

Wednesday, 16th October 2019

(10.00 am)

**SIR BRIAN LANGSTAFF:** Our first witness this morning is, as I told those who were here yesterday, anonymous. Indeed, both our witnesses this morning are anonymous.

So let me tell you the order that applies in his case.

He is witness 1387. It is ordered that the name and address of witness 1387 -- now, he will be known as Mr AN, that's Alpha November, Mr AN to you and me -- and any other identifying information, such as the witness's image or a description of their appearance, cannot be disclosed or published in any form unless express permission is given by me or by the Solicitor to the Inquiry on my behalf. Witness W1387 must be referred to only as "Mr AN".

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 the order by making a further order during the course of the Inquiry.

Mr AN, please.

**MR AN (sworn)**

**Questions by MS RICHARDS**

**MS RICHARDS:** It may be in the course of your evidence that you refer to yourself or your former partner by

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- A.** Same old story, really, with severe haemophiliacs. I did miss quite a bit of schooling, both, you know, secondary and junior. I didn't do too badly, but yes, I missed more than I should have done.
- Q.** You record in your witness statement being told when you were relatively young -- and this is before you were informed of your infection through blood products -- that you wouldn't live past 35.
- A.** No, that's right. That was quite a common thing on the ward at the Children's Hospital. When we used to miss -- if you were in there for more than two or three days, then they would try to give you basic schooling. Some of them were just -- the one nurse just said, "Well, you know, you may as well just have a bit of a play, because you are not expected to live over 30, 35 years". So, you know, looking back on it, I don't know how I accepted that, but yes.
- Q.** You said in your statement at some stage it made you resolve that you would live to at least 36.
- A.** Well, yes, yes.
- Q.** But you also say you were made to feel like a burden to the NHS.
- A.** Yes, very much so, because you didn't seem to fit into one category or another. It was odd, because you could sometimes walk about, so you weren't a disabled

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name. For the avoidance of doubt, although those in the room will hear those names during the course of your evidence and the evidence of the next witness, they are covered by the restriction order and are not to be repeated.

You were diagnosed with severe haemophilia A as a baby.

**A.** Yes, that's correct.

**Q.** And you were treated at the Birmingham Children's Hospital, initially with cryoprecipitate.

**A.** Yes.

**Q.** Your statement explains that from about late 1974 onwards you received cryoprecipitate at home.

**A.** Yes.

**Q.** You were about ten years old at the time. Was that partly for reasons of geographical distance from the hospital?

**A.** Yes. We lived about 25/30 miles away. So we were deemed -- yes, we could go on home treatment. So my parents invested in a large deep freeze, because cryo was quite a large commodity in those days, and, yes, we went from there, so ...

**Q.** What was the effect of your haemophilia and your need for treatment on your education as you were growing up?

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- person, but you weren't -- you fell between two stools, if you like. Even though haemophilia is a disability, you were treated in a very strange way at the Children's Hospital, very strange.
- Q.** Now, you were first offered Factor VIII products in 1977. You would have been early teens at that point.
- A.** Yes.
- Q.** You said in your statement you think it was by Dr Gilian Man but it could have been Dr Frank Hill.
- A.** Yes, it was one of the two.
- Q.** That was Factor VIII products by way of home treatment.
- A.** Yes.
- Q.** Can you recall what your parents or you were told about any risks?
- A.** We weren't told of any risks and I have confirmed that with my parents. All we were told was that this was a groundbreaking medical development.
- Q.** You said in your statement the impression was you were told that Factor VIII was "the miracle cure that would solve all of our problems".
- A.** Yes.
- Q.** Your parents weren't told of risks of infection and you or they weren't warned to look out for any adverse reactions to treatment.

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1 A. No, nothing at all.  
 2 Q. You have also I think a recollection of being told by  
 3 Dr Hill that the products were sourced from the  
 4 United States.  
 5 A. Yes, I do, yes.  
 6 Q. We can see a list of the products that you received.  
 7 Henry, can we have 1387002, please? We can see here  
 8 particulars of blood products, batch numbers by month  
 9 and year, and we won't obviously go through the detail  
 10 of all the batch numbers, but we can see here the vast  
 11 majority of the products that you received, with very  
 12 few exceptions, were Armour Factor VIII?  
 13 A. Yes, that is correct.  
 14 Q. If we just look at the next page as well, please,  
 15 Henry, we can see that continuing through 1981,  
 16 through the 1980s.  
 17 In 1981 you fell ill after you had injected  
 18 yourself with Factor VIII. What can you remember  
 19 about that?  
 20 A. Not a great deal, really. This isn't the glandular  
 21 fever incident?  
 22 Q. No. You said in your statement you subsequently  
 23 learned that you were infected with hepatitis B at  
 24 this time.  
 25 A. Yes. I don't actually remember a lot about that, to

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1 a horrendous illness. Although I have got severe  
 2 haemophilia, I am not ill usually and I was bedridden  
 3 with this.  
 4 I do remember that our local village doctor came  
 5 out, our family doctor came out to see us, and he said  
 6 to me, "I am diagnosing you with glandular fever, but  
 7 I think you should see a specialist in haemophilia".  
 8 I genuinely believe he knew more than he was letting  
 9 on, or wanted to let on professionally.  
 10 Q. The way you have put it in your statement is that the  
 11 GP said that this fever would have been triggered by  
 12 something --  
 13 A. Uh-huh.  
 14 Q. -- and that there were some things that were above his  
 15 knowledge, or words to that effect.  
 16 A. That's correct, yes.  
 17 Q. With the benefit of hindsight --  
 18 A. Yes.  
 19 Q. -- you now think that's around the time that you were  
 20 seroconverting.  
 21 A. Yes, yes, because that just ties in with everything  
 22 that we found out. The amount of people who have had  
 23 glandular fever when they were seroconverting is  
 24 almost 100%, so ...  
 25 Q. I think you didn't, in fact, go and see

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1 be honest, other than I was ill and that was it.  
 2 Q. There are in your records, and you have recorded this  
 3 in your statement, positive tests for hepatitis B  
 4 surface and core antibodies, May 1981.  
 5 A. It turned out to be, yes.  
 6 Q. Do you know whether you or your parents were told at  
 7 the time you were being tested for hepatitis B?  
 8 A. No. I have asked them this question and no.  
 9 Q. Were you told or your parents told that you had, in  
 10 fact, tested positive for hepatitis B?  
 11 A. No.  
 12 Q. So in about early 1984 you fell ill with glandular  
 13 fever.  
 14 A. Yes.  
 15 Q. Can we just have up on screen, please, Henry 1387010.  
 16 We can see it's a letter from Dr Hill dated  
 17 20th January 1984 to you:  
 18 "I am sorry to hear that you have glandular fever  
 19 and hope that you are beginning to improve. I presume  
 20 this is why you could not come to my clinic today."  
 21 He offers further clinic dates.  
 22 What do you recall about that episode of glandular  
 23 fever?  
 24 A. It was quite worrying, because I was planning to get  
 25 married in the not too distant future. It was

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1 the Haemophilia Centre.  
 2 A. I didn't, no. Certainly not Frank Hill, but there you  
 3 go.  
 4 Q. In 1984, you married.  
 5 A. Yes.  
 6 Q. And your former wife will be giving evidence after  
 7 you --  
 8 A. Yes.  
 9 Q. -- this morning. Up to this point, apart from the  
 10 illnesses you have described and apart from the  
 11 obvious effects of the haemophilia that you have  
 12 described, you were leading a busy, normal life?  
 13 A. Yes, yes.  
 14 Q. Working, good social life.  
 15 A. Yes, very good.  
 16 Q. Looking forward to marriage.  
 17 A. Very good, yes. The haemophilia didn't really -- it  
 18 was just one of those things, you know. I just  
 19 treated myself when I did and that was it, so ...  
 20 Q. I think you and your partner had bought a house  
 21 together.  
 22 A. Yes, we did, yes.  
 23 Q. At some point in the early part of 1985, you had  
 24 a urinary infection and passed out.  
 25 A. Yes.

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1 Q. Can you tell us what you remember about that and what  
 2 happened immediately afterwards?  
 3 A. Yes. We had only been married about a year, so  
 4 [redacted] couldn't drive. My father picked me up.  
 5 I was taken to A&E at the Queen Elizabeth Hospital,  
 6 the Old Queen Elizabeth Hospital. I was on a trolley  
 7 and a junior doctor came to see me. He was stood  
 8 there to my left, flicking through the notes, and he  
 9 just turned round and said, "This looks like HIV  
 10 developing into full-blown AIDS", and that was it.  
 11 I was -- well, I was already lying down, but I was  
 12 floored, because I just -- I didn't even though what  
 13 AIDS was anyway, really, and to be tested for it and  
 14 then to be told I was positive as such a casual thing,  
 15 I didn't know what to do or what to say, so ...  
 16 Q. As I understand it, you are not sure whether he used  
 17 the words HIV or not or HTLV-III.  
 18 A. No, but I remember the word "AIDS" and "full-blown".  
 19 That's how ...  
 20 Q. Now, there is no record of this in your medical  
 21 records.  
 22 A. Apparently not, no.  
 23 Q. But I think it is right to say that the records you  
 24 have got do not appear to be complete in any event.  
 25 A. No, no, they are not.

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1 Q. We will just again look at a record in relation to  
 2 that. 1387008, please. If we look down the very  
 3 bottom of the page, we can see an entry for  
 4 [redacted]. It says:  
 5 "Married for 1 year. Wife pregnant."  
 6 Then it says this:  
 7 "HTLV-III status not known."  
 8 Then there appears to be a further line under  
 9 that, but this is the only form in which you have  
 10 a copy of your records.  
 11 A. Yes.  
 12 Q. So we don't know what that further line might say.  
 13 A. No, no.  
 14 Q. As I understand your evidence, you and your wife did  
 15 go to see Dr Franklin on 1st August 1985.  
 16 A. Yes.  
 17 Q. You went to see him in part, at least, because your  
 18 wife was pregnant.  
 19 A. Yes.  
 20 Q. And because you had this information --  
 21 A. Yes.  
 22 Q. -- from the accident and emergency admission that you  
 23 might have AIDS.  
 24 A. Yes, yes.  
 25 Q. And you wanted to talk about that with Dr Franklin.

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1 Q. You don't, I think, have your GP records either.  
 2 A. No. Mysteriously they vanished in 1985, 1984 or 1985.  
 3 Q. The only record that we have -- if we have up on  
 4 screen, please, Henry, 1387013 -- prior to August 1985  
 5 is the UKHCDO records. We will just look at that  
 6 briefly. We can see there it says "Date first  
 7 positive: 28th April 1985". That would be  
 8 consistent --  
 9 A. Yes.  
 10 Q. -- with your recollection of being given some  
 11 information --  
 12 A. Yes.  
 13 Q. -- in the way you have described in the first part of  
 14 1985.  
 15 A. Yes.  
 16 Q. But it is right, I should point out, if we go to the  
 17 next page, please, Henry, there is an obvious error on  
 18 this page, because it says "Date condition diagnosed:  
 19 1st January 1999". You have no idea, I think, where  
 20 that date comes from.  
 21 A. No, no.  
 22 Q. So the first reference in your actual medical records  
 23 to HTLV-III appears to be August of 1985, 1st  
 24 August 1985.  
 25 A. Yes.

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1 A. Yes.  
 2 Q. Could we have up on screen, please -- it's a document  
 3 with a reference number for the next witness, Henry.  
 4 So it is 1388002.  
 5 So we can see the date is 1st August 1985, the  
 6 date of that entry in your records, the date you went  
 7 to see Dr Franklin. It is a letter from  
 8 Dr Franklin -- we can just about see that at the  
 9 bottom -- to Dr Jones, who was your wife's GP, not  
 10 yours.  
 11 A. Yes. He refused to have me.  
 12 Q. It says this:  
 13 "This 19-year-old girl who is the wife of  
 14 a patient of mine who has severe haemophilia A came  
 15 together with her husband to see me today. As you  
 16 know, she is 3 to 4 months pregnant and would prefer  
 17 to terminate the pregnancy. Any child of this union  
 18 would be a haemophilia carrier if female, but  
 19 haemostatically normal if a male. There would  
 20 therefore appear to be no grounds for a termination  
 21 from the haemophilia point of view.  
 22 "However, the current concern amongst the  
 23 haemophiliacs regarding the acquired immune deficiency  
 24 syndrome (AIDS) has been causing us to modify our  
 25 advice to haemophiliac patients who wish to undertake

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a family at the moment. Our present advice to these couples is that they should not have children until the infectivity of the AIDS virus has been clarified. We also recommended that all haemophiliacs use contraceptive sheaths for sexual intercourse since it is well-established that the AIDS virus is transmitted in semen. In the USA there have been cases of AIDS being transmitted from AIDS patients to female sexual partners and also from mothers to newborn babies. Unfortunately we have been so far unable to test [you] to see whether he has been exposed to the HTLV-III virus in the past. I have today carried out the necessary investigations on himself and his wife, but these will probably not be available for some weeks.

"I would consider that, in view of the current nationally agreed advice given to haemophiliac patients, together with the likelihood of [you] being positive for HTLV-III antibody (70% of our severe haemophiliacs are positive) that the possible risks of transmission of the HTLV-III virus from [you] to his wife and hence to a foetus is sufficiently likely to represent grounds for termination under the Abortion Act."

