 12 **A.** Yes.  
 13 **Q.** And that wasn't the normal procedure?  
 14 **A.** No.  
 15 **Q.** You did as you were told. You went back home and then  
 16 it was that week-end you think there was a knock on  
 17 the door and some Jehovah's Witnesses and you bought  
 18 a magazine.  
 19 **A.** I did. I bought the Awake magazine, which I often  
 20 did. I put the kiddies to bed and everything. I was  
 21 sat there and just having a read of it. In the  
 22 magazine was a piece about that big (*indicated*) about  
 23 people dying in America of what they called a gay  
 24 plague and I was reading it and the symptoms was spots  
 25 that turned into sores and dizziness and sickness and

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1 tiredness and my head was just -- I am thinking, "It  
2 can't be. How can it be? It can't be something like  
3 that", but after the experiences I've had at the  
4 hospital and the doctor not coming in, I didn't know  
5 what I was doing.

6 So I took him back to Pendlebury Hospital. The  
7 clinic was on and I thought, "Right. I am going to  
8 the clinic". So I went to the clinic and I took him  
9 back to the hospital there, straight into the clinic,  
10 because I was driving that day. When we walked in,  
11 Daniel went "What are they going to do to me?"  
12 I went, "Nothing", but even the doctor in the clinic  
13 had the same things, the gloves, the mask, the plastic  
14 apron. The nurse and the other lady who used to talk  
15 to you like a social worker, even she was gowned up.  
16 That was not just for Daniel. That was for the whole  
17 clinic.

18 So I told them what had happened and what I had  
19 read and everything else. They just said, "You are  
20 just imagining it and you are just getting hysterical  
21 over nothing. There is nothing wrong with him. It is  
22 your imagination. You are just getting too upset over  
23 nothing".

24 Of course, by this time I am crying, I am  
25 screaming, I think, "You are lying to me", blah, blah,

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1 I will stay with her and then I will go up to the  
2 clinic".

3 Anyway, I was going up the M62. I'd just got on  
4 the A1 -- I nearly said it then, didn't I -- one of my  
5 sons said to me, "Mam, Daniel's bleeding". So I said,  
6 "Right. Okay". So I come off the A1 and parked in  
7 the little layby thing. When I turned round  
8 I couldn't believe my eyes. He was covered in blood.  
9 My two sons was covered in blood. I just couldn't  
10 believe what I was seeing, so I jumped out of the car,  
11 ripped my blouse off and tied that round him and got  
12 a towel out of the boot and tied that round him.  
13 I thought, "What am I going to do", so I got them all  
14 back, one in the front and the other two in the back  
15 to separate them.

16 The look on my face must have been horrendous  
17 for the boys, because they were like, "We haven't done  
18 anything". I said, "I know. Just don't touch him.  
19 Just don't touch him". It was an awful thing to say  
20 about your son, but it had to be said.

21 Anyway, I got back in the car and I started to  
22 drive to Newcastle. The petrol, I didn't know how  
23 much petrol I had. My head was all over the place.  
24 Daniel was still bleeding. So instead of going will  
25 there I went the other way to Middlesbrough, which was

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1 blah. "There is something going on and I want to know  
2 what it is", and they escorted me off the premises.  
3 As soon as I came out of the room I told everybody in  
4 the centre what I had read and what I had heard and  
5 they just couldn't get me out of the door fast enough,  
6 so I never went back.

7 **Q.** You describe that night having been sent home from the  
8 hospital. You were awake all night and you couldn't  
9 close your eyes. You kept going into the room to  
10 check that Daniel was all right but also to check that  
11 Daniel wasn't in the same bed as his brothers --

12 **A.** I know. I know.

13 **Q.** -- because you were worried about them.

14 **A.** It is an awful thing to be worried about your other  
15 two sons because one could infect them with something  
16 but, yes, I was, up and down all night.

17 **Q.** So you kept the children off school after that.

18 **A.** I did. I knew the only person that ever spoke any  
19 truth was the RVI in Newcastle. So I phoned them up  
20 and I asked them could I come up and visit and could  
21 I speak to them. They said, "Well, you will have to  
22 get here as soon as you can. We will see you. If  
23 not, you can come to the clinic in the morning", but  
24 I had a friend who lived up there anyway and  
25 I thought, "If I can't get there in enough time, then

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1 nearer. I got to Middlesbrough Hospital, got the two  
2 boys out of the car, got Daniel out and I am carrying  
3 this -- carrying my son, who was looking like he was  
4 asleep and so pale, I have never seen anything like  
5 it.

6 The other two boys was like coming behind me.  
7 I didn't even lock the car, to be honest. I was just  
8 went in the hospital and they just helped me. They  
9 just came running in, took Daniel off me, took off the  
10 boys. I am in this babbled English trying to tell  
11 them what was going on and I was on my way to the RVI  
12 and this, da, da, da. They just took over everything.  
13 They put Daniel on pints of blood and what have you  
14 and I found out -- they phone the RVI and told them  
15 I was there and one of the nurses from the RVI came  
16 down in an ambulance to take us back -- take Daniel  
17 back up there, but in Middlesbrough they told me he  
18 had three and a half pints of blood left in his body  
19 and if I hadn't done that, he would have died.

20 **Q.** They arranged for an ambulance to take you from  
21 Middlesbrough to Newcastle.

22 **A.** They took Daniel and I followed behind in the car.

23 **Q.** A matron from Newcastle came down and travelled in the  
24 ambulance with Daniel?

25 **A.** Yes.

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1 Q. Middlesbrough gave you some money because you didn't  
2 have money for petrol?  
3 A. They did, because when I left home I had £30 but  
4 I bought them sandwiches and crisps and put petrol in  
5 the car, like you do. I didn't have enough money.  
6 They actually gave me £50 to get me up to Newcastle  
7 and to see me through.  
8 Q. Daniel was admitted to the hospital in Newcastle --  
9 A. Yes.  
10 Q. -- and treated.  
11 A. Yes.  
12 Q. And you were given tea and sandwiches and looked  
13 after?  
14 A. They actually gave us a room for myself and the two  
15 boys. Daniel was obviously -- they were taking care  
16 of Daniel on the ward. Then eventually got the boys  
17 sorted and they fell asleep and I went outside.  
18 I just couldn't believe what was happening. How had  
19 I got there. I don't really remember how I got there.  
20 I don't remember any of it properly. I just couldn't  
21 believe what had gone on and I knew then that  
22 Pendlebury was lying and they knew everything what was  
23 going on.  
24 It is just -- you can't believe that people who  
25 you believe in would lie to you like that. Anyway,