Then he goes on to say he is not the medical practitioner and not in a position to be a signatory,

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There's just two further documents to complete this sequence of events.

Could we have up on screen, please, 1387012. It's the GP's response to Dr Franklin, and we will just look at the first sentence of it. It says this, from a GP, 14th August 1985:

"Thank you for your letter about [Mr AN]. I found your statements rather frightening."

So the GP himself regarded what was being said as rather frightening.

A. Yes. Can I point out in that letter it says the problem is I am not registered. He wouldn't let me register with him. So, you know, some of these letters are ridiculous. They really are.

Q. Do you know why you were not permitted to be registered with him?

A. Oh, yes. He was quite open about it. It is because I was HIV. Very open about it.

Q. You have then described in your witness statement being called back for the results of the test that we just looked at, the HTLV-III test. You have estimated in your witness statement it was about six weeks later.

A. Yes, thereabouts.

Q. What can you recall being told?

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but he will inform the doctor of the results of the HTLV-III testing as soon as these become available.

Now, you and your wife didn't see this letter at the time.

A. No.

Q. It was written by Dr Franklin to Dr Jones. But we can see the advice being set out there --

A. Yes.

Q. -- by Dr Franklin.

A. Yes, and that's August.

Q. And that's 1st August 1985.

A. Yes.

Q. You were tested after that.

A. Yes.

Q. We have the test result at 1387011. We can see there, bottom of the page, the date the sample was taken, 1st August, and positive for antibodies of HTLV-III, and the date stamp: 12th August 1985.

You did I think consent to being tested on this occasion when you saw Dr Franklin.

A. On that occasion, yes.

Q. You and [redacted] did go ahead with the termination --

A. Yes.

Q. -- based upon the advice that you were given.

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A. It was quite a cold meeting. It was basically, you know, "You've got this and you have got approximately three years to live". There never ever seemed to be a start date for that three years. I could have been two years, six months down the line for all I knew. It was just, "Yes, that's it, now go home", as cold as that, really.

Q. There is no record in such medical notes as you have, as I understand it, of the follow-up consultation --

A. No.

Q. -- at which the test result was communicated to you.

All we have is something from the following year, May of 1986, so we will just look briefly at that.

1387009. We see the date, 1st May 1986, then the last two lines it says:

"Repeated advice re barrier contraception."

Then:

"Advised HTLV-III positive."

But you are confident, as I understand it, you had been told that in the aftermath of the August 1985 consultation --

A. Yes.

Q. -- and not as late as May 1986.

A. No, no, no.

Q. Were you told anything when you went to see the

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1 doctors in the autumn of 1985 or indeed at any later  
 2 stage about whether you should tell other people or  
 3 not about your infection?  
 4 A. Yes. It was pretty much, "Don't tell anybody". He  
 5 knew that we were a young married couple and -- yes,  
 6 it was "Just don't tell anybody". Not that we were  
 7 going to anyway, because we still didn't know what  
 8 this was. So, yes.  
 9 Q. [Redacted] is going to be giving evidence about this,  
 10 but you were, as you describe in your statement, very  
 11 young, very frightened.  
 12 A. Yes.  
 13 Q. And bombarded with information about the risks of  
 14 AIDS.  
 15 A. Yes.  
 16 Q. And that really continued for the following years.  
 17 A. Oh, yes, yes.  
 18 Q. You said in your statement that it was around this  
 19 time that there was a change, a shift, in the  
 20 atmosphere and workings of the Haemophilia Centre.  
 21 A. Very much so. I didn't go -- after this diagnosis,  
 22 I very rarely went to the haemophilia unit, but what  
 23 was very, very noticeable is you used to go into the  
 24 waiting room and there were many, many, many chairs  
 25 and it was full, always full. The clinic appointments

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1 A. No, I don't.  
 2 Q. -- record of what triggered testing.  
 3 A. No. I don't. Anybody in the room that knows me knows  
 4 that I have little regard for the Haemophilia Society.  
 5 I would not have taken -- well, we would not have had  
 6 any literature come through to us from the Haemophilia  
 7 Society, full stop. If by any chance we did, it would  
 8 have gone straight in the bin. So that does not ring  
 9 true.  
 10 Also, 1995, that's a very, very, very late date  
 11 for hep C. I just think that is a letter of  
 12 convenience, as far as I'm concerned. It ties  
 13 everything up nicely for the records. So ...  
 14 Q. And you don't know why you weren't called in for  
 15 testing in relation to hepatitis C earlier than 1995.  
 16 A. No.  
 17 Q. So precisely what triggered the test, it hadn't been  
 18 done prior to this year?  
 19 A. I don't know, but I hadn't sanctioned it, if it was.  
 20 Q. And you have said in your statement that having  
 21 received the hepatitis C diagnosis, at that time it  
 22 was the bottom of your list of things for you to worry  
 23 about.  
 24 A. Very much so. I did get on with Dr Wilde, my  
 25 haematologist. I went there for the -- I think it was

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1 that I had afterwards, there was just one or two  
 2 people or [redacted] and myself on our own, and that  
 3 really struck out at us, you know, what's gone on? It  
 4 was just so odd. Very, very odd. So ...  
 5 But I basically stopped going to the clinic  
 6 appointments. The arrogance of the doctors I was  
 7 seeing, you couldn't ask them questions, really. They  
 8 just told you what they wanted to tell you and that  
 9 was it, so ...  
 10 Q. It was some ten years later in 1995 that you found out  
 11 that you had been infected also with hepatitis C.  
 12 A. Apparently, yes.  
 13 Q. Again, we will have a document up on screen. It is  
 14 1387006. It helps us date this. So it is  
 15 31st March 1995. It is from Dr Wilde, who by this  
 16 time was your consultant, and it says this:  
 17 "[You] attended the clinic this morning requesting  
 18 hepatitis C serological testing, having been prompted  
 19 to do so by a communication from the Haemophilia  
 20 Society. The blood test was duly performed and he  
 21 will be informed of his result."  
 22 Now, the blood test was performed and you were  
 23 informed of the result and it was positive.  
 24 A. Yes.  
 25 Q. But I think you don't believe this is a correct --

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1 a clinic appoint. It wasn't just for the results, but  
 2 he actually said, "I have the results of your hep C".  
 3 He said something like, "Do you really need to ask?"  
 4 I just shrugged my shoulders and said, "No, not  
 5 really". A bit further on in the consultation I said,  
 6 "About this hep C". He said, "I wouldn't worry about  
 7 it. You have to prioritise things. Your haemophilia  
 8 is going to come above the hep C and HIV and AIDS is  
 9 top of your list". That was it. He really didn't  
 10 speak much about it then.  
 11 Q. In 2000, so five years after the hepatitis C  
 12 diagnosis, you went on a treatment strike, because you  
 13 wanted to be on recombinant. Again, we will just look  
 14 at a letter to help put this in context. It is  
 15 1387005, please, Henry. It is dated 19th May 2000.  
 16 It is a letter from you to Dr Wilde and it says this:  
 17 "As you are aware, recently I sent a batch of  
 18 Factor VIII back to the unit as I was not happy with  
 19 its appearance. I read the letter from Grifols, the  
 20 manufacturer, but I am afraid I was not convinced.  
 21 "In their opinion it may be within the colour  
 22 ranges allowed, but there seems to have been no  
 23 specific testing of this batch other than when it was  
 24 packed for distribution.  
 25 "I know that you as a doctor cannot comment and

20

1 I am also aware that you cannot guarantee to me where  
2 the blood plasma contained in this product is from,  
3 only where it is manufactured."

4 Then you say this:

5 "Well, over the past few months I have had less  
6 and less faith in these products, and I feel that at  
7 the moment I would rather risk severe bleeds than  
8 treat myself with something that I cannot wholly  
9 trust, especially considering the fact that I have  
10 already had my health severely compromised with two  
11 blood-borne infections.

12 "I am sorry to be a difficulty to you as  
13 a patient, but I feel I must write to you and let you  
14 know of my feelings on this subject. The problem is  
15 only made worse for the fact that there is a synthetic  
16 product that is available to haemophiliacs which could  
17 reduce the fear and risks of other infections  
18 drastically.

19 "You know I have the greatest respect for yourself  
20 as my doctor, but I feel whilst I am still prescribed  
21 human-based Factor VIII, I would rather accept the  
22 problems with bleeds as a physical one rather than the  
23 anguish of injecting these products with the worry  
24 that it has now become."

25 What can you recall about that?

21

1 Mark Winter actually put in his letter that  
2 I think it lasted slightly longer -- the recombinant  
3 lasted slightly longer than human-derived anyway, so  
4 you would have to buy less. As soon as they saw that,  
5 we had recombinant.

6 Q. That was middle of 2000, we have seen, when you were  
7 writing, expressing your concern --

8 A. Yes.

9 Q. -- about what else might be in the products you were  
10 injecting yourself with.

11 A. Yes, but I wasn't the only one, so ...

12 Q. But it was the very next year, 2001 --

13 A. Yes.

14 Q. -- when you received letters saying you might have  
15 been exposed to variant CJD.

16 A. Yes, so somewhat proved a point.

17 Q. What was the effect on you of being told of the risk  
18 that you had been exposed to vCJD?

19 A. It was extremely concerning, actually. The hepatitis  
20 C had not given me any worries. I had had HIV related  
21 illnesses, quite bad ones. [Redacted] and I had --  
22 our marriage had broken up by then, and I had to take  
23 on board that this CJD, which was similar to the way  
24 it was being treated as AIDS was in the 1980s. There  
25 was a lot of shock, horror media stories and you

23

1 A. That was a difficult time. I had a good friend of  
2 mine from up north you had gone on a treatment strike  
3 and he was quite ill. He shouldn't really have done  
4 it, but he did. And I felt very strongly about this,  
5 because there were certain other viruses that had  
6 already been identified, Parvovirus being one. Our  
7 immune systems had already been damaged. To expose  
8 them to any other virus was just ridiculous. You  
9 know, how can anybody do that? So a few of us stopped  
10 taking Factor VIII, and that was it, basically.

11 Q. You I think wrote to and got support from Mark Winter.

12 A. Yes.

13 Q. If you can explain who that was.

14 A. Dr Mark Winter was -- I don't know where he was  
15 a haematologist. I think it was down south somewhere.  
16 But he was a MacFarlane Trust trustee as well.  
17 I asked him a statement: "Would you agree with the  
18 fact that Parvovirus can and is found in human-derived  
19 Factor VIII?" He said yes. He also sent a supporting  
20 letter that I had to send to the Worcester Health  
21 Authority at the time, because it came down to  
22 finances, and it didn't matter -- this is the  
23 frightening thing -- it didn't matter how efficacious  
24 Factor VIII was, the recombinant, compared to  
25 human-derived; it came down to cost and that was it.

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1 weren't alive very long. Let's put it that way.

2 But again, prioritise it, you know. I hadn't  
3 known anybody that had died of it that I know of, so  
4 ...

5 Q. If we go back then to the second half of the 1980s,  
6 when you had been given the diagnosis of HIV, you were  
7 about 21 years old at the time. You were newly  
8 married.

9 A. Yes.

10 Q. And you say in your statement that that diagnosis  
11 destroyed yours and your wife's lives and changed the  
12 course of those lives forever.

13 A. Yes, yes. I think I have said to you there were three  
14 people in the marriage, three individuals in the  
15 marriage, and one of them was this big virus. And it  
16 did, it just ripped us apart. [Redacted] was 18 when  
17 we got married. We wanted to buy a house, settle  
18 down, you know, do the things that normal people do,  
19 and not 12 months after, it was ripped apart,  
20 completely ripped apart.

21 Q. Can I ask you first about the physical health impact  
22 of infection and treatment. What had been the  
23 predominant physical effects of the HIV infection?

24 A. From -- initially, not much. A lot of mental anguish,  
25 but initially not much physical. I had a lot of sort

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1 of little opportune infections that were all put down  
 2 to being related to HIV. It wasn't until 1999 that  
 3 I had to go and see Dr Wilde because I had fell  
 4 seriously ill. That's when we had the conversation  
 5 about antiretrovirals, et cetera, so ...  
 6 **Q.** Just before we get to that, you had declined treatment  
 7 with AZT.  
 8 **A.** Yes, I had.  
 9 **Q.** Why was that?  
 10 **A.** Because some of the haemophiliacs I had seen, to me  
 11 they just looked worse than the ones that weren't on  
 12 AZT. I asked -- I am pretty sure it was Frank Hill --  
 13 I asked about AZT, what it was. I was told, "There is  
 14 no need for you to know, you just take it". That's  
 15 the sort of attitude, which is why I stopped going.  
 16 But I am glad I didn't take AZT. That's my personal  
 17 choice, and I still think, you know, in some cases it  
 18 should never have been given, but ...  
 19 **Q.** As you were just saying, it was around the late  
 20 1990s --  
 21 **A.** Yes.  
 22 **Q.** -- that Dr Wilde said to you, "Get treatment now or  
 23 you will be dead within three months".  
 24 **A.** Yes. I went to see him. I was very weak at the time.  
 25 I had oesophageal candida, which is a typical

25

1 thighs, and I actually -- once I had started it,  
 2 I thought, "Right, well, I am going to carry on". Sam  
 3 came round and asked me how I was getting on. I think  
 4 I had been on them for a matter of weeks. I said,  
 5 "Oh, okay apart from this rash". I showed her the  
 6 rash and she went ballistic and said, "You should have  
 7 told me about it. Your body is rejecting it". So  
 8 I was a little bit annoyed because I just thought it  
 9 was one of those things. But I then got put on  
 10 another drug, Delavirdine, which was named patient at  
 11 the time. I was on that for years.  
 12 **Q.** You also said in your statement you think that first  
 13 drug regime led to you having a duodenal ulcer.  
 14 **A.** Yes, yes.  
 15 **Q.** Since that time, what have been the side effects of  
 16 the medications as they have changed over the years?  
 17 **A.** Multiple ulcers, which I have been in and out of  
 18 hospital. Touch wood, I hope that this has now been  
 19 sorted.  
 20 It is hard to put your finger on it, really,  
 21 because you just live with it every day. But  
 22 appetites, tiredness. I was forever going to see the  
 23 doctor about why am I so -- why do I feel so lethargic  
 24 and tired and can't concentrate? I was always told,  
 25 "Well, it could be the hep C, it could be the HIV, it

27

1 HIV-related illness. He did some bloods on me. We  
 2 had a chat. I always asked him to be straight with  
 3 me. He said, "Look, you have never taken  
 4 antiretrovirals. In my opinion, you have got about  
 5 three months to live. So go home. Don't take too  
 6 long to think about it, but have a think what you want  
 7 to do". So I had to go home and have a think about  
 8 it, so ...  
 9 **Q.** You have described in your statement you were still  
 10 unsure whether you wanted to start the medication or  
 11 just let nature take its course.  
 12 **A.** Yes.  
 13 **Q.** But you had a home visit from one of the haemophilia  
 14 nurses, Sam.  
 15 **A.** Yes, Sam, yes, yes. She was a rod to many of us. She  
 16 basically convinced me to give it a go. I think she  
 17 said something like, "You can die later if you really  
 18 want to". It's very flippant, but that's the sort of  
 19 relationship we had with her, so ...  
 20 **Q.** You did start the antiretrovirals, but the first set  
 21 of drugs that you had caused significant problems.  
 22 **A.** Yes.  
 23 **Q.** What were those?  
 24 **A.** I believe it was Nevirapine. I had -- I was burning  
 25 up, but I had massive rashes on the inside of my

26

1 could be the meds for the HIV. We don't know". It  
 2 has just been an ongoing thing, really. So ...  
 3 **Q.** One of the concerns you voiced in your statement about  
 4 your medical care is that your HIV care remained in  
 5 the hands of haematologists.  
 6 **A.** Yes. It was a concern, because they weren't HIV  
 7 specialist doctors. However, with Dr Wilde,  
 8 I preferred it that way, because I could have an open  
 9 chat with him about things and we literally did muddle  
 10 through together. That was a sentence when he retired  
 11 that he came out with. And I am still here. So, you  
 12 know, he did all right by me.  
 13 **Q.** You have said in your statement, in relation to HIV,  
 14 this:  
 15 "It is true that today HIV is a treatable disease.  
 16 This has not always been the case and being diagnosed  
 17 with HIV today is not the same as being diagnosed back  
 18 in the 1980s, when there was either no treatment or  
 19 only experimental treatment available. Some of the  
 20 medications given at that time did as much harm, if  
 21 not more, than the virus itself."  
 22 **A.** That's correct, and also this is happening now.  
 23 Truvada, which I was put on, which was named as the  
 24 wonder drug only last year, there is now a legal  
 25 action in America for fatalities of people who have

28

1 been taken it. I have been taken off it because of  
 2 kidney results that started to fail, and numerous  
 3 other people have in this country. This was held up  
 4 as a wonder drug only last year. So it carries on.  
 5 Q. Hepatitis C treatment. You have said in your  
 6 statement that some time after 2005 you were referred  
 7 to see a Dr Mutimer.  
 8 A. Yes.  
 9 Q. And you underwent a fibre scan and blood tests.  
 10 A. Yes.  
 11 Q. You were offered pegylated interferon and Ribavirin.  
 12 A. Yes.  
 13 Q. What was your decision in relation to that?  
 14 A. No. At that time I had been involved with Birchgrove.  
 15 We were receiving numerous letters from people who had  
 16 been on this. I asked him -- it was a loaded  
 17 question. I asked him what the side effects were.  
 18 I knew what the side effects were because I had spoken  
 19 to these people and it was horrific. He came out  
 20 with, "Oh, well, it is mild flu". I challenged him  
 21 about this and the meeting did not go very well.  
 22 Q. You also, I think, raised concerns about the  
 23 interaction --  
 24 A. Yes.  
 25 Q. -- with your HIV medication --

29

1 on.  
 2 Q. You have described in your statement an incident in  
 3 which you were in an ambulance.  
 4 A. Yes.  
 5 Q. This was in 2016.  
 6 A. Yes.  
 7 Q. Can you tell us about that?  
 8 A. That was a burst ulcer. I had been vomiting and  
 9 passing blood in large amounts. I felt very, very  
 10 faint. [Redacted] called the ambulance. I thought  
 11 I was going to pass out. So I automatically, as  
 12 haemophiliacs do, you reach for your Factor VIII,  
 13 because there is nobody else can have it. I had  
 14 a large dose of Factor VIII and sat on the bed. The  
 15 paramedics, two young ladies, turned up. We had  
 16 a chat. They did blood pressures, et cetera. They  
 17 wanted to take me to hospital. Took me down to the  
 18 ambulance, and they were just sorting me out on the  
 19 stretcher and everything and I asked, "Where are you  
 20 taking me?" She said "Warwick". I said, "Well,  
 21 I don't want to go to Warwick hospital, I won't come  
 22 out of there alive, and also they won't want me". So  
 23 she said, "Where do you want to go?" I said "Queen  
 24 Elizabeth".  
 25 She put the radio, whatever it was, on hands free,

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1 A. Yes.  
 2 Q. -- and didn't get very clear answers.  
 3 A. No, didn't get very far with that either.  
 4 Q. So you declined the treatment. At the time you wrote  
 5 your witness statement you were receiving reasonably  
 6 regular liver function tests.  
 7 A. Yes.  
 8 Q. But the question of further treatment was left open.  
 9 What's the current position?  
 10 A. Now, as of this year, I have got chronic liver  
 11 disease. There is scarring and fatty tissue. I am  
 12 going back to see Mutimer in November, hopefully with  
 13 a view to going on the latest medication, if we manage  
 14 to have a decent talk about it, so ...  
 15 Q. How have the events that you have described affected  
 16 your trust in medical professionals?  
 17 A. I have no trust. I have no trust. As [redacted], my  
 18 partner, will bear out, it's getting worse in the  
 19 health authorities, especially with haemophilia. My  
 20 life has actually been literally threatened -- and  
 21 that's not an exaggeration, is it? -- twice in the  
 22 last three years by one doctor asking me when  
 23 I contracted haemophilia, and at this time I was in  
 24 accident and emergency with severe internal bleeding,  
 25 and yes, it's just -- the list goes on. The list goes

30

1 sat it there, called through and said, "I have  
 2 a severe haemophiliac with internal bleeding, blah,  
 3 blah, blah. What shall we do?" They said, "I would  
 4 rather you took him somewhere else". She said,  
 5 "That's what we do".

6 They actually had a shift change midway. So we  
 7 had to work out where to meet the other shift and  
 8 change ambulance crews.

9 Q. How has the risk of exposure to vCJD affected your  
 10 medical treatment?

11 A. Quite drastically, and I think it's affected quite  
 12 a few people and they don't know it. With the ulcers  
 13 that I have had, there was one surgeon, [redacted],  
 14 who ran the endoscopy unit. I had to go there,  
 15 because this was at the start, with a suspected ulcer,  
 16 for an endoscopy. He came in and he said, "Oh, it is  
 17 good news, you don't have to have an endoscopy".

18 Well, I have always been a bit outspoken when it  
 19 comes to doctors, because you have to be. I said,  
 20 "I am not going anywhere until you actually perform  
 21 an endoscopy, because I have an ulcer. I have had one  
 22 before. I know what it feels like". We argued, quite  
 23 politely, but he bowed down and said, "Okay, I will  
 24 give you an endoscopy". That came back with nothing,  
 25 did it, apart from a hernia.

32

1 Not long after that I started vomiting blood, so  
 2 I had another endoscopy, which we -- I think they said  
 3 it was 10 o'clock in the morning. I rang them up and  
 4 said, "Are you sure it is 10 o'clock in the morning?"  
 5 "Yes, why?" I said, "Because you don't usually get  
 6 seen until after 4.00", "No, 10 o'clock in the  
 7 morning". We got there at 10 o'clock in the morning  
 8 and we weren't seen until after 4.00. That's how it  
 9 is.

10 I noticed the endoscope in the blue bag at the  
 11 bottom of the pile. I sat and watched these others in  
 12 the yellow bags being used and the blue one was mine.

13 I have spoken to a nurse, a good friend of mine,  
 14 who is retired from the haemophilia unit. She told me  
 15 that there was a memo, for want of a better word, sent  
 16 out about the non-risk of CJD now on instruments, but  
 17 certain doctors and surgeons were taking it upon  
 18 themselves to actually still carry out procedures that  
 19 took place a long time ago.

20 Q. You do say in your statement that you have had  
 21 brilliant support from your pharmacist in terms of  
 22 assisting you to get medication for your ulcers --

23 A. Yes.

24 Q. -- and for your dental care from the Maxillofacial  
 25 Department at the hospital.

33

1 whatsoever. We were literally just like rabbits in  
 2 headlights. It was more than advice about getting  
 3 a termination; it was actually, "We are leading you  
 4 down this path", which we took.

5 Q. In terms of the day of the termination itself, you  
 6 have recorded two details in your witness statement.

7 A. Yes.

8 Q. One is the biohazard warnings on the door of the room.

9 A. Yes.

10 Q. And the other is you effectively being required to  
 11 leave the room?

12 A. Yes. I didn't know half of what [redacted] went  
 13 through, because I buried my head in the sand. I just  
 14 shut it all out. But I have heard what she had to  
 15 say. I have pieced it all together now, that  
 16 particular night when the termination was carried out.

17 I was sat on the edge of the bed with her. It was  
 18 in a very small room. I was told basically to leave  
 19 in no uncertain terms, quite rudely. Obviously I had  
 20 other things on my mind at the time. I just thought,  
 21 "That's quite rude". That ties in with what you will  
 22 hear [redacted] say later, and I didn't know she'd  
 23 gone through all that. I just didn't know.

24 Q. You have said that you and she never really discussed  
 25 it again.

35

1 A. Yes, yes.

2 Q. I wanted to ask you next, if I may, about the effects  
 3 of the HIV diagnosis on your marriage and your private  
 4 life.

5 You have described already how very young you were  
 6 and what happened in 1985.

7 A. Uh-huh.

8 Q. In 1989, your wife was pregnant again. We will be  
 9 hearing more evidence from her about this later this  
 10 morning.

11 A. Yes.

12 Q. But your witness statement records that when she went  
 13 to the GP, she was told that the baby might well have  
 14 HIV.

15 A. Yes.

16 Q. You decided, the two of you, that she would have  
 17 a termination.

18 A. Yes.

19 Q. You have described this in your statement as something  
 20 that was very much pressured onto a young, scared and  
 21 ill-informed couple. Is there anything else you want  
 22 to say about the decision-making in relation to that  
 23 and what the doctor said to you?

24 A. Hindsight is a wonderful thing. We were just so  
 25 frightened. We didn't get any proper advice

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1 A. We never. We never discussed it again.

2 Q. Your marriage had been deteriorating since the HIV  
 3 diagnosis.

4 A. Yes, yes.

5 Q. You had to give up work.

6 A. Yes.

7 Q. She was caring for you and having to hold down  
 8 numerous jobs.

9 A. Yes.

10 Q. In the end, you separated.

11 A. Yes, yes.

12 Q. In 1999, after you had separated -- and we will hear  
 13 more about this later from her -- she found out she  
 14 was HIV positive.