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1 Daniel", because I was out of their catchment area.  
2 So he kept Daniel and he said, "I will bombard  
3 him with everything I have got. I have got other  
4 children in the clinic that are at the same stage as  
5 Daniel and some of them had actually gone into  
6 remittance and they are still here, thank God, but  
7 unfortunately we have lost a couple, but I will do the  
8 best I can to help you and to help Daniel", so I said,  
9 "Right", so that's where we stayed, really.  
10 Q. You don't have a complete set of Daniel's records but  
11 the records that you do have show that at Newcastle  
12 the HIV test was undertaken on 11 September 1985?  
13 A. Yes.  
14 Q. So that's when [redacted] communicated the diagnosis  
15 to you?  
16 A. Yes.  
17 Q. [redacted] also told you about the rest of the family  
18 needing to be tested?  
19 A. Yes. We was all tested. My husband was away. He was  
20 a farmer, so he used to work away. So he was away at  
21 the time and then when he came back, he had to go up  
22 to Newcastle and be tested and we was all okay.  
23 Q. You said in your statement, Maggie, that when you were  
24 having this discussion with [redacted] and asking if  
25 there was anything could be done or Daniel could be

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1 the next morning I was woke up by the tea trolleys and  
2 everything and I went on Daniel's ward. I got the  
3 boys ready, got the boys ready and we went on the ward  
4 to Daniel and he looked rosier and he was sat up in  
5 bed. Maureen came up and she said, "[redacted] wants  
6 to speak to you now. Do you want to go to the  
7 office". I said, "Yeah". I took the boys. I said to  
8 you Daniel, "See you later, alligator", that's what he  
9 used to say and went down to the office. Maureen took  
10 the two boys and I went in with [redacted].  
11 Q. And [redacted] is [redacted], the Haemophilia Centre  
12 Director there?  
13 A. Yes. He sat down at the side of me and said, "We have  
14 done lots of tests on Daniel while we have had him  
15 these few hours, plus Middlesbrough have done the  
16 same. He said, "I hate to tell you this but what you  
17 think is actually right and he had immune deficiency  
18 syndrome". I am like, "What's that?" He explained it  
19 to me and I said -- he said, "But he could die within  
20 the next six weeks".  
21 I'm like, "How can this be happening when all  
22 I have done is trusted the National Health Service and  
23 the government or whatever, anybody, for it to be  
24 happening to my son", and he said, "Really, you will  
25 have to pretend you are on holiday so I can treat

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1 cured you were screaming saying, "I have killed my  
2 son"?  
3 A. I have killed my son. I was the one that was  
4 injecting him and I was thinking about my mum and our  
5 Ronald. That's what it feels like if you are  
6 injecting somebody with something that's a killer,  
7 then it is your fault and I still feel like that  
8 today. There's nothing I can say more about that,  
9 because that's how I feel.  
10 Q. You made arrangements to stay with a friend in the  
11 local area.  
12 A. I did.  
13 Q. So that Daniel could continue to be under the care of  
14 Newcastle because you didn't want him going back to  
15 Pendlebury?  
16 A. No, never. We went up and down from Darlington to  
17 Newcastle every day and the hospital helped me out,  
18 backwards and forwards, you know, staying at my  
19 friend's.  
20 Q. The point in time came when you decided to rent  
21 somewhere. You saved some money to rent. You found  
22 a farmhouse in a secluded area?  
23 A. Yes, I did. I found this ad in the paper for the  
24 farmhouse to let. So I thought, "Well, we'll be safe  
25 there", like you do, so I rented the farmhouse and we

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1 was there something like five or six months and I got  
 2 a letter off the farmer and he said he would like us  
 3 to vacate immediately because your son could  
 4 contaminate my 2,000 chickens -- turkeys, and the only  
 5 people who knew anything about Daniel or his status  
 6 was the Social Security and the Social Services,  
 7 nobody else and there were nobody for miles. It is  
 8 not as if they were going to shout it from the tree  
 9 tops. They were the only people who knew anything.  
 10 Q. It was just as you moved into the farmhouse that you  
 11 finally told Daniel.  
 12 A. I went for a walk through a field full of daffodils,  
 13 picking them. He was helping me to pick them. I sat  
 14 down with him and I explained to him that he couldn't  
 15 allow anyone to help him to give him the injection,  
 16 only me, and if he was given an injection or he had  
 17 a bleed or fell over and cut himself he couldn't let  
 18 anybody anywhere near him because it could make them  
 19 really poorly and he said, "Is that what I am? I am  
 20 really poorly?" I said, "Yes, you are really poorly  
 21 but you are a lot better now than you was". I said,  
 22 "But you might get poorly again", and he just went  
 23 "Oh, right, okay, Mam". What could you say.  
 24 Q. He was 14 then. After you had got the letter from the  
 25 farmer asking you to vacate the property because of

101

1 grovel on the floor to pick the money up.  
 2 Q. And you described it as being treated as though you  
 3 had leprosy?  
 4 A. Yes. I didn't care for me. It was my sons. It was  
 5 more important for them.  
 6 Q. Both your other sons have given statements to the  
 7 Inquiry and I am going to just read a passage from one  
 8 of their statements, which talks from their  
 9 perspective about the treatment that you were all  
 10 receiving at that time?  
 11 A. Yes.  
 12 Q. He says this:  
 13 "There was an enormous stigma surrounding HIV at  
 14 the time of Daniel's diagnosis which affected the  
 15 whole family. I began to notice that everyone was  
 16 avoiding Daniel and the whole family. Parents would  
 17 not allow their children to mix with us. I used to  
 18 feel like people were always looking at me and talking  
 19 behind my back, even the teachers at school treated me  
 20 completely differently. At its worst, the stigma was  
 21 so bad that my parents' properties were actually  
 22 vandalised and we were subjected to outright  
 23 harassment. We had red crosses painted on our front  
 24 door on numerous occasions. On another our windows  
 25 were smashed during the night, waking us all up. We

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1 Daniel's condition your car was vandalised?  
 2 A. Yes.  
 3 Q. Your tyres were slashed?  
 4 A. Yes. It was daubed all over my car.  
 5 Q. With AIDS?  
 6 A. They smashed my window. We had AIDS written all over  
 7 it and crosses.  
 8 Q. You ended up homeless for a couple of weeks living in  
 9 your car --  
 10 A. Living in my car, yes.  
 11 Q. -- with Daniel. You found somewhere else for about  
 12 three months but what happened there?  
 13 A. They found out again and they daubed the house,  
 14 smashed my car -- put knives in my car wheels and  
 15 threw paint on my car. We had to leave in the middle  
 16 of the night. We had to find somewhere else. That  
 17 happened about four times.  
 18 Q. Four times that happened, and you remember going into  
 19 a shop and that shopkeeper tipping the change into  
 20 your hand from a height so he wouldn't have to touch  
 21 you.  
 22 A. Yes. I had to pick it up off the floor. I had to  
 23 pick it up, because we didn't have any money --  
 24 Q. Sorry, Maggie. Carry on.  
 25 A. It is all right. Every penny counted, so I had to