15 A. She did, yes.

16 Q. In terms of your career, you had previously had jobs  
 17 that you loved.

18 A. Yes.

19 Q. And there was an exciting moment at which you were  
 20 offered a fantastic job in the States.

21 A. Yes, yes.

22 Q. You had to turn that down.

23 A. I had to turn it down because I couldn't -- at that  
 24 time it was difficult to get a travel visa, let alone  
 25 a work visa. So we just -- again, we never spoke

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1 about it. I had the job offer and it literally got  
2 thrown in the bin.  
3 Q. You say in your statement that you not only lost out  
4 on a career, but the feeling of being useful in life.  
5 A. Yes, very much so, yes. You can never get that back.  
6 Yes. Whether it's the doctors or whatever, you are  
7 a disposable commodity that doesn't mean anything, and  
8 I think that's why a lot of haemophiliacs strive in  
9 whatever career they do to get to the top or be better  
10 than somebody who hasn't got haemophilia. I don't  
11 know. It is like a challenge. So it's worse to be  
12 knocked flat than if you hadn't had haemophilia,  
13 that's how I look at it, because we had the challenge  
14 of it anyway, so ...  
15 Q. You threw yourself into campaigning work.  
16 A. Yes.  
17 Q. In particular your work with the Birchgrove Group.  
18 A. Yes.  
19 Q. You describe yourself in your statement as constantly  
20 in fear of the stigma attached to your infections,  
21 particularly in relation to the HIV.  
22 A. Yes.  
23 Q. I wondered if you could tell us about that.  
24 A. Well, a lot of people say there is no stigma to HIV  
25 anymore, and in London, no, there isn't, and most big

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1 was overwhelming --  
2 A. Yes.  
3 Q. -- and there were horrible jokes --  
4 A. Oh, yes.  
5 Q. -- everywhere.  
6 A. Yes, yes.  
7 Q. You would pretend to laugh along.  
8 A. Yes. You would be sat in a pub and, you know, even  
9 the crowd of my good friends would tell AIDS jokes and  
10 I would just have to sit and laugh, you know. You  
11 have to be the third person and remove yourself from  
12 that. Some quite horrific things when Rock Hudson  
13 died and all that sort of stuff. It was terrible.  
14 And I think a lot of this mentally has never been  
15 looked at. The attitude towards haemophiliacs and  
16 AIDS has never -- [redacted] and I closed the door and  
17 that was it. We shut the world out. We didn't buy  
18 newspapers, we didn't watch the news, because it was  
19 just terrifying, absolutely terrifying, and then I go  
20 out with my friends and it is reinforced that that  
21 attitude is there, so ...  
22 Q. You are still to this day very selective about --  
23 A. Very selective.  
24 Q. -- who you tell.  
25 A. Yes.

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1 cities probably not. I live in a small [redacted]  
2 village. I tell you now, if I walked in the pub with  
3 a red ribbon on, I dread to think what would happen.  
4 It is still the same. There is still the same stigma.  
5 Maybe not as violent or as vicious, but there is a lot  
6 of stigma around HIV and AIDS, and a total  
7 misunderstanding of haemophilia and HIV, even today.  
8 Q. You have referred in your statement to -- because of  
9 the known association between haemophilia and HIV and  
10 AIDS --  
11 A. Yes.  
12 Q. -- you began to downplay the fact of your haemophilia  
13 and not tell people you were a haemophiliac.  
14 A. Yes. From my teenage years I rode scooters, and all  
15 my friends knew I was a haemophiliac in case I had  
16 an accident. I stopped telling anybody that I met,  
17 because haemophilia just equated to AIDS. I think  
18 I did put it in my witness statement, because again it  
19 is sort of gallows humour, but I was on a rally in  
20 I think it was Great Yarmouth and a friend of mine  
21 shouted across "Oh, you are one of those  
22 necrophiliacs, aren't you?" I actually preferred being  
23 called a necrophiliac to a haemophiliac. That's how  
24 bad it was.  
25 Q. You say in the 1980s and 1990s, the fear about AIDS

38

1 Q. You have said in your statement that the village you  
2 live in is not a place in which you would even say the  
3 word "HIV".  
4 A. No, no.  
5 Q. You also describe how there have been occasions where  
6 you have been in hospital and a ward sister might  
7 call-out in front of our patients --  
8 A. Yes.  
9 Q. -- "Your HIV meds are ready".  
10 A. Yes. I think that was when I had my ankle done. They  
11 take your meds off you when you go in, which I have  
12 got a problem with to start with because you need to  
13 take them at set times, and these times never fall in  
14 line with when they come round with the medicine  
15 trolley. So that was one thing.  
16 The other thing is that I was on a public ward and  
17 the nurse shouts, "I have your HIV meds for you". It  
18 shouldn't happen.  
19 Q. Over the years from 1985 onwards, what support or  
20 counselling, psychological assistance has been offered  
21 to you?  
22 A. None.  
23 Q. You say in your statement there are no drop-in  
24 sessions, no support, no counselling made available,  
25 and the only assistance you have had are from

40

1 individuals such as nurses at the haemophilia unit.  
 2 A. Yes.  
 3 Q. Mark Simmons, the social worker attached to the unit.  
 4 A. Yes.  
 5 Q. You have also referred to a benefits adviser from the  
 6 MacFarlane Trust. Some individual pockets of  
 7 assistance?  
 8 A. Yes. She was brilliant. She turned my life around.  
 9 I was in a very dark place. I had no money coming in.  
 10 I didn't want to fill out any forms or anything.  
 11 I just couldn't cope. I don't think they do it now,  
 12 but I was awarded a DS1500, which means sort of  
 13 imminent death, I think it is death within 12 months  
 14 or something. Obviously that didn't happen. But,  
 15 yes, within a couple of days she turned it all around  
 16 for me, so ...  
 17 Q. You were involved in the 1991 HIV litigation and you  
 18 recall having to sign a waiver.  
 19 A. Yes.  
 20 Q. What were you told? What were the circumstances in  
 21 which you signed that?  
 22 A. We were basically told, "If you don't sign it, nobody  
 23 else will get the money", and that was it. That was  
 24 basically -- I think it was at the office in  
 25 [redacted], the solicitors' office in [redacted]. We

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1 A. If I had had gay relationships, was I an intravenous  
 2 drug user. These were implied, that I was  
 3 an intravenous drug user. When you read the  
 4 deposition, I don't think it does justice to how we  
 5 were treated over there. You were almost a guilty  
 6 party. I also -- do you want me to say about the  
 7 blood transfusion subject now?  
 8 Q. Yes.  
 9 A. That was after the gay sex and the intravenous drug  
 10 use, apparently. There was an entry in my medical  
 11 notes that said that I had had a blood transfusion.  
 12 Well, ironically, I hadn't, and I know I hadn't,  
 13 because I had only had one transfusion up until then,  
 14 and that was when I was 12 months old. So my lawyer  
 15 was trying to keep me quiet. She didn't want me to  
 16 say anything. But I was just so disgusted, because it  
 17 was a false statement that was entered into my  
 18 records.  
 19 Q. And the purpose of the question, as you understood it  
 20 at the time --  
 21 A. Yes.  
 22 Q. -- was to try to suggest that there was a source of  
 23 infection --  
 24 A. Yes.  
 25 Q. -- other than the American pharmaceutical products.

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1 just signed it. That was it.  
 2 Q. You spoke to a solicitor about seeking financial  
 3 advice after the payment had been received?  
 4 A. Yes.  
 5 Q. What was the response?  
 6 A. Basically he turned round and said, "Why would you  
 7 want to? You are going to die fairly quickly. Go out  
 8 and enjoy it". Again, for the solicitor to be saying  
 9 that, you know -- because I still didn't believe this  
 10 was going to happen. I felt healthy. I was young,  
 11 but obviously it was going to happen. So we did.  
 12 Q. You were also involved in US litigation --  
 13 A. Yes.  
 14 Q. -- against the pharmaceutical companies in the States.  
 15 A. Yes.  
 16 Q. You have a memory of flying out to the States and  
 17 giving evidence.  
 18 A. Yes.  
 19 Q. Or giving a deposition.  
 20 A. Yes.  
 21 Q. We have got a record of some of what you said, but you  
 22 have a recollection of being asked other questions.  
 23 A. Yes.  
 24 Q. Can you tell us what your memory is of the kind of  
 25 things you were asked about?

42

1 A. Yes, yes.  
 2 Q. It is that memory that led you to say in your  
 3 statement that you think there were things in your  
 4 medical records --  
 5 A. Oh, definitely.  
 6 Q. -- that were not true.  
 7 A. Yes.  
 8 Q. You are not talking about the records that we have  
 9 seen but records you have not been able to locate.  
 10 A. No, no.  
 11 Q. Can I ask you about the MacFarlane Trust. First of  
 12 all, your direct experiences in making applications.  
 13 You applied after the break-up of your marriage --  
 14 A. Yes.  
 15 Q. -- for a grant to do some basic work to your house?  
 16 A. Yes.  
 17 Q. You were offered a loan.  
 18 A. Yes.  
 19 Q. And that was put as a charge on your house.  
 20 A. Yes.  
 21 Q. As a understand it, when you and your new partner then  
 22 purchased a house, the charge was transferred over.  
 23 A. Yes.  
 24 Q. Is that right?  
 25 A. Yes.

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1 Q. It was then, when the MacFarlane Trust ceased to  
2 exist, was wound up, that charge was transferred to  
3 the Terrence Higgins Trust, and we have heard that  
4 from other witnesses.  
5 A. Yes, without my knowledge.  
6 Q. Without your knowledge. Do you know what has happened  
7 to that charge now?  
8 A. I believe that the charges have been dropped, for want  
9 of a better phrase. Yes, I think there were nine  
10 registrants altogether, and I believe now they have  
11 been removed.  
12 Q. You have said in your statement that you were at some  
13 stage a trustee of the MacFarlane Trust.  
14 A. Yes.  
15 Q. What can you tell us about the trust from that  
16 perspective?  
17 A. Not very good things. It seemed that they always  
18 wanted to bring people down to a level, not raise them  
19 up to a level. There's very little empathy with HIV  
20 or AIDS-related conditions, what people were going  
21 through. It was just not fit for purpose.  
22 There were two of us that were infected  
23 haemophiliacs and worked as trustees. There was  
24 definitely a trustee board within a trustee board, and  
25 we weren't part of that. Some of the decisions that

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1 activities, have had some knowledge of. One was about  
2 a member of your group, the Birchgrove Group, who was  
3 taken ill on holiday.  
4 A. Oh, yes.  
5 Q. What do you recall about that, without mentioning any  
6 names?  
7 A. No. He will mention his own name. Yes. He was taken  
8 ill on holiday and there was a shortfall in holiday  
9 insurance, and they basically refused to pay. It was  
10 £100-odd, something like that. They refused to pay  
11 because it was HIV related. Again, it is all sorted  
12 now, that HIV thing. It's all gone away.  
13 The other was a funeral grant. If you have got  
14 hep C, you can get a funeral grant, but HIV is nowhere  
15 on the list and people are still dying of HIV-related  
16 conditions.  
17 Q. There's a passage in or a couple of passages in your  
18 witness statement I am just going to read out, with  
19 your agreement, where you try and describe what the  
20 effect overall has been on your life, of the events  
21 you have described. You say this:  
22 "From that brief time in 1985, my life both  
23 physically and mentally have never been the same. How  
24 can it be? I can only speak from my perspective as  
25 a man of 20, just married, with my whole life ahead of

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1 were made, although they were supposed to be  
2 throughout the board, we were never consulted. This  
3 happened without us.

4 Some of the -- I sat on the NSSC, which was the  
5 grant-making, and I use that term loosely. I will  
6 bring one example up, which proves the mentality. At  
7 that time you had to send pictures in if you wanted  
8 things like your windows replacing for damp or  
9 whatever. A lad had sent in a picture of a bay window  
10 which was completely rotten. Photograph got passed  
11 around. Open and shut case. Windows are rotten.  
12 A particular individual pointed out, "Well, he can  
13 afford a PlayStation and a packet of cigarettes, can't  
14 he?"

15 Now, a lot of individuals when they were  
16 diagnosed, especially young individuals, never left  
17 the house. They lived on a computer. They lived, you  
18 know, a different life. So it just proved there was  
19 no understanding there whatsoever, at all, and I don't  
20 believe he got the grant, so ... But that's just one  
21 example.

22 Q. You have given, I think, two examples in your  
23 statement of the decisions of the EIBSS; not decisions  
24 personally in relation to any application by you, but  
25 that you, through your campaigning or Birchgrove Group

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1 me, with my new wife, who wanted to grow old, to  
2 become a parent, a grandparent, and then to find out  
3 in that way that it wasn't to be. From that day on,  
4 nobody can ever be the same. I, we, carried on, not  
5 telling anybody for fear of what may happen. We would  
6 see 'AIDS scum' on the news, on the TV and sprayed on  
7 walls and think, 'Luckily nobody knows about us', but  
8 we were still afraid of coming home and finding that  
9 written on our house or car as many others did."

10 You say this:

11 "This isn't over. The mental and physical anguish  
12 goes on. The gallows humour of who will be the last  
13 one of us standing hides what we all fear and have  
14 feared for many years. Our lives ripped apart by  
15 this, and even further infections in following years,  
16 and yet we are okay according to medical sources."

17 Then you say this:

18 "Those of us alive who are walking and breathing  
19 can hold conversations about normal daily things, but  
20 the viruses are always lurking in the background.  
21 Nobody who hasn't been in our position could ever  
22 understand, and that isn't meant as a sympathy  
23 statement. It's a fact."

24 Those are the questions I have for you, but before  
25 I ask you what else you would like to add, I am just

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1 going to ask Mr Snowden if there's anything else  
 2 he would like me to ask. No.  
 3 What else would you like to say?  
 4 **A.** Just a couple of sort of angry, bitter points that  
 5 I usually bring up.  
 6 I think our community has been let down  
 7 historically by the Haemophilia Society, who pushed  
 8 Factor VIII at a time when haemophiliacs were dying in  
 9 America. They carried on and carried on pushing the  
 10 fact that we should use Factor VIII more and more and  
 11 more.  
 12 After that time, they vanished from the community.  
 13 There was token gestures, but they didn't want  
 14 anything to do with the HIV community. It disgusts  
 15 me. It really does.  
 16 When I worked on the Birchgrove, the individual  
 17 that ran the society at the time used to pay us as  
 18 Birchgrove to cover any HIV-related stories so the  
 19 haemophilia magazine didn't have to cover it. That's  
 20 what -- they didn't want to frighten off the newly  
 21 diagnosed haemophiliac children, et cetera, et cetera,  
 22 and also with the ties with the pharmaceutical  
 23 companies.  
 24 That's one thing I really hope that this Inquiry  
 25 brings out, the in-depth links with the society.