102

1 have received many nuisance phone calls at random  
 2 times of the day and night. People would also send  
 3 all sorts of the tradesmen to the door."  
 4 A. Undertakers, fire engines.  
 5 Q. Even undertakers. He believed they did this to bother  
 6 you and try to drive you out of the area.  
 7 A. Yes.  
 8 Q. That was treatment you received but also Daniel's  
 9 father who was at that time living in Manchester.  
 10 A. One of my sons had gone back to live with his dad and  
 11 the eldest one stayed with me. So it was obviously  
 12 still going on where we were before.  
 13 Q. Over the next few years how was Daniel's health?  
 14 A. He wasn't too bad actually. He sort of -- well, he  
 15 picked himself up and he wouldn't let anybody give him  
 16 his injections. He used to do it himself, unless he  
 17 had a bad arm and then I would do it or whatever. He  
 18 seemed to be okay and then he ended up being really  
 19 thin and not eating and went back to the RVI and,  
 20 well, they thought he would die. He nearly died on us  
 21 twice and then he got thrush, which stopped him eating  
 22 altogether.  
 23 So from like November to August when he died he  
 24 didn't eat a thing. He just lived on icecubes that  
 25 I made for him with fruit juices and crushed up fruit

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1 to make him have some kind of vitamins to go into his  
 2 system because he couldn't eat. The thrush was that  
 3 bad you could peel it off his tongue. He starved to  
 4 death, sorry.  
 5 **Q.** There is no need at all to apologise, Maggie. If you  
 6 need a break.  
 7 **A.** I'm all right. Go on.  
 8 **Q.** Are you okay?  
 9 **A.** It's all right.  
 10 **Q.** You said how you and he would spend hours talking  
 11 about his illness?  
 12 **A.** Why me? I couldn't answer any questions, because  
 13 I didn't know myself. I don't know where it come  
 14 from, what happened. I don't know who did it. I wish  
 15 to God I did, but I don't know. I didn't know  
 16 anything. I couldn't answer any questions for him,  
 17 but he wasn't scared to die. He knew he was going to  
 18 die. He had nearly died twice. He just knew. His  
 19 last words were, "Get them, ma'am. Get them for what  
 20 they've done".  
 21 **Q.** One point, you and Daniel talked about driving a car  
 22 over a cliff.  
 23 **A.** Over a cliff. We thought that was a damn good idea at  
 24 the time but he never gave me a chance to do that  
 25 because he wouldn't go into hospital until it was the

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1 get Daniel to Manchester was to put him in a wooden  
 2 box and cover him with sawdust and he had to be buried  
 3 in a lead-lined coffin obviously so he couldn't  
 4 contaminate the dead. That's the only thing I could  
 5 think of that for.  
 6 By this time my sons had come up and a couple of  
 7 my friends and my middle son took all the seats out of  
 8 Daniel's car and he slid -- we all slid the coffin in,  
 9 covered him with a table cloth and we drove him all  
 10 the way back to Manchester.  
 11 **Q.** You and Daniel's brothers were determined to carry out  
 12 Daniel's wishes?  
 13 **A.** Yeah, nobody was covering my son in sawdust and  
 14 putting him in a box either. When we got to the other  
 15 end we had to get another undertaker. He thought he  
 16 was coming to the house to see a body. When he saw  
 17 the coffin, he couldn't believe what we had done. He  
 18 just looked at us and it was like astonishment on his  
 19 face. We explained the situation and he just took  
 20 over from there and he was lovely.  
 21 **Q.** It was years after Daniel's death that you discovered  
 22 that he had also been infected with hepatitis C?  
 23 **A.** I got a phone call from the RVI in Newcastle, because  
 24 I had moved on by then, and they told me there was  
 25 a form I had to fill in for -- I have forgot now --

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1 last few hours.  
 2 **Q.** He was in and out of hospital?  
 3 **A.** He went in on the night-time and he was dead by 5.50  
 4 the next morning, because he didn't -- he didn't want  
 5 to go to the last minute. That's what he did. I got  
 6 to him to the hospital and I couldn't even carry him  
 7 out of the car and he was so thin. He was 6'1". He  
 8 weighed 6 stone and a chap came out of the hospital  
 9 and he picked him up like he was a doll and carried  
 10 him in for me, because I couldn't carry him.  
 11 I couldn't pick him up, because it was killing me.  
 12 **Q.** That was 19 August 1992 that Daniel died.  
 13 **A.** Yes.  
 14 **Q.** 20 years old?  
 15 **A.** He would have been 21 in the September.  
 16 **Q.** What happened in terms of the arrangements for  
 17 Daniel's funeral?  
 18 **A.** Do you really want me to tell that?  
 19 **Q.** It is entirely up to you. It is in your statement and  
 20 your son's. Only if you want to, Maggie.  
 21 **A.** Well, got him back to the house where we lived in  
 22 Stockton and the funeral directors did it for us.  
 23 They picked him up from the hospital, brought him  
 24 back. Daniel's wish was to be buried in Manchester  
 25 where he came from. They said the only way they could

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1 a payment.  
 2 **Q.** For the Skipton Fund?  
 3 **A.** That's it, the Skipton Fund, but they had filled most  
 4 of it in for me and all I had to do was add a little  
 5 bit on the bottom and sign it and I sent it back to  
 6 them and got a payment off the Skipton Fund and  
 7 I shared it between my boys. I shared it between my  
 8 boys. That was it.  
 9 **Q.** You mentioned in your statement involvement in some  
 10 form of litigation and having to sign something and in  
 11 your statement you put you thought you had to sign the  
 12 Official Secrets Act?  
 13 **A.** Yeah, but now I realise it is not the Secrets Act.  
 14 **Q.** I think it may have been a waiver to do with the  
 15 litigation?  
 16 **A.** You can't tell anybody anything. You can't talk about  
 17 it and at the -- while Daniel was alive I was doing  
 18 an innocent victims campaign and I had to stop doing  
 19 that or else nobody could get a payment. You could  
 20 not get a payment off anybody if you didn't sign this  
 21 waiver and every haemophiliac must know we all had to  
 22 sign it and say nothing.  
 23 **Q.** We have mentioned your cousin, Ronald.  
 24 **A.** Yes. I grew up with Ronald. He was like my brother  
 25 and he died -- he was a haemophiliac and he died of

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1 AIDS and hep C as well.  
 2 Q. That was in 1994, March 1994, I think.  
 3 A. Was it '94. Yes. This is his sister. Nobody knew he  
 4 had hep C either until after his death, no more than  
 5 I knew Daniel had hep C until after his death, so he  
 6 must have had all these things anyway.  
 7 Q. Now, we mentioned your mother being a haemophiliac and  
 8 she herself had received factor treatments.  
 9 A. Yes.  
 10 Q. Your understanding is she was under the care of  
 11 Manchester Royal Infirmary.  
 12 A. All her life.  
 13 Q. She received Factor VIII there.  
 14 A. Yes.  
 15 Q. And she was infected with hepatitis C --  
 16 A. Yes.  
 17 Q. -- in consequence of her treatment.  
 18 What do you know about the circumstances in  
 19 which she found that out?  
 20 A. Well, I phoned her from the RVI to tell her, I think  
 21 it was when Danny had his knee done. I can't  
 22 remember. I phoned her anyway to tell her Daniel was  
 23 okay. She said, "They have told me I have something  
 24 in my blood". I said, "What do you mean you have got  
 25 something in my blood?"