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1 **A.** Yes.  
 2 **SIR BRIAN LANGSTAFF:** So by medical people, you mean who?  
 3 Doctors?  
 4 **A.** Yes. Clinicians and surgeons. Even to this day we  
 5 found an air of arrogance to certain individuals --  
 6 not all, but certain ones. I mean, for example, all  
 7 of my haemophilia nurses have retired and left because  
 8 they couldn't take it anymore, and they helped me  
 9 historically and many others in this room over the  
 10 years beyond the pale, literally beyond the pale.  
 11 **SIR BRIAN LANGSTAFF:** So you saw tension between them and  
 12 the medical staff?  
 13 **A.** Yes, very much so, and I believe that carries on now,  
 14 without mentioning any names, because there are  
 15 a couple of who are still in post. Yes. They try and  
 16 do their best for us, and there's just no urgency for  
 17 anything -- other than the nursing staff to do  
 18 anything for us. And that's a haemophilia thing.  
 19 That's not a HIV thing. That is a haemophilia  
 20 problem.  
 21 **SIR BRIAN LANGSTAFF:** And do you have any insight from  
 22 actual experience as opposed to from opinion as to why  
 23 the medical staff relate to you in that way when  
 24 others in the clinical field don't?  
 25 **A.** Again, I think it harps back to when I was young and

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1 Also, the mattress(?) which we have spoken about.  
 2 Again, I think all the trusts warrant their own  
 3 Inquiry. Again, the thing we touched on is I do  
 4 believe that haemophilia, whether it is infected,  
 5 co-infected, whatever, people need more education  
 6 through the hospitals about haemophilia. They haven't  
 7 a clue, and in an emergency situation, haemophilia  
 8 will kill you in a short amount of time. This  
 9 knowledge seems to have vanished over the last ten  
 10 years.  
 11 So I think, yes, I think that's about all I have  
 12 got to rant on about really.  
 13 **MS RICHARDS:** Thank you. Sir Brian.  
 14 **SIR BRIAN LANGSTAFF:** Well, rant on you certainly haven't.  
 15 Can I just ask you a question? In one of the  
 16 passages of your evidence you described how you were  
 17 quite argumentative at times, and you added this:  
 18 "You have to be with the medical profession."  
 19 **A.** Yes.  
 20 **SIR BRIAN LANGSTAFF:** Can I just explore how far that  
 21 goes, because you have said quite a lot of very  
 22 positive things about nurses --  
 23 **A.** Yes.  
 24 **SIR BRIAN LANGSTAFF:** -- about social workers, about the  
 25 professions allied to medicine.

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1 you just feel like you are a disposable commodity.  
 2 You are neither one thing or the other. You know, you  
 3 are looked upon -- you can walk in, but you are  
 4 a disabled person. I don't know what goes on in their  
 5 mind, but we have certainly come across arrogance in  
 6 the last few years beyond belief, and it should really  
 7 stop. You know, we live in a different time now,  
 8 which is probably going to be one of the argument for  
 9 the doctors a few years ago that infected us. But  
 10 there's a lot of education that needs bringing forward  
 11 about haemophilia and that sort of illness really.  
 12 I can only talk about haemophilia. No doubt other  
 13 people are worried to death about thrombosis or  
 14 whatever, how they are treated and the knowledge  
 15 behind that, so ...  
 16 **SIR BRIAN LANGSTAFF:** Well, thank you very much for that,  
 17 and thank you in particular for coming and giving your  
 18 evidence. From what you have said, you have explained  
 19 very clearly, as I see it, the tension between being  
 20 very apprehensive about saying anything at all -- you  
 21 put it that you are very selective about who you tell  
 22 in those last few extracts that were read to you about  
 23 how the stigma has affected your life. You have  
 24 explained exactly why you wanted to keep everything  
 25 quiet -- and yet you have got the desire to be useful,

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1 in particular to tell people, to communicate, to  
 2 educate, and the two pull in different directions.  
 3 Certainly your giving evidence has been much more of  
 4 the latter than the former, although I know it has  
 5 been a struggle for you to bring yourself here.  
 6 **A.** It has, yes.  
 7 **SIR BRIAN LANGSTAFF:** And I very much appreciate that.  
 8 **A.** I do believe that this has to be the end, this  
 9 Inquiry. Many of us have campaigned for years and  
 10 years and years in this room. We have come so close  
 11 and we have had two inquiries that have just been  
 12 utter whitewashes. We have had to step up again and  
 13 try and see justice this time. And that to me is what  
 14 it's all about.  
 15 I have spoken to you, obviously, and I -- what  
 16 I want to see is criminal charges. That's my goal,  
 17 and that's Birchgrove's goal, but we will see. I know  
 18 the Inquiry hasn't got the teeth to do that, but ...  
 19 **SIR BRIAN LANGSTAFF:** No. The Inquiry has no -- I have no  
 20 power, no right to determine criminal liability. I am  
 21 able, I think -- and if I find it, I will -- to say  
 22 that fault occurred, but that's rather different.  
 23 **A.** Yes.  
 24 **SIR BRIAN LANGSTAFF:** Thank you very much.  
 25 **A.** Thank you.

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1 identity.  
 2 Could we have Frankie, please.  
 3 **FRANKIE (sworn)**  
 4 **Questions by MS RICHARDS**  
 5 **MS RICHARDS:** Frankie, as with the previous witness, who  
 6 you were formerly married to, you may be using names  
 7 in the course of your evidence, because it may be  
 8 easier for you to refer to names, but that is covered,  
 9 as with the previous witness's evidence, by the  
 10 restriction order and those names cannot be repeated.  
 11 You were 15 years old, I think, when the two of  
 12 you first met.  
 13 **A.** Yes.  
 14 **Q.** And you have described your former husband in this  
 15 way:  
 16 "He lived a very normal life. You wouldn't have  
 17 known he was a severe haemophiliac. He lived life to  
 18 the extreme and then an extra 10%, to the annoyance of  
 19 his parents."  
 20 **A.** Yes.  
 21 **Q.** You bought a property together at a very young age.  
 22 **A.** Yes.  
 23 **Q.** And you married at a very young age --  
 24 **A.** Yes.  
 25 **Q.** -- in 1984, when you were just 18.

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1 **(Witness withdrew)**  
 2 **SIR BRIAN LANGSTAFF:** Well, we'll take a break until  
 3 11.40.  
 4 **(11.09 am)**  
 5 **(Short break)**  
 6 **(11.43 am)**  
 7 **SIR BRIAN LANGSTAFF:** Our next witness also is anonymous  
 8 and there will also be no live streaming of her  
 9 evidence. She is witness W1388, but in her case,  
 10 rather than use letters, we are going to use the name  
 11 Frankie: that's at her request.  
 12 The name and address of witness W1388 -- to you  
 13 and me, Frankie -- and any other identifying  
 14 information, such as the name of the witness's former  
 15 partner, the witness's image or a description of their  
 16 appearance, cannot be disclosed or published in any  
 17 form unless express permission is given by me or by  
 18 the Solicitor to the Inquiry on my behalf. Witness  
 19 W1388 must be referred to only as "Frankie".  
 20 This order remains in force for the duration of  
 21 the Inquiry and at all times thereafter unless  
 22 otherwise ordered, and I may vary or revoke the order  
 23 by making a further order during the course of the  
 24 Inquiry.  
 25 That is the order which protects Frankie and her

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1 **A.** Yes.  
 2 **Q.** We have already heard from him about the glandular  
 3 fever that he had in 1984, early 1984. Can you recall  
 4 anything about that?  
 5 **A.** Yes. At the time I was living with his parents,  
 6 because we'd bought the house and it was just going  
 7 through and I had to find a job in that area, so we  
 8 moved in with his parents so I could work and find  
 9 a job. I mean, it was pretty different times then.  
 10 You know, we had 100% mortgage. We realistically had  
 11 no idea what we were doing. We just knew what we  
 12 wanted to do. I knew that I wanted to move forward  
 13 with my life. I wanted, you know, to, dare I say it,  
 14 have more than my parents. My father always said --  
 15 sorry.  
 16 **Q.** It is all right. Take your time.  
 17 **A.** Blimey. I have got no chance if I'm crying already,  
 18 have I?  
 19 My father always said that we were cannon fodder,  
 20 you know. As working class people, that's what we  
 21 were. Well, I didn't want to be cannon fodder. So  
 22 I met [redacted]. We both were very focused on doing  
 23 the best we could, achieving the best we could. Yes,  
 24 we had aspirations, but they weren't mad aspirations;  
 25 they were just aspirations of being the very best we

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could.

The ironic thing is we both thought Maggie Thatcher was amazing and, in fact, she was killing us. So, you know, she said, "You can be anything you want to be, it is just up to you". We said, "We can be anything we want to be, it is up to us", and that's the decision that we made. That's who we were. I'd just like to lie that down because, you know, everything that came afterwards totally destroyed that.

Q. And that's how you had started your married life at this very young age.

A. Yes.

Q. With buying a home and with aspirations to do the very best for yourselves that you could.

A. Yes.

Q. We have already heard about [redacted] being taken ill in the early part of --

A. I'm sorry, you asked me about glandular fever.

Q. No, that's all right.

A. I completely went off on a tangent.

Q. Don't worry, I had forgotten I asked the question.

A. So we were living with his parents and he got really ill, but [redacted] was the type of person that didn't really get ill, and even though he had bleeds and he

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so poorly that we rang his parents.

Now, God bless them, they didn't do a lot for us, but they did actually do that. So we went up to accident and emergency, and obviously [redacted] was dropped off by his father with me at the emergency doors and then gone away to park the car. I mean, if anybody has been to the Queen Elizabeth, they know just what it is like to park a car at the QE. So I would imagine that his father was gone for quite some time.

I remember us going into accident and emergency, I remember him being put on a stretcher, and I remember a conversation about the mention of AIDS. Like [redacted] said earlier, I don't know whether it was AIDS that was mentioned or whether it was, you know, HIV that was mentioned, but there was something, and there was something that was in the public persona.

We were kids, you know. I'd just -- I don't think I was even 19 then. He was 21. We had no concept of the real world, you know, we just ran about on our scooters, the same as what we did when we were 15/16. We may have had a mortgage, we may have had bills, but we got this mortgage and we got these bills at the end of the month, I thought, "Oh, my God, how am I going

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had issues with haemophilia, it was never an issue.

We used to -- I mean, like he said, we had scooters. We had Lambrettas and we used to travel around the country. You know, these things, they could stop at any time, you could come off and then be on the floor, but it didn't seem to bother him whatsoever. So that's what we did. We got into all sorts of trouble with it, aiding an abetting and all sorts of stuff. We were proper get out there and do.

So when he was laid flat with glandular fever, it was quite surprising how ill he actually was. So, yes, it was quite a significant thing that you don't forget.

Q. And then the following year, in the first half of 1985 -- the records don't reveal any kind of date -- your statement talks about [redacted] being taken to hospital in an emergency and you were taken there, I think, by his father.

A. Yes. So --

Q. What can you recall about that?

A. I can recall that, again, because [redacted] wasn't ill that often. I didn't drive at the time. I didn't actually learn to drive until a few years later, because (a) we had no money for driving lessons and (b) we had one car, so it was irrelevant. So he was

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to pay these bills because I have already spent my money".

So we had no concept. I think people have to understand though we did these things, we had no methodology. For want of a better word -- I was not particularly well educated at that time and I guess we just went on.

So we heard this information and we heard this stuff that never really got into the psyche but was there. I hope that makes sense, because it didn't really register with any of it. Yes. Anyway ...

Q. And it was then, at the beginning of August of the same year, 1985, you were pregnant.

A. Yes.

Q. And you and he went to see Dr Franklin.

A. Yes.

Q. And as I understand both his evidence and your written evidence, the reason you went to see Dr Franklin was because you were pregnant and because of this information and fear about the risk of AIDS.

A. Yes. We were scared, but we didn't really quite understand, and I guess what happened is because -- I keep saying because we were young, but we had no support, we had no one around us. So if you can imagine you have got somebody that's 18 and 20

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1 discussing this about this thing, whatever this thing  
2 is. We don't really know about it and we are being  
3 taken along with the current, if that makes sense. So  
4 our sensible option is to do what it is that we chose  
5 to do, and, you know, as we carry on with this and  
6 other things happen, it's not even the virus anymore.  
7 It is about the support about how you kind of -- you  
8 are kind of in an arena, kind of like a gladiator, you  
9 know.

10 Q. You put it this way in your statement, talking about  
11 those events in August of 1985. You say:

12 "We were being bombarded with information about  
13 the risk of HIV. It was a terrible time and we were  
14 at a loss about what to do."

15 A. We didn't really know what to do, because, as you have  
16 already shown, [redacted] hadn't even got an actual  
17 diagnosis. So, you now, we are in August 1985 and  
18 [redacted]'s actual diagnosis was May 1986. So can  
19 you even think what was in our head? Because I can't.

20 What we were told -- because we weren't actually  
21 officially told anything, but yet in my notes it  
22 refers to HTLV, but I don't even know what that is,  
23 but we are taken with a current that there is  
24 something there that isn't right. So you are moved  
25 along with that. So it no longer becomes your

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1 the test came back negative.

2 A. Correct.

3 Q. In the years that followed the diagnosis in 1985, you  
4 have described them in your statement as being  
5 incredibly difficult years.

6 A. Yes.

7 Q. You thought your husband was going to die.

8 A. Yes, but he never did. So basically our life just  
9 carried on the same, and all that happened is it  
10 became more and more difficult for [redacted] to act  
11 rationally. I am sorry, because, you know, he  
12 obviously is in the room. It was difficult, you know.  
13 I was working four jobs. I didn't drive. So I used  
14 to ring him at night to come and pick me up and he was  
15 so pissed that he couldn't. So I'd either walk or I'd  
16 drive -- sorry -- or I'd get somebody to give me  
17 a lift or I'd bus.

18 So I used to do split shifts. So I used to get up  
19 in the morning, walk to the bus stop, catch two buses,  
20 walk to work, finish my shift, catch two buses, go  
21 home, catch two buses, walk. Okay? So this was my  
22 life. All it was was a drudgery to try and keep us  
23 together as a couple and try and maintain some sort of  
24 normality.

25 Well, I don't -- when I look back at those times,

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1 decision. It is just something else that in the end  
2 of this you would put in a box and it's there.

3 Q. We looked during his evidence at the letter that was  
4 written by Dr Franklin to your GP, Dr Jones, about the  
5 risk of transmission of HIV to mother and to foetus.  
6 You didn't see that letter at the time, but you have  
7 made this observation about it in your witness  
8 statement. You have said that:

9 "That effectively confirms the terrifying position  
10 that we were in. We didn't know if he was going to  
11 test positive, but we were being told that the risk of  
12 our baby having HIV, if he was positive, was  
13 sufficient to justify an abortion."

14 A. Uh-huh.

15 Q. You have told us how very young you were at the time.  
16 We have got a photo that shows that very clearly.  
17 Could we put up the photo, please? It is only going  
18 to be shown in this room. We can see there a picture  
19 on the screen of the two of you at this time, little  
20 more than children.

21 A. Yes.

22 Q. You did have a termination in August of 1985.

23 A. Yes.

24 Q. That [redacted] was HIV positive was subsequently  
25 confirmed. You were tested and at that point in time

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1 I don't actually know how we got through them. And  
2 people talk about their experiences with HIV and, you  
3 know, how they had support of their family, they had  
4 support of people around them. Some did; some didn't,  
5 you know. We had nothing, you know, and to this day,  
6 to this day, you know, for every bit that we have,  
7 a new chair and everything else at the Haemophilia  
8 Society, you know, I swear to God that Haemophilia  
9 Society, regardless of whether we were on their  
10 membership, they should have come and knocked our door  
11 and said, "Can we help you? How can we help you?  
12 What can we do?" But no, they didn't. No, they  
13 didn't. Nobody cared, and you couldn't talk about it.

14 So in the drudgery and keeping the bills going and  
15 [redacted] not working and [redacted] drinking,  
16 I don't know where I fitted in with that, because all  
17 I did was act like that was my husband and there was  
18 no restriction at all, because he was my husband and  
19 what else could I take away? I am sorry if that  
20 sounds right, wrong or indifferent, but that's how it  
21 was.

22 Q. In 1989 you found out that you were pregnant again.

23 A. Yes.

24 Q. You discovered that I think quite late.

25 A. Yes.

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1 Q. And you went to see your GP.  
 2 A. Yes.  
 3 Q. What can you recall your GP saying to you?  
 4 A. I don't -- if I'm honest, I don't -- I think, if  
 5 I look back on it now and if I'm perfectly truthful  
 6 with you, probably since that day, which is, what,  
 7 30 years ago, 20 years ago -- no, 30 years ago, my two  
 8 pregnancies have been one, because I can't actually  
 9 cope mentally with one, let alone two. Okay? So  
 10 I don't know what I said to that GP. I don't know the  
 11 conversations that we had. I just know that if I'm  
 12 not working and I've got a child and we are in this  
 13 situation, truthfully, is that a good environment, bad  
 14 environment, you know? I'm just scared and I don't  
 15 know what to do, and I'm still scared, because I made  
 16 that decision. The worst part about that decision is  
 17 that 30 years later I'm having to justify that  
 18 decision and I don't know that I can. Sorry.  
 19 Q. Would you like a break?  
 20 A. I'm so sorry.  
 21 Q. There's no need to apologise at all. Would you like  
 22 a break?  
 23 A. No. I'm okay.  
 24 Q. There's some water beside you.  
 25 A. I'm not sure I can hold it, but yes, thank you.

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1 I do.  
 2 Now, the worst part about being in this room is  
 3 actually thinking that I am going to be judged, and  
 4 that is so difficult, and that actually is a situation  
 5 that I've been put into that is absolutely no fault of  
 6 my own, you know. I cared for my husband. I loved my  
 7 husband. You know, how much do you take away? You  
 8 know, we are in a situation where we were at an age  
 9 where, if we had had kids then, we would have done.  
 10 We missed out on the sperm washing. We were too old  
 11 for that.  
 12 Now, if I look back and think about the fact I am  
 13 not a grandchild -- sorry -- grandmother, you know,  
 14 I am bitter, and I am really sorry for everybody that  
 15 I have hurt in that bitterness, but I cannot keep  
 16 justifying and keeping our story told, because every  
 17 time it gets told, it kills me a little bit more. And  
 18 I don't want to die anymore, you know. I want to  
 19 live. That's what I want, and that's all I want from  
 20 this Inquiry.  
 21 I am sorry. I have gone off on a tangent again.  
 22 Q. You haven't at all.  
 23 You have in your statement described what happened  
 24 on the day of the termination.  
 25 A. Yes.

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1 Q. You have said in your statement -- and I will read  
 2 a sentence from your statement, if I may -- about this  
 3 time:  
 4 "I was a frightened young woman who went to my GP  
 5 for help and I was made to feel like I had no other  
 6 option than to terminate my pregnancy. I can no  
 7 longer even comprehend what was said to me to make me  
 8 agree with what they wanted."  
 9 A. No. I don't -- so we talk about, you know, having to  
 10 recall what we went through and, you know, the more  
 11 conversations that people have, the more this isn't  
 12 virus-led at all, you know. I don't care.  
 13 Virus-wise, I don't care about animosity. I don't  
 14 care. All I care about is decisions that people had  
 15 to make that are just beyond comprehension.  
 16 You know, every person in this room has got  
 17 a story. Every person has got an individual story.  
 18 People have lost people. People have grown up without  
 19 their dads. Even grandchildren are involved in this.  
 20 It is just so wrong. It is just so wrong that we are  
 21 having to recall this stuff, and not only has it  
 22 destroyed us then, but it is destroying us again and  
 23 again and again. I hope this is an end to that, you  
 24 know, because I don't want to wake up every morning  
 25 and class myself as a murderer, because that is what

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1 Q. And I have heard you talk about that before.  
 2 A. Yes.  
 3 Q. It is entirely a matter for your decision as to  
 4 whether you want to say anything about that now,  
 5 whether you would like me to read that passage from  
 6 your statement, or whether you would rather we did not  
 7 talk about it further.  
 8 A. I think that you have to talk about it, because that  
 9 is what happened. You know, we are in 1989. We are  
 10 in a situation where celebrities are dying, you know.  
 11 This is not underground anymore. This is massive, you  
 12 know, and even I don't talk about [redacted] being  
 13 a haemophiliac. We don't talk about [redacted] being  
 14 a haemophiliac, even to people we have known for  
 15 years, you know. We just do not talk about it.  
 16 When I went in, I was put in a room on my own, and  
 17 there were not only biohazard stickers everywhere but  
 18 everybody -- you know, when you get people coming back  
 19 from Ebola, that's all I can liken it to, and you saw  
 20 them being wheeled across with all their stuff in.  
 21 That's the situation that I was in.  
 22 I was treated by the nurses like I was a murderer,  
 23 like what I was doing was completely and utterly  
 24 wrong. I wasn't allowed to leave the room. I had to  
 25 use the commode. [Redacted] was asked to leave. He

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1 couldn't be there, couldn't be by my side. Nobody  
 2 spoke to me during the whole time that I was there.  
 3 They were just rude. And at the end of it, when the  
 4 doctor came in to see me the day afterwards -- because  
 5 you have to remember that I had to give birth to that  
 6 child, you know. I don't -- and when you have to  
 7 completely shut that out in your mind, because on  
 8 Monday you have got to go back to work and keep the  
 9 house over your head, it becomes something rather --  
 10 an out of body experience, you know. It didn't happen  
 11 to me. It wasn't me. I didn't do that. But I did.  
 12 And then at the end, you know, when I am being checked  
 13 out, whatever it is, the doctor said to me, "Women  
 14 like you should be sterilised". What do I say to  
 15 that, you know? But that's what she said on her  
 16 parting shot.  
 17 Q. You said in your statement you went home. The two of  
 18 you never discussed it again, and then you have no  
 19 idea how you made it through the weekend, and on  
 20 Monday you had to go back to work as if nothing had  
 21 happened.  
 22 A. Yes.  
 23 Q. You were offered at that time no counselling and no  
 24 support.  
 25 A. No. I wouldn't even know what that was, if I am

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1 recognise us, because we are here.  
 2 Q. We will come back to your reference to Positive Women  
 3 and some of the complaining work you have done in  
 4 a little while.  
 5 A. Yes, yes.  
 6 Q. Following 1989, you and [redacted] increasingly lived  
 7 separate lives. You have described how you were  
 8 working multiple jobs. You felt isolated in a private  
 9 world in which you had no-one else to talk to, and you  
 10 have said in your statement that seeing each other was  
 11 a constant reminder.  
 12 A. Yes. So realistically I guess that 1989 was my  
 13 turning point of intelligence, for want of a better  
 14 word, and I thought about me for once, you know. In  
 15 all that time I thought about me and the need to  
 16 protect me, you know, and then I guess that is where  
 17 the disconnect began, because how can you love  
 18 someone, marry someone and take away that intense love  
 19 that you have without destroying it, without  
 20 destroying the marriage? You can't. They can't exist  
 21 side by side. They don't. They can't, you know. Not  
 22 for us, because we were passionate people. We were  
 23 believers. But the belief was going and the passion  
 24 was going too.  
 25 So I lived a separate life, you know. I didn't

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1 honest. What is that? You know, at the time I wasn't  
 2 aware -- I know it sounds ridiculous -- that  
 3 counselling even existed. What is that? I don't  
 4 know. I didn't know at the time.  
 5 Q. You have said in your statement that the fact that you  
 6 had two terminations as a result of the Contaminated  
 7 Blood Scandal is something you struggle to live with  
 8 on a daily basis. You don't know how you made those  
 9 decisions and you have been unable to forgive  
 10 yourself.  
 11 A. I can't. How can I, you know? How can I? And how  
 12 can you move forward, because time and time and time  
 13 again, when you think that you can settle, that you  
 14 can get on, it comes back. It comes back and we are  
 15 here again talking about it.  
 16 Realistically, did I want to come in and give this  
 17 statement? No, not a cat in hell's chance. I don't  
 18 want to be here. Do I want to put my life on the line  
 19 and what people think of me? No, I absolutely do not.  
 20 Because I hate me. So why would I want to give other  
 21 people that benefit? I wouldn't, but I have to.  
 22 I have to. Who knows how many Positive Women died?  
 23 I am not even sure there are any figures. We cared  
 24 and we loved our husband, and for that, some of us  
 25 became infected and some of us died. So please

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1 tell people about [redacted]. People didn't even know  
 2 I was married. I took my ring off, you know.  
 3 I completely and utterly blocked myself off from it,  
 4 and I used to go home and look after [redacted].  
 5 I used to go to the hospital. He wouldn't go to the  
 6 hospital. He wouldn't have medication. He wouldn't  
 7 eat properly. You know, all this stuff just mounts  
 8 and mounts and mounts and mounts, and you become so  
 9 oppressed by this as a person, taking away what we  
 10 have already been through, because by this point I am  
 11 like, "Right, that's it now", because I have to be  
 12 strong. I have to forget that, because that's gone,  
 13 that's done. Okay? Then you become strong.  
 14 So your compassion is gone, because all you've got  
 15 is fear, hate, regret, resentment, and that builds and  
 16 builds and builds and builds, and you build a barrier,  
 17 and the barrier you build is so strong, it is so  
 18 forceful, because it is not only protecting people  
 19 around you, because you might hurt them seriously with  
 20 either your words or your actions, but it's protecting  
 21 me. It is protecting my soul, because if I lose a bit  
 22 of it more, I am not sure what I am going to do, and  
 23 each time this happens, that little bit of soul goes,  
 24 you know.  
 25 People talk about suicide and they post their

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1 statuses up and they post -- I have thought about it  
2 loads. I have thought about it loads. I am too shit  
3 scared to do it, but I have thought about it. I just  
4 think if I just had the strength to do that, these  
5 voices in my head might -- might -- just for  
6 one minute stop destroying my soul. But I pick myself  
7 up and I say, "No, that's fine, we will carry on", and  
8 that's what I do every time.