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1 on for, what, about a year or something, didn't it?  
 2 Then I took her to a routine appointment and this  
 3 doctor -- can I mention his name?  
 4 Q. Yes.  
 5 A. Dr Hay at Manchester Royal Infirmary, he also told us  
 6 she had been in contact with variant CJD. I asked him  
 7 about the status of hep C and how long she had had it.  
 8 He said, "It is nothing to do with you". In other  
 9 words, mind your own business. I said, "My Mam can't  
 10 tell". They knew my mum since she was little. They  
 11 knew she couldn't read or write because she never went  
 12 to school so how could she tell me anything other than  
 13 this woman had told her. He just dismissed it  
 14 completely, didn't want to talk about it, and didn't  
 15 want to talk about variant CJD. He just said, "There  
 16 might be, you know, an infection from this Factor  
 17 VIII".  
 18 Q. Now, your mother's health deteriorated.  
 19 A. Fast.  
 20 Q. She was in a nursing home towards the end because you  
 21 yourself had serious health problems at the time.  
 22 A. I had organ failure, yes. She was living with me at  
 23 the time, my mother. She had to go into a nursing  
 24 home. When she went into the nursing home, she was  
 25 vicious, violent. If I went to visit, she would be

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1 "I don't know. I have got something in my blood  
 2 but I don't know what it is." I said, "Okay then. We  
 3 will talk" -- I was in the office of the haemophilia  
 4 centre. I said, "Okay. I'll sort it when I get  
 5 home", like you do. So she said, "Okay".  
 6 Anyway, when Daniel died and I went back home,  
 7 I obviously took up the treatment of looking after my  
 8 mum again and obviously our Ronald was still alive, so  
 9 I was helping him as well. A friend of hers had come  
 10 to visit her that she knew from the RVI and she was  
 11 telling my mum all what she had, that she had this hep  
 12 C and it was contagious and other people could get it  
 13 and different things like that and my mum, she just  
 14 lost it. It just changed her completely. She  
 15 wouldn't let people in her flat. She wouldn't talk to  
 16 anybody. She just changed completely into something  
 17 like a -- I don't know. She was like a mad woman,  
 18 wasn't she. She was just like a mad woman, because  
 19 she thought that everybody didn't like her and  
 20 everybody was frightened of her. This was in her  
 21 mind. Nobody really knew anything, but the way my Mam  
 22 were dealing with it, like I said, she wouldn't let  
 23 anybody in the house or anything.  
 24 Q. She had been a strong independent lady before?  
 25 A. Very, very much so, and very much a lady. This went

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1 pulling my hair. She would be fighting me, but she  
 2 was doing this before I took poorly, because she  
 3 didn't know who I was. She had this weird idea that  
 4 everybody was going to kill her. She went funny,  
 5 didn't she, bless her. Bless her, wanted to kill her  
 6 at the time really.  
 7 When she was in the nursing home, she stopped  
 8 eating and got very thin and very frail. Then I got  
 9 this -- I will just have a drink -- I got this phone  
 10 call off the nursing home asking me -- telling me that  
 11 my mum had took to her bed and she wouldn't get out of  
 12 her bed and she wouldn't eat or anything, so I wasn't  
 13 fit enough to drive then, so I got a taxi to the home  
 14 to see my mum and she was just like a withered old  
 15 lady. She was yellow. Her eyes was like sunk in her  
 16 head and I said, "I will take her to Manchester Royal  
 17 Infirmary".  
 18 So I ordered another taxi and I got her in  
 19 a wheelchair and I put her in the taxi and I took her  
 20 to Manchester Royal Infirmary. To the Haemophilia --  
 21 well, it wasn't a centre then. It was just the blood  
 22 bank where they used to go in them days.  
 23 They told me there and then that she was dying  
 24 of cirrhosis of the liver and it wouldn't be very long  
 25 before she died, so I went back to the nursing home

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1 and I explained it to Margaret, who owned the nursing  
 2 home. Lovely lady, she was brilliant with my mum.  
 3 Then I went back home and then about two or three days  
 4 later I got this phone call that they had had to  
 5 take her to Crumpsall Hospital in Manchester, because  
 6 that was the nearest hospital, and she died there.  
 7 **Q.** And that was December 2005?  
 8 **A.** Yes.  
 9 **Q.** One of the documents that you have given to the  
 10 Inquiry about your mum is a letter from one of the  
 11 doctors that says that the hepatitis C wasn't  
 12 a contributory cause of her death.  
 13 **A.** Uh-huh.  
 14 **Q.** Do you think that's right?  
 15 **A.** No, I don't.  
 16 **Q.** Why do you think that?  
 17 **A.** Because they told me at Manchester Royal exactly what  
 18 she had, which was -- this was just -- what do you  
 19 call it when they have got hep C and it goes further  
 20 along. This was just what happened.  
 21 **Q.** Cirrhosis, is the word you have used in your  
 22 statement.  
 23 **A.** Cirrhosis, yeah, but there was no medical records of  
 24 that. In fact, there is no medical records of my mum  
 25 as far as I know, because they burnt them all, because

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1 people who has tried and where has it ever got us?  
 2 Nowhere. We actually have faith in all of you and  
 3 I hope to God that we are all still here to find out  
 4 what has happened.  
 5 **MS RICHARDS:** I am just going to ask Mr Snowden if there  
 6 are any questions he has. No, thank you.  
 7 Sir?  
 8 **SIR BRIAN LANGSTAFF:** I have no questions either, but I do  
 9 have some thanks for you for coming to tell us about  
 10 your son and your cousin and your mother.  
 11 **A.** Thank you.  
 12 **SIR BRIAN LANGSTAFF:** Thank you very much.  
 13 **A.** Thank you. Thank you, all.  
 14 **SIR BRIAN LANGSTAFF:** We'll take a break until 3 o'clock,  
 15 when I think we are due to hear from Megan and Robert.  
 16 **MS RICHARDS:** That's right, sir.  
 17 **SIR BRIAN LANGSTAFF:** 3 o'clock.  
 18 (2.33 pm)  
 19 (A short break)  
 20 (3.01 pm)  
 21 **SIR BRIAN LANGSTAFF:** So we have Megan and Robert.  
 22 **MS RICHARDS:** Yes, sir.  
 23 **SIR BRIAN LANGSTAFF:** Please.  
 24 **LAURA MEGAN RYAN and ROBERT DEREK RYAN, affirmed**  
 25 **Questioned by MS RICHARDS**

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1 I have tried, tried and better tried and not been able  
 2 to get any.  
 3 The only thing I managed to get hold of was what  
 4 the nursing home actually kept for me. On the nursing  
 5 home document the doctor that took care of my mum, it  
 6 is all crossed out as to what was wrong with my mum.  
 7 It is in most medical records, they are all crossed  
 8 out, so that was what happened with my mum.  
 9 **Q.** Maggie, is there anything you'd like to say about how  
 10 the experiences you have described, the death of  
 11 Daniel, your cousin, your mum and all your care and  
 12 responsibilities impacted on you and your family?  
 13 **A.** It shouldn't have happened. Why did it happen? We  
 14 all want to know why? Why? What happened? Was it --  
 15 did they do it for the money, because that's the only  
 16 thing I can think of. They must have been getting  
 17 backhanders from somebody. I am sorry, but what else  
 18 would you -- they have committed mass murder and  
 19 I think it should be treated like the Nuremberg trials  
 20 and I think they should all be put away. I am sorry,  
 21 but I do.  
 22 **Q.** Is there anything else you'd like to say, Maggie?  
 23 **A.** Yeah, I would like to say thank you to every one of  
 24 you, everybody that has been helping us and standing  
 25 beside us for justice, because we have had so many

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1 **MS RICHARDS:** Megan, I am going to start with some  
 2 questions for you and then for your son Robert.  
 3 **MEGAN:** Yes.  
 4 **MS RICHARDS:** In about October 1979 you moved to Germany.  
 5 You are going to have to forgive my German  
 6 pronunciation of the names. You moved to a place  
 7 called Soest?  
 8 **MEGAN:** Soest.  
 9 **MS RICHARDS:** You met Chris who was in the army and you  
 10 got married and in 1981 you found out you were  
 11 pregnant.  
 12 **MEGAN:** Yes.  
 13 **MS RICHARDS:** But you started losing weight in the  
 14 pregnancy?  
 15 **MEGAN:** Mm-hm.  
 16 **MS RICHARDS:** It was discovered you had anaemia?  
 17 **MEGAN:** Mm-hm.  
 18 **MS RICHARDS:** You went to one of the military hospitals in  
 19 June of that year?  
 20 **MEGAN:** Yes.  
 21 **MS RICHARDS:** You were given plasma?  
 22 **MEGAN:** Yes.  
 23 **MS RICHARDS:** But your haemoglobin levels remained low?  
 24 **MEGAN:** Yes.  
 25 **MS RICHARDS:** You were admitted to the same British

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1 military hospital for a blood transfusion?  
 2 **MEGAN:** Yes.  
 3 **MS RICHARDS:** What can you remember about that?  
 4 **MEGAN:** I remember it being on 29 July 1981, because it  
 5 was the day Diana and Charles got married and I was in  
 6 a bed on my own while everybody was celebrating,  
 7 tripped up at the other end. I was given four pints  
 8 of blood.  
 9 **MS RICHARDS:** You were given four pints of blood. You  
 10 were in a British military hospital but in Germany.  
 11 **MEGAN:** Yes.  
 12 **MS RICHARDS:** You don't know what the source of that blood  
 13 was?  
 14 **MEGAN:** No.  
 15 **MS RICHARDS:** Whether it was brought to the British  
 16 hospital from the United Kingdom or sourced locally in  
 17 Germany?  
 18 **MEGAN:** No, no idea.  
 19 **MS RICHARDS:** That transfusion was effective for a while  
 20 in maintaining your haemoglobin levels but they  
 21 reduced down again?  
 22 **MEGAN:** Yes.  
 23 **MS RICHARDS:** So you were re-admitted in September for  
 24 another couple of weeks to the same British military  
 25 hospital and you received more four pints of blood?

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1 the hospital.  
 2 **MS RICHARDS:** So they did tests on you back at the  
 3 hospital. What did they tell you have?  
 4 **MEGAN:** I had got hepatitis B.  
 5 **MS RICHARDS:** So hepatitis B and they intimated you had  
 6 probably been infected through the blood  
 7 transfusions --  
 8 **MEGAN:** Yes.  
 9 **MS RICHARDS:** -- that you had received, probably the  
 10 July 1981 transfusion.  
 11 **MEGAN:** Yes. They said it was a six-month incubation  
 12 period so probably that one.  
 13 **MS RICHARDS:** What treatment did you receive in the  
 14 hospital?  
 15 **MEGAN:** Multivitamins. That was it.  
 16 **MS RICHARDS:** You said in your statement the doctors told  
 17 you there was nothing else they could do. They seemed  
 18 to think the infection would cure itself?  
 19 **MEGAN:** Yes, yes.  
 20 **MS RICHARDS:** Robert was a very young baby. He was in the  
 21 hospital with you. You have a recollection of some  
 22 doctors standing around the bed. What can you tell us  
 23 about that?  
 24 **MEGAN:** Yes. Robert was about two weeks old. I was laid  
 25 in bed and he was in my arms. Three doctors stood at

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1 **MEGAN:** Yes.  
 2 **MS RICHARDS:** You gave birth to Robert?  
 3 **MEGAN:** Mm-hm.  
 4 **MS RICHARDS:** In [redacted] 1981?  
 5 **MEGAN:** Yes.  
 6 **MS RICHARDS:** Again, in a British military hospital, this  
 7 one Rinteln?  
 8 **MEGAN:** Rinteln. We'd moved by then.  
 9 **MS RICHARDS:** You had a further blood transfusion a couple  
 10 of days after Robert's birth?  
 11 **MEGAN:** Yes.  
 12 **MS RICHARDS:** You were discharged back to where you were  
 13 living?  
 14 **MEGAN:** Uh-huh.  
 15 **MS RICHARDS:** How did you start to feel in the days after  
 16 that?  
 17 **MEGAN:** Extremely tired. I just put that down to being  
 18 a new mum. Then I started itching in my feet and my  
 19 legs. I didn't really put much thought to it. I was  
 20 just really, really tired and then one of the SSAFA  
 21 sisters came to visit me. She looked at me and she  
 22 said, "You are yellow and your eyes are brown", which  
 23 I had noticed they were. I said, "I have got a new  
 24 baby. I am not sleeping". She looked and she said,  
 25 "You are yellow", and two hours later I was back in

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1 the end of my bed discussing me, not talking to me,  
 2 just discussing me, but I remember one saying very  
 3 clearly, "What about the baby? Shall we take the baby  
 4 off her?" Naturally as a new mum I thought, "Nobody  
 5 is having my baby", and the second one said, "Do we  
 6 need to test him?" and the third one, who was older  
 7 and I have a very clear picture of him down to the  
 8 colour of his hair and everything, said "No. She is  
 9 breast feeding. He will be fine".  
 10 **MS RICHARDS:** You were discharged from the hospital --  
 11 **MEGAN:** Yes.  
 12 **MS RICHARDS:** -- not long after that and your symptoms did  
 13 indeed disappear.  
 14 **MEGAN:** Yes.  
 15 **MS RICHARDS:** You were no longer yellow. You were no  
 16 longer itchy?  
 17 **MEGAN:** Yes.  
 18 **MS RICHARDS:** You don't recall being given any information  
 19 at the hospital about any risks of transmission?  
 20 **MEGAN:** No, nothing at all, no.  
 21 **MS RICHARDS:** And about 12 months later you went back to  
 22 the British Military Hospital. You were tested and  
 23 you were told you had cleared the infection?  
 24 **MEGAN:** Yes.  
 25 **MS RICHARDS:** Then you thought no more of it for many

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1 years?