9 So I guess it's a coping strategy, you know, that  
10 I made. I paid all the bills, you know. I mean, we  
11 were in such debt, it was incredible, you know.  
12 I picked up things from the MFT that I had sent for.  
13 Incoming, £500. Outgoings, £730. What? You know,  
14 how was I even existing? I have no idea.

15 Q. In 1997 the two of you separated, 1997/1998, and you  
16 went to stay with your mum.

17 A. Yes.

18 Q. You became over the following months very ill and you  
19 lost an awful lot of weight.

20 A. Yes. So in -- see, I don't know when I left, whether  
21 it was 1997 or 1998, to be honest.

22 Q. Don't worry.

23 A. I think it was 1998. So I went to live with mum, God  
24 bless her, and on the New Year's Day 1998 I was  
25 violently sick. I had walked home from a friend's.

73

1 A. Yes.

2 Q. But when you were tested again in 1999, the test came  
3 back positive.

4 A. Yes.

5 Q. And you were told, your statement says, that you had  
6 probably been infected by then for a number of years.

7 A. They say -- I mean, obviously it is very hard to say  
8 with HIV. So you can't categorically say, "This is  
9 when I was infected". But it could be to my mind that  
10 when I was tested in 1989 there was, you know, a false  
11 positive or whatever. But honestly I don't know.  
12 I think it's got to be there, but I don't know.

13 Q. You say in your statement that you had been advised by  
14 the MacFarlane Trust not to keep going for tests --

15 A. Yes.

16 Q. -- because that might impact upon your ability to get  
17 a mortgage or insurance.

18 A. Yes, yes. I mean, you've got to remember at that time  
19 we couldn't have any insurance because of [redacted].  
20 We couldn't have any cover on our mortgage. So every  
21 time he'd lose a job, we'd get no cover, we'd get no  
22 support, and then we'd get another loan to cover that  
23 bit, you know, and it built up and it built up.  
24 I could not put myself into a position of losing my  
25 grip the same way as [redacted] had, because who else

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1 She always had a New Year's Day party and I was just  
2 violently sick. Nothing else, no other symptoms, just  
3 this sick. I just got progressively worse. So I was  
4 going into work and I just was going for different  
5 tests. So I had all sorts of tests. I had endoscopy,  
6 every test going. I couldn't keep food down.

7 I got to such a point that I hadn't eaten or drunk  
8 for three days. A friend of mine took me to hospital  
9 and they took me in straightaway. I was 5.5 stone by  
10 then. I am not a big girl anyway, you know, so  
11 I didn't -- it was quick for me to lose the weight.  
12 But I was dying, basically.

13 They discovered oesophageal candida in my throat  
14 and the doctor said to me, "You have either got cancer  
15 or you've got AIDS". Of course I've got AIDS,  
16 because, you know, that's history. Not my history,  
17 because I believed I didn't, because at the beginning  
18 I would have said -- I don't know whether I became  
19 complacent that I was okay. I don't know. But  
20 I never, ever thought that I was HIV positive.

21 Q. And you had been tested in 1985 --

22 A. Yes.

23 Q. -- and in 1989.

24 A. Yes.

25 Q. Those tests were negative.

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1 is there then? We are going to lose everything. So  
2 that was my decision to make. And to be honest with  
3 you, I do think that I was complacent, that I thought  
4 I was okay.

5 Q. Over the years that followed you have suffered from  
6 a number of opportunistic infections --

7 A. Yes.

8 Q. -- through having HIV, and the treatment process for  
9 you has been far from straightforward. We have got  
10 a letter that shows some of the problems you have had  
11 with the different medication regimes.

12 A. Yes.

13 Q. Henry, it is 1388004, please: it says this. It is  
14 a letter dated September 2019 from Dr Roberts:

15 "To whom it may concern."

16 It explains you have:

17 "... had a complex antiretroviral history, having  
18 been initially on a combination of Combivir with  
19 Efavirenz from July 1999 to June 2005. She started to  
20 develop lipodystrophy which was a well-recognised  
21 complication of AZT component of Combivir and  
22 therefore switched to Truvada in June 2005."

23 Pausing there, I think you have had to have  
24 reconstructive surgery because of the lipodystrophy.

25 A. Yes.

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Q. "In March 2009 it became clear that she was developing classical side effects to Efavirenz with memory and sleep disturbance and made a further switch to Truvada with Atazanavir/Ritonavir."

A. The Efavirenz or however we say it -- because I have no idea what tablets I am even on now, they are yellow -- that was probably one of the most destructive drugs, because you got psychotic issues, real psychotic issues. I think we have heard from a few people that were on different drugs over the years and they have made decisions about things. Now, that might be the HIV or it might be AIDS or it might be the drugs.

So, you know, a lot of these drugs had side effects and had debilitating issues on your life while you were taking them, but you didn't really know that they were doing it. Did that make sense?

Q. It does.

A. So, you know, it is only when you talk to other people and you think, "I am on that drug and that does do that for me", because you just accept that is a process within your infection, so ...

Q. Then we can see that the letter records as recently as 2018:

"In 2018 we observed a deterioration in her renal

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exercise. I do look out for myself. This is even destroying that. I can't run anymore. I find it difficult to walk because of my hips, because they are in pain. You know, it stops every single thing you do every step of the way, you know, and it is so frustrating, because you don't want it to, but it does.

So I don't know what effects this has had on my renal area. I don't actually know what that means. Actually, I don't really want to know, you know. It is just something else to worry about, you know. I had an opportunistic infection in a very vile place that now means that from a -- I am sorry if this is -- from a toilet point of view it makes my life difficult, you know.

But you can't see that, and the DLA or whatever it is, they don't care. They don't want to know. You are just -- that's just happened to you because it is okay, because you can have a tablet a day, you know. And if I hear anybody say that to me, my God, I might just deck them, because come and sit in my shoes. Come and sit in all our shoes.

I am not taking anything away from anybody else and I never would and I never have, but they want to take it away from me, you know, and I will fight you

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function, and as data concerning the use of TDF tenofovir became clearer that this agent can be associated with reasonable tubular disorders, added to which we undertook a bone density scan on 9th April 2018 which showed a minimal density in the lumbar spine and both hips ..."

It goes on to record that those are recognised complications of the drug regime. It then refers to a switch to TAF and Genvoya in February 2018 with an improvement in your renal function, but then again it reports recent complications in May of this year, weight gain, troublesome central distribution of fat deposition, an increasingly recognised complication of integrase inhibitors which are contained within the Genvoya combination started in 2018.

So yet again very recently your drug regime has changed last month to Symtuza. It says you are very pleased with the current combination therapy and have ongoing virological suppression. That has been ongoing for about a month.

A. Yes. The thing is with each drug and each different side effect -- so I am a big believer in looking after yourself and looking the best you can and being the best you can. Whatever happens to us, that has never been taken away. I look after myself. I eat well and

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every step of the way for you to understand what we have been through, not just psychologically, not just physically, but our whole life, you know. 35 years. 35 years of trouble, stress, unhappiness. Enough now.

Q. You have related in your statement that you have suffered from cognitive difficulties in relation to concentration and memory.

A. Very difficult when you are an accountant, you know. When [redacted] and I were going through really, really rough times, I decided that I was going to take myself back into education. So in 1996 I signed up for -- I don't even know -- HNC -- I don't know if they even do them anymore -- in business management and economics. Now, this is a girl that failed elementary maths and basically, you know -- but what I have done is I have run a house and I know how to rob Peter to pay Paul. So really that's just mathematics, isn't it? Because you just balance things out.

So during the time that was going on with [redacted] I spent two nights a week at college, because it was respite, and it kept my mind active. I didn't think about stuff, I just was busy with learning. Everything was a thirst to learn.

So I finished my HNC, which I passed with

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1 distinction, and I started my foundation degree.  
2 I started my foundation degree in 1998, and quite  
3 clearly I was sick then. So even though I'd got  
4 admitted into hospital in the August when, you know,  
5 we are in recess, in September I am back in college  
6 doing my foundation degree. So that is where I am,  
7 you know.

8 I have lost my way a bit, haven't I?

9 So during all that time I always kept active with  
10 my education. So I went from the foundation degree  
11 and I did a Bachelor's degree in business and  
12 economics, which I again passed. I started my  
13 Master's, but it was just too much. Enough now,  
14 council girl, you have reached your limit of your  
15 education.

16 So, you know, for me there's always been  
17 a distraction. I went on then to do my English and  
18 maths GCSEs just to prove I could. I did sign  
19 language. I kept busy with different things and  
20 I always wanted to aspire to be -- I don't know what  
21 that aspiration was. At one time it was a teacher,  
22 another time it was nutrition, but I just wanted  
23 a focus, and that's where I was.

24 The more time has gone on, the more difficult it  
25 is to concentrate. I am not just talking about going

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1 Then we had to find it. Then I had to make sure he  
2 was okay, that we didn't know.

3 So you have got to understand that protection  
4 aspect of loving someone so much that it doesn't  
5 matter what the situation is. If anyone in this room  
6 married somebody and something happened to that  
7 person, they'd do everything, because they love them,  
8 you know, but this has been allowed to take that love  
9 away. It's been allowed to take my compassion away.  
10 I don't want to do that anymore. So ...

11 Q. You have told us how there was an absence of help and  
12 support in the early years. Very recently, this year,  
13 you have been receiving trauma therapy --

14 A. Yes.

15 Q. -- from a clinical psychologist.

16 A. Yes.

17 Q. You say in your statement over the years you have  
18 tried some forms of earlier therapies.

19 A. Quite generic. You know, you could go through the  
20 National Health Service before, because there was some  
21 kind of help for mental health. I mean, there is  
22 nothing now. You can try generic therapists. But, to  
23 be honest, they never really get to it, because it is  
24 packed so tightly away that you don't want to bring it  
25 out. Unless you bring it out, you can't address it,

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1 upstairs, forgetting the fact -- what you have walked  
2 up for. I am 53. That happens. It is just -- you  
3 know, I am here now in a situation that I feel so  
4 passionately about and I believe so much about, so  
5 I can tell you that as soon as I am in a situation  
6 where I am not comfortable and I am learning and I am  
7 educating myself, it is not so simple anymore. That's  
8 the difference.

9 So if you are going to sit and read something that  
10 you know nothing about, you have got no knowledge  
11 about and it goes in and, you know, you can absorb  
12 that -- you have to take into account I am getting  
13 older as well -- you can absorb that -- you can't.  
14 You can't. I can't even tell you what it is. I have  
15 a conversation with [redacted]. By the end of the  
16 conversation neither of us know what either of us is  
17 talking about.

18 At the end of the day, we were in a marriage like  
19 that, because realistically I was infected and neither  
20 of us were on drugs, you know, and the whole thing  
21 just became this great big, huge monster that we had  
22 got no control over that you take distraction tactics  
23 about. [Redacted]'s distraction tactics were  
24 scooters. He didn't care how much anything cost  
25 because the money was there. Until it wasn't there.

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1 you know.

2 This lady has tried a technique on me, because she  
3 diagnosed me with post-traumatic stress, which we had  
4 a laugh about last night, because it is not really  
5 post, is it, because it is still going on.  
6 Post-traumatic stress syndrome. She has been amazing,  
7 because although I haven't been able to hold it  
8 together that much here today, I don't want to be  
9 angry and bitter anymore. I just want it to stop. So  
10 in order to do that I need to find therapy that will  
11 do that, you know.

12 So she's been really good, and I have to say, you  
13 know, through everything with EIBSS -- and I know  
14 everybody has problems and everybody has issues, and  
15 I am not saying that they're any good because none of  
16 us want a support system. We all talk about benefits  
17 and passporting -- I have never had a benefit in my  
18 life apart from DLA when I was first diagnosed with  
19 HIV, or AIDS, should I say. I don't want to be on a  
20 benefit system. I'm sure nobody in here wants to be  
21 on a benefit system. We want to be able to live our  
22 life, you know, and be afforded that opportunity to do  
23 so.