2 **MEGAN:** Yes. Can I just add there because --

3 **MS RICHARDS:** Of course, you can.

4 **MEGAN:** -- because I had forgotten. I spoke to my

5 [redacted] this morning. I need to mention that he

6 was tested at the time and he was clear because they

7 wanted to make sure it hadn't come from him. He was

8 clear. There was no sign of infection with him.

9 **MS RICHARDS:** You returned to the UK at the end of 1985.

10 **MEGAN:** Yes.

11 **MS RICHARDS:** Robert was about 4?

12 **MEGAN:** Mm-hm.

13 **MS RICHARDS:** You and your husband separated that point?

14 **MEGAN:** Yes, yes.

15 **MS RICHARDS:** But it was a number of years later, in about

16 2000, you saw a new GP at your GP practice. Can you

17 tell us what happened.

18 **MEGAN:** Yes. I went in to see the GP about something.

19 I forget what. He looked through my notes and said,

20 "Oh, I see you have had hepatitis B. what is the

21 status there?" I just said, "As far as I am aware

22 I am clear of that". He said, "What about your son?"

23 I said, "Oh, I don't know".

24 Whilst I was in the room he phoned up the

25 infectious diseases people and the man on the phone

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1 **MS RICHARDS:** But you received this message. What do you

2 recall about that?

3 **ROBERT:** Basically just got told to go see my GP and get

4 tested for hepatitis B, which I did, and that turned

5 out to be positive. It was a chronic infection.

6 **MS RICHARDS:** You were told by your GP chronically

7 infected with hepatitis B?

8 **ROBERT:** Yes.

9 **MS RICHARDS:** And you were referred to a specialist or

10 consultant at Middlesbrough General Hospital?

11 **ROBERT:** Yes.

12 **MS RICHARDS:** And what did he tell you was the likely

13 cause of your infection?

14 **ROBERT:** Passed on from my mother through the blood

15 transfusion that she had.

16 **MS RICHARDS:** And he suggested to you that it was likely

17 you had been infected since birth?

18 **ROBERT:** Yes.

19 **MS RICHARDS:** And there were no other reasons why he could

20 see you would have contracted hepatitis B?

21 **ROBERT:** No.

22 **MS RICHARDS:** Can you recall what information or advice

23 you were given about the hepatitis B at the time?

24 **ROBERT:** Very little. I was informed about the risk of

25 bleeding and people contracting it and the sexual

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1 spoke to me and then he was put back on to the GP and

2 he said he recommended that I get my son -- told my

3 son to get tested.

4 **MS RICHARDS:** And other than that conversation, the three

5 doctors at the end of the bed in the British Military

6 Hospital when you were there back in 1981, Robert was

7 now 1 years old --

8 **MEGAN:** Mm-hm.

9 **MS RICHARDS:** -- and this was the first time anyone had

10 suggested to you that Robert might need to be tested?

11 **MEGAN:** Yes, yes.

12 **MS RICHARDS:** So you called Robert --

13 **MEGAN:** Yes.

14 **MS RICHARDS:** -- and passed on the message?

15 **MEGAN:** Well, my ex-husband, because Robert was living

16 with Chris then. I phoned him and he passed it on to

17 Robert, yes.

18 **MS RICHARDS:** So, Robert, turning to you --

19 **ROBERT:** Mm-hm.

20 **MS RICHARDS:** At that point in time you were unaware of

21 any health issues?

22 **ROBERT:** Yes, completely.

23 **MS RICHARDS:** You had grown up healthy and strong, as far

24 as you were concerned.

25 **ROBERT:** Yes.

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1 issue of passing it on. I was made aware current

2 partners would have to be tested or immunised and

3 children likely the same.

4 **MS RICHARDS:** You have said in your statement that the

5 doctors bombarded you with technical terms that you

6 didn't really understand.

7 **ROBERT:** Yes, all these numbers and three letter acronyms

8 that I didn't have a clue.

9 **MS RICHARDS:** You were told about how others could

10 contract the virus but you weren't given any advice

11 about the psychological or emotional impact of the

12 infection.

13 **ROBERT:** Yes.

14 **MS RICHARDS:** You think you should have been given more

15 information, if not counselling, to help you process

16 the diagnosis?

17 **ROBERT:** Yes.

18 **MS RICHARDS:** Now you had a liver biopsy soon after that.

19 **ROBERT:** Three in total.

20 **MS RICHARDS:** What can you tell us about those.

21 **ROBERT:** They hurt. It is basically a great big needle.

22 They numb the area, ram it -- it's about that long

23 (indicated) -- straight into your side, a little bit

24 of your liver out and do some tests on it.

25 **MS RICHARDS:** You were advised to take some treatment.

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1 **ROBERT:** Yes, I was.  
 2 **MS RICHARDS:** Interferon alfa for three months to try and  
 3 reduce the viral load?  
 4 **ROBERT:** Actually six, as I spoke to my father, yeah, six  
 5 months.  
 6 **MS RICHARDS:** What can you recall about that treatment?  
 7 What does it entail?  
 8 **ROBERT:** Self administration kind of an Epipen style  
 9 straight into your stomach. The side effects of that  
 10 are absolutely awful. I wouldn't wish it on anyone to  
 11 be brutally honest. It is like having the flu  
 12 constantly every other day for six months.  
 13 **MS RICHARDS:** You said you would be red hot but feel  
 14 freezing cold.  
 15 **ROBERT:** Yes.  
 16 **MS RICHARDS:** The day after the injection you could hardly  
 17 function and you'd end up sleeping for most of the  
 18 day.  
 19 **ROBERT:** I was recommended to take it at night to try and  
 20 sleep through the effects of it. That didn't work.  
 21 It kept me awake all night. I had to keep having red  
 22 hot baths in the middle of the night because I was so  
 23 cold.  
 24 **MS RICHARDS:** You had been told there is about a 50/50  
 25 chance of the treatment succeeding and clearing the

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1 I didn't really let it go. I obviously had to inform  
 2 people who I needed to inform at work and family and  
 3 partners, but apart from that I didn't really tell  
 4 anyone.  
 5 **MS RICHARDS:** Around the time that you found out your  
 6 diagnosis you had been applying to the Royal Air  
 7 Force?  
 8 **ROBERT:** Yes.  
 9 **MS RICHARDS:** What happened with that application?  
 10 **ROBERT:** It was declined because they found out I had  
 11 hepatitis.  
 12 **MS RICHARDS:** You actually got through I think to quite  
 13 a late stage of the process, the recruitment process?  
 14 **ROBERT:** Yes.  
 15 **MS RICHARDS:** And that was the reason that was given to  
 16 you?  
 17 **ROBERT:** Yes.  
 18 **MS RICHARDS:** It was the hepatitis B?  
 19 **ROBERT:** I actually aced the pilot test and got to the  
 20 medical and that's when they refused me.  
 21 **MEGAN:** I went with him to get the results. He had come  
 22 top of the class in everything. I waited outside,  
 23 wandered round town while he got the results. He came  
 24 out. He was devastated, absolutely devastated.  
 25 **MS RICHARDS:** You put it in what I understand from you and

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1 virus.  
 2 **ROBERT:** Yes.  
 3 **MS RICHARDS:** Did it succeed?  
 4 **ROBERT:** No.  
 5 **MS RICHARDS:** What other treatments were available to you?  
 6 **ROBERT:** None, none at all.  
 7 **MS RICHARDS:** What, if any, advice were you given about  
 8 prognosis?  
 9 **ROBERT:** I kind -- when I was first diagnosed I kind of  
 10 went off the rails a bit, started drinking very  
 11 heavily for quite a number of years, as it turns out.  
 12 I didn't think it was years but it turns out people  
 13 have told me otherwise.  
 14 **MS RICHARDS:** As I understand it, Robert, you feel it was  
 15 a few months, but your mum says it was years?  
 16 **ROBERT:** Yes, yes. I went back to see my consultant and  
 17 he said to me, "If you carry on, you will be dead at  
 18 40".  
 19 **MS RICHARDS:** Did you at that point heed the advice in  
 20 relation to alcohol?  
 21 **ROBERT:** It dropped considerably but it didn't stop  
 22 altogether.  
 23 **MS RICHARDS:** How did you feel about the diagnosis and  
 24 telling people about it?  
 25 **ROBERT:** Kind of quite stubborn. Kept things to myself.

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1 your mum is typically understated terms. You said it  
 2 was a huge disappointment to you.  
 3 **ROBERT:** Yes.  
 4 **MS RICHARDS:** And has probably been one of the most  
 5 significant consequences of the infection?  
 6 **ROBERT:** Yes, because all my family have been in the  
 7 forces and it is what I wanted to do. Father and  
 8 grandfather, army; uncles, navy; I wanted to go in the  
 9 RAF.  
 10 **MS RICHARDS:** Have you since that time, and since the  
 11 initial treatment failed, have you been having regular  
 12 follow ups, regular appointments?  
 13 **ROBERT:** I have been seeing them but not regularly, down  
 14 to my own fault, getting married, having children,  
 15 moving house a few times, lost contact with my  
 16 original consultant. I've started seeing a new one,  
 17 but father-in-law died and I moved house again.  
 18 Basically life got in the way.  
 19 **MS RICHARDS:** 2015 you saw a new consultant, who told you  
 20 that your medical records relating to when you had  
 21 seen the first consultant had been lost?  
 22 **ROBERT:** Yes.  
 23 **MS RICHARDS:** That consultant suggested a new treatment.  
 24 You read up on the side effects and what did you  
 25 decide?

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1 **ROBERT:** Not to take it, because the side effects -- one  
 2 of side effects was damage to the liver and hepatitis  
 3 B is damage to the liver, so I didn't see the point in  
 4 hurting myself anymore to be honest.  
 5 **MS RICHARDS:** You said at the time of your statement that  
 6 your most recent blood test was a couple of years ago  
 7 and it showed fluctuating viral load?  
 8 **ROBERT:** Yes.  
 9 **MS RICHARDS:** Is that still, as far as you are aware, the  
 10 position?  
 11 **ROBERT:** That's still the last and the current one that  
 12 I have.  
 13 **MS RICHARDS:** You have not, as I understand it from your  
 14 statement, Robert, experienced particular physical  
 15 symptoms from the hepatitis?  
 16 **ROBERT:** No.  
 17 **MS RICHARDS:** The treatment caused you the side effects  
 18 you have described?  
 19 **ROBERT:** Yes.  
 20 **MS RICHARDS:** But for you it is the potential knowledge of  
 21 long-term damage to your liver and shortened life  
 22 expectancy that has played on your mind?  
 23 **ROBERT:** Yes. I am quite a stubborn person. I keep  
 24 things to myself and I don't show things very often,  
 25 but it has been made clear to me it has affected me in

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1 He has this last couple of years pinked up and  
 2 put a bit of weight on. People might not think he is  
 3 thin, but you should have seen him before. Hopefully  
 4 there is maybe a bit of a corner. I spoke to Robert's  
 5 consultant when he was going through the tests.  
 6 I used to come up and sit with him while he had to lie  
 7 flat in a bed for 24 hours. He didn't like that.  
 8 **ROBERT:** Yes.  
 9 **MEGAN:** And asked his consultant what the diagnosis was --  
 10 what the prognosis was and he said he couldn't say  
 11 much because of patient confidentiality, but he did  
 12 say if he didn't drink he had got 30 to 40 years but  
 13 if he did drink he had got 20 to 30 years. So you can  
 14 imagine how I felt watching him drink for 12 years  
 15 knowing that he is shortening his life -- awful.  
 16 **MS RICHARDS:** But even the prognosis with not drinking was  
 17 still --  
 18 **MEGAN:** Still, yes.  
 19 **MS RICHARDS:** -- a significantly shorter life expectancy.  
 20 **MEGAN:** So you would have been talking 50 to 60.  
 21 **MS RICHARDS:** It is the understanding of both of you that  
 22 the hepatitis B may have caused or be causing ongoing  
 23 damage to Robert's liver and you have said in your  
 24 statement, Robert, you have been told that there might  
 25 come a point where you will need a liver transplant.

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1 ways that I haven't realised. Hence why my mother has  
 2 had to give up her life and career down in Stoke and  
 3 move up here to stay with me because she thought a few  
 4 years ago I was close to death.  
 5 **MS RICHARDS:** Megan, what's your take on how it has  
 6 impacted, first of all, on Robert?  
 7 **MEGAN:** I think from how he was from a teenager to how  
 8 after the diagnosis, how deep he's gone in himself, he  
 9 is very quiet and doesn't speak. His wife along the  
 10 years has spoke to me and has been worried because he  
 11 doesn't even speak to his wife about it, so I have  
 12 seen that change in him, though he doesn't realise it,  
 13 but I have, and he said it doesn't affect his health  
 14 probably because he doesn't know any different, but  
 15 five years ago when I came up to visit at Christmas he  
 16 was grey. His colour was grey and his wife took me to  
 17 one side and said, "I am really, really worried about  
 18 him, Megan". I said "I can see that".  
 19 I took him out for a drink and had a chat with  
 20 him and said -- sort of gave him a bit of a mother's  
 21 nagging. "You need to do something about this. You  
 22 have got children and everything", and made the  
 23 decision to sell up, leave a good job and to come and  
 24 live closer to him because I thought, as he just said,  
 25 I thought he was dying. He looked that bad.

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1 **ROBERT:** Yes, I have been told that, yes.  
 2 **MS RICHARDS:** Robert, you have never received any  
 3 financial assistance from any trust or scheme?  
 4 **ROBERT:** No.  
 5 **MS RICHARDS:** You read an article once and did a bit of  
 6 research on the Skipton Fund, but found out that it  
 7 wasn't concerned with hepatitis B.  
 8 **ROBERT:** No, it is only hepatitis B that applied -- C.  
 9 **MEGAN:** C and HIV.  
 10 **MS RICHARDS:** You did phone an NHS helpline and you asked  
 11 if there was any help for those infected with  
 12 hepatitis B through blood and what was the response?  
 13 **ROBERT:** No.  
 14 **MS RICHARDS:** Megan, what has been the impact been on you  
 15 in your life. You cleared the virus, but then  
 16 18 years later discovered that your son had been  
 17 infected.  
 18 **MEGAN:** It was very hard when I first heard about it,  
 19 because knowing that your child will die before you is  
 20 not good. It is not what any parent wants to hear.  
 21 We are very lucky he is still with us and hopefully he  
 22 is for a long time to come. Sorry.  
 23 **MS RICHARDS:** It is all right. You said you blamed  
 24 yourself for long time.  
 25 **MEGAN:** Yes, I did, yes.

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1 **MS RICHARDS:** And you took a number of life decisions --  
 2 you have touched on them -- in order to live close to  
 3 Robert --  
 4 **MEGAN:** Yes.  
 5 **MS RICHARDS:** -- and his children so you could be there,  
 6 maybe continue to remind him.  
 7 **MEGAN:** Yes, to help out because the children are a lot  
 8 younger, obviously. They still are young. They are  
 9 still in primary school. To be there for him. Yes,  
 10 I'd gave up a good job as manageress of a shop.  
 11 I owned my own house, was saving for my retirement.  
 12 I gave all of that up to move to a place I didn't know  
 13 and now live on universal credit. Can't get a job  
 14 because of my age and my health reasons, my own health  
 15 reasons not connected to this, and I am absolutely  
 16 a pauper. I have to go to food banks to live. I have  
 17 got nothing. So I have done all that because of this  
 18 illness to be closer to my family to help out and,  
 19 like I said, I thought this was the beginning of the  
 20 end five years ago.  
 21 **MS RICHARDS:** That's exactly what you have said in your  
 22 statement. You were worried, about 15 years after  
 23 Robert's diagnosis, you were worried he was nearing  
 24 that 20 year life span the consultant had mentioned.  
 25 You thought if it was going to be the beginning of the

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1 any -- the kind of counselling and support that might  
 2 have helped him when initially diagnosed.  
 3 Have you ever been offered any counselling or  
 4 support?  
 5 **MEGAN:** Nothing, nothing. In fact, I was treated  
 6 appallingly when I was in hospital, absolutely  
 7 appallingly, shoved to the end of it, a long corridor  
 8 in a room on my own and my food was pushed round the  
 9 floor -- round the door on the floor. People wouldn't  
 10 come in. It was awful.  
 11 **MS RICHARDS:** Was that at the British Military Hospital  
 12 when you had the hepatitis B?  
 13 **MEGAN:** Yes, when I went back in with Robert. There was  
 14 one decent nurse out of the lot, male nurse.  
 15 **MS RICHARDS:** Have you experienced that again in the  
 16 NHS --  
 17 **MEGAN:** Yes.  
 18 **MS RICHARDS:** -- when you told people you had hepatitis B?  
 19 **MEGAN:** Yes. Yes, I had to have a mole taken from under  
 20 my foot once. It was about 10 or 12 years after. We  
 21 were down for the first surgery in the afternoon and  
 22 at 5 o'clock me and my dad -- my dad came with me --  
 23 were still sat there. I said, "When are we going to be  
 24 seen?" They said, "We are leaving you to last because  
 25 we have to scrub down everything after we have done

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1 end for him, you wanted to be there. If it was going  
 2 to be drawn out you wanted to be there and be able to  
 3 help out.  
 4 **MEGAN:** Of course, yeah.  
 5 **MS RICHARDS:** You said in your statement that the most  
 6 difficult thing for you as Robert's mum has been  
 7 watching Robert go through all this.  
 8 **MEGAN:** Yes, absolutely, and not really being able to do  
 9 anything to take it away from him.  
 10 **MS RICHARDS:** Those are the questions that I have for you.  
 11 Is there anything that either of you would like to  
 12 add?  
 13 **MEGAN:** I would just like to say that we feel -- I think  
 14 I speak for both of us, that we both feel very  
 15 aggrieved that hepatitis B isn't recognised, whereas  
 16 hepatitis C is. So thankful that, you know, we have  
 17 been brought to this Inquiry. We knew nothing about  
 18 it, nothing until just before Christmas. We have had  
 19 no support. I just feel that financially we should be  
 20 added to the Skipton Fund to be recognised, not to  
 21 be -- I phoned the Skipton Fund up. It was one of the  
 22 shortest phone conversations I have ever had.  
 23 Basically, "No" and that was it, so rude. We want to  
 24 be recognised.  
 25 **MS RICHARDS:** Robert has explained how he was not offered

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1 you". I have now stopped telling people I had it but  
 2 it's just in the tick boxes. I just don't tell  
 3 anybody anymore. I have had it in the dentists and  
 4 everything. I just don't say any more that I've had  
 5 it.  
 6 **MS RICHARDS:** Robert, is there anything you would like to  
 7 add?  
 8 **ROBERT:** No. I think my Mum has covered it all, to be  
 9 fair.  
 10 **MS RICHARDS:** I am just going to ask Mr Williams who  
 11 represents you, Robert, if there is anything else.  
 12 No. Nothing.  
 13 **SIR BRIAN LANGSTAFF:** I have nothing of my own to ask.  
 14 Can I thank you both for coming and being victims of  
 15 HBV infection as so many that we have heard from are  
 16 not, so thank you very much for your evidence.  
 17 **ROBERT:** Thank you for having us.  
 18 **SIR BRIAN LANGSTAFF:** Now that concludes our first week in  
 19 Leeds.  
 20 **MS RICHARDS:** It does, sir.  
 21 **SIR BRIAN LANGSTAFF:** We will start again at 10.30 on  
 22 Tuesday.  
 23 What do we have in store on Tuesday?  
 24 **MS RICHARDS:** We have three witnesses on Tuesday, sir. We  
 25 have Nicola Leahey, we have an anonymous witness and

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1 we have Suresh Vaghela.  
2 **SIR BRIAN LANGSTAFF:** Thank you. 10.30 on Tuesday.  
3 (3.26 pm)  
4 (Adjourned until 10.30 on Tuesday, 18 June 2019)  
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