24 I have lost track again. I am sorry. What did  
25 you ask me?

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1 Q. Not at all. You were talking about the counselling.  
 2 That has been funded through the EIBSS.  
 3 A. So I had to obviously jump through a large amount of  
 4 hoops in order to get this, but I believe that I need  
 5 to heal and I'm passionate enough that I can put this  
 6 together to get this healing, because it is the right  
 7 time for me. It might not be the right time for  
 8 everybody else, but I feel it is the right time for  
 9 me, and EIBSS, although they are a pain in the arse,  
 10 compared to the MFT, my God, they are kittens.  
 11 So I guess we are all hardened to that aggressive,  
 12 matter of fact, throwaway of us, because we've put up  
 13 with it for so long, but, you know, we are human and  
 14 we do want to be treated that way. So no support  
 15 system, no matter what support system they put in  
 16 place, will ever recognise that because it is just  
 17 a support system. That is not what we want and not  
 18 what we deserve.  
 19 Q. You heard the evidence that [redacted] gave about the  
 20 American litigation.  
 21 A. Yes.  
 22 Q. I think you too went to the States for the purposes of  
 23 that litigation.  
 24 A. Yes.  
 25 Q. And you have a recollection of the questions that you

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1 Do you know how hard it is to walk into that room  
 2 and sit in front of five people who are  
 3 cross-examining you? It is horrendous, absolutely  
 4 horrendous. Not only did they cross-examine you, they  
 5 were so aggressive that I thought to myself, "Who am  
 6 I doing this for? Because this is not for me", you  
 7 know. But I just think, "I am just going to do it".  
 8 Q. Can I ask you a little bit about the MacFarlane Trust.  
 9 One of the observations you've made in your statement  
 10 about the recent dissolution of the MacFarlane Trust  
 11 was the transfer of its funds to the Terrence Higgins  
 12 Trust.  
 13 A. Yes.  
 14 Q. And the point you have made in your statement was that  
 15 that was undertaken with no consultation with the  
 16 community.  
 17 A. No. So I didn't find out about the THT until it was  
 18 all done. I don't think any of us found out about the  
 19 THT until it was all done. I don't have a problem  
 20 with THT, but THT, really they are about a homosexual  
 21 environment, you know, not -- and everybody needs  
 22 support in a different way. We all need support in  
 23 a different way.  
 24 So your first aspect of that is: why would  
 25 somebody do that, because what is our association with

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1 were asked.  
 2 A. Yes. Well, first and foremost, when I went in to give  
 3 my evidence, I was told not to look like a woman.  
 4 Does that make sense? As in sexual, as in as a woman,  
 5 as in, you know, that you would prefer to dress, that  
 6 you would -- does that make sense?  
 7 Q. Yes.  
 8 A. So I had to change my dress. That was the very first  
 9 thing, because I had a shift dress on, and at the time  
 10 I was very, very slim, so I guess -- you know. That  
 11 was number 1.  
 12 So you go into a room and I think there were five  
 13 attorneys there, and they were so aggressive you would  
 14 not believe. So I am here as -- I don't know how old  
 15 I was at the time. So it would be 15 -- I was  
 16 probably early 30s. So I was a little bit more savvy  
 17 by then, a little bit more. So I went into a room  
 18 with these five solicitors and basically you were made  
 19 to feel like a prostitute, a drug user, and when they  
 20 talked about my terminations, they basically just made  
 21 me feel the way I feel in this room today, you know.  
 22 So I guess that kind of sticks with you, and we  
 23 went through all that, for what? Another  
 24 disappointment, another cast-off, you know. You keep  
 25 going through this stuff to be cast aside again.

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1 that, you know? It is difficult enough that we are in  
 2 MFT when you have got male, female -- you know, you  
 3 have already got a division of men, you have different  
 4 aspects of it, you have already got a bit of a melting  
 5 pot, and then you have introduced another bit of  
 6 a melting pot. So I don't know why they did that, you  
 7 know. It was another way of the MFT saying, "You mean  
 8 nothing. We are not going to consult you. We are  
 9 just going to do whatever it is we are going to do".  
 10 The complete arrogance of these people is beyond  
 11 reproach.  
 12 So I think all of us -- I say all of us -- a few  
 13 of us who obviously knew about that contacted THT. So  
 14 you have got a massive organisation here, THT, which  
 15 gets a lot of publicity, which has got processes  
 16 an procedures in place that have been in place for  
 17 years and years and years, and they have got this  
 18 little -- it is not even a lot of money, you know.  
 19 They have got this tiny little fund.  
 20 So we get somebody allocated to us initially that  
 21 we talk to. You know, obviously people had real  
 22 worries, you know. There were loans that they didn't  
 23 know what was happening to these loans. People had  
 24 been held back for 30-odd years, not being able to  
 25 move, not being able to live their lives because of

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1 a decision they made when they were on the floor. So  
2 this has been transferred to somebody else, who has no  
3 face, that's part of an organisation that is in place  
4 for years. It is like going into a door and saying,  
5 you know, "We are here".

6 So we get allocated this guy and have some  
7 communication with him and you go through the whole  
8 rigmarole of what your problems are. All of a sudden,  
9 this guy disappears, not to be heard of again. You  
10 contact THT and they say, you know, "We are just  
11 recruiting for somebody". So they went through  
12 a process of recruiting somebody and now they have  
13 recruited somebody. So you have a communication with  
14 this recruited person, who initially was lovely, you  
15 know. I have to say he helped me set up my  
16 counselling, you know, he started the ball rolling, he  
17 helped me with things. They helped with the loans.  
18 They have dispensed with the loans, which is fabulous.  
19 But where is this person today? Nowhere to be seen.  
20 He was on Twitter supporting us. He is not on Twitter  
21 anymore. Disappeared.

22 So yet again, it is not even a lot, but it is our  
23 identity for what was given to us, for what has  
24 happened to us, has just been dumped somewhere that we  
25 have no communication with, that doesn't support us,

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1 Q. And because you were infected as a result of your  
2 relationship with your husband --

3 A. Yes.

4 Q. -- you are what the MacFarlane Trust termed  
5 "an infected intimate".

6 A. Yes.

7 Q. That's a phrase which you have described in  
8 communications to the MacFarlane Trust as insulting  
9 and dated, and you asked over a number of years for  
10 that term to be abandoned.

11 A. Yes. Since 2005.

12 Q. You believe that women infected in the way that you  
13 were infected have been overlooked or disadvantaged by  
14 the trusts and schemes.

15 A. Yes. I mean, I don't -- again, you know, I am not  
16 putting us above anybody. I just want us to be looked  
17 at as an equal thing, to be recognised of who we were.

18 We looked after our husbands. Some people looked  
19 after their husbands and they didn't become infected,  
20 you know, and they lost their husbands, and they are  
21 recognised. We supported our husbands. Some of us  
22 lost our husbands, some of us didn't, but we became  
23 infected. That's not recognised.

24 I have had somebody say within my vicinity that  
25 people like us are only infected because our husbands

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1 that doesn't speak for us. Yet another trust that has  
2 got money that has been given to support us that isn't  
3 doing anything else -- anything but.

4 So we have had the MFT, who shit on us for years.  
5 We get put in another support system, with has got its  
6 own problems, a different community of people. Please  
7 don't -- I am not taking anything away from anybody.  
8 Every single one of us is a different case. Every  
9 single one of us is an individual. Every single one  
10 of us has had a different experience. You cannot lump  
11 this into a big thing, because all it becomes is  
12 a melting pot of aggression.

13 So that's purposeful. Of course that's  
14 purposeful, because they want us to fight. They want  
15 us to say "I am better than you. What's happened to  
16 me is more important than you". It's not. Everything  
17 has happened to everybody and that individual case  
18 needs to be looked at and, you know, addressed. That  
19 is my real thing. I hope that happens.

20 So you've got 35 years of nobody speaking to you,  
21 nowhere you can go, no-one that supports you, and you  
22 are still trying to get your voice heard.

23 Q. You have had numerous dealings with the MacFarlane  
24 Trust over the years.

25 A. Yes.

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1 didn't love us. Now, I can't get my head round that,  
2 but it comes in my psyche all the time and it makes me  
3 so angry, but that is people's perception, and it's  
4 not, because you had to be there. They did love us  
5 and we loved them, and you had to be there to  
6 understand that protection, and unless you were, don't  
7 say anything.

8 Q. You've sought to raise your concerns about the  
9 differential treatment of this category the MFT termed  
10 "infected intimates" over the years with the  
11 MacFarlane Trust, Department of Health, EIBSS and  
12 others.

13 A. Yes. Haemophilia Society. The term doesn't -- they  
14 have taken some of the deed -- I mean, I don't even  
15 know what this deed was or what was in it or what we  
16 signed -- I have no idea. They have taken some parts  
17 of this deed to EIBSS and they have taken away some  
18 parts of this deed. So they pick and choose what they  
19 want. So we have an antiquated system on EIBSS of  
20 ridiculous stages of payment depending on whether you  
21 were a child, depending on whether you were married,  
22 depending on whether you had children. Ridiculous,  
23 you know. That should be gone. It should be sorted  
24 out, rectified, and everything with the other -- as  
25 far as hepatitis stage 2 is concerned, you get 20,000

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1 at stage 1, you get 50,000 at stage 2. You are not  
2 judged on whether you have children or no children, or  
3 like us, you are an infected intimate, where you are  
4 down here. You are even below.

5 So "infected intimate" is not known in the  
6 hepatitis world. It doesn't exist. So if somebody  
7 had hepatitis through their partner, they are treated  
8 as a registrant the same as everybody else, but we are  
9 not.

10 **Q.** It is the fact that this category was treated under  
11 the MacFarlane scheme differently, receiving less  
12 money than those directly affected, and then the  
13 differential under EIBSS between the categories of  
14 those infected --

15 **A.** That's correct.

16 **Q.** -- through one route or falling into different  
17 categories compared to those who can just go through  
18 the stage 1 and stage 2 process --

19 **A.** Yes, that's correct.

20 **Q.** -- have been the concerns you raised.

21 **A.** Yes, and that's not just for me. That is for lads who  
22 were young at the time who were given different to  
23 somebody who was married with children. Well, those  
24 lads now, some of them are married with children. So  
25 why is that difference still there?

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1 different in our personalities. We are very different  
2 in who we are. But we have a common goal in the fact  
3 that it is not about gender. It is about recognition  
4 of who we are, you know. I am not a women's liber.  
5 I am not into all that stuff. But, you know, at the  
6 end of the day, we should be recognised for who we are  
7 and we shouldn't be fighting, and these lads, you  
8 know, some of these lads have had no life. They have  
9 had no girlfriends, you know. And I just think this  
10 recognition just isn't there, because of the fact of  
11 HIV. Nobody wants to talk about HIV. I am sorry.  
12 Even the Haemophilia Society still don't want to talk  
13 about HIV. You know, I have spoken to Liz and I have  
14 spoken to Jeff, both of whom say the right words, you  
15 know, but they don't do anything. Nothing changes.  
16 And we are here again because nobody wants to talk  
17 about HIV, because it's been talked about. We have  
18 been sorted. We have had loads of money over the  
19 years. Have we?

20 You know, there's this belief about who we are.  
21 You know, there's belief about who I am. Do you know,  
22 I am passionate about what we have been through. I am  
23 not dispassionate to other people who have been  
24 through other things. I do recognise that. I just  
25 want people to recognise what we have been through

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1 So they have taken that antiquated bit of the deed  
2 and they have applied it in EIBSS, but as far as HIV  
3 is concerned, you can't get any grant for health  
4 purposes, you can't get any funeral plan, because  
5 apparently nobody is dying of AIDS anymore. Well,  
6 they might not be dying of AIDS anymore, but they are  
7 probably dying of everything else that they have got  
8 over the last 30 years.

9 So wake up and smell the roses. We might not be  
10 dying, but you must accept that every time something  
11 is brought in, we are -- it is like we are thrown  
12 away. It is like what we have lived through, what we  
13 have had to put up with, is just dispelled, because,  
14 "Well, you had AIDS, but you haven't got AIDS  
15 anymore". No, I might not have AIDS and there might  
16 be advancements in drugs, but you have seen the  
17 letter. Those drugs could come with an added issue of  
18 my health, and an added issue on my day-to-day life  
19 and way I want to live my life. Let's recognise this,  
20 please.

21 **Q.** Those, as I understand it, are the principal issues  
22 that you as part of I think the campaign organisation  
23 Positive Women, have sought to raise over the years  
24 with these various organisations?

25 **A.** Yes. Well, myself and another lady, we are very

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1 too. That's all.

2 **Q.** Those are the questions I have for you. Before I ask  
3 you if you have anything you want to add, I am just  
4 going to ask Mr Snowden if there's any further  
5 questions he has. No.

6 Is there anything further you want to say?

7 **A.** I just want to say to everyone in this room, I know we  
8 have all been infected, I know we have all had crappy  
9 lives. You know, I think that I have been -- I have  
10 probably been guilty of lashing out and, you know,  
11 appearing to be dispassionate, but that's because  
12 that's what has been shown to me, you know. You act  
13 as you find. From today, you know, enough, because my  
14 PTSD counselling is bringing my compassion forward.  
15 That's where I want to be. I don't want to be there  
16 anymore. So I am just going to be there. Thanks for  
17 listening, everyone.

18 **MS RICHARDS:** Thank you. Sir Brian.

19 **SIR BRIAN LANGSTAFF:** Can I tell you that in this room  
20 there is Bishop James Jones, the former Bishop of  
21 Liverpool, and I suspect that he might say that in  
22 scripture there are the words, "Judge not lest ye be  
23 judged".

24 Can I be very clear. In this room, you are not  
25 being judged for what you did, but valued for what you

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are and for what you have said, and for having had the strength to give evidence when you did not wish to do so, when it was obvious you were terrified about aspects of it, when you feared another American litigation experience, and somehow you have given us the enormous benefit of helping us to see things from your perspective. That is to my mind of great value, and that, and not judgment, is what we are about here today.

I wouldn't myself use words like "angry" or "bitter" to describe what you have saved. I think rather the words that come to my mind are "fierce" and "passionate" about what has happened to you and what should in the future happen to you, and I hope that your hopes for the future are realised.

A. Me too.

SIR BRIAN LANGSTAFF: Thank you very much.

A. Thank you.

(Witness withdrew)

SIR BRIAN LANGSTAFF: We'll take a break till 2 o'clock.  
2 o'clock.

(12.47 pm)

(Lunch break)

(2.03 pm)

SIR BRIAN LANGSTAFF: Our next witness I gather will be

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in the room that will remember that band and Andrew having to do the electrics of it and so on, but he was very happy when he was doing that and it is a happy memory.

Q. Can you tell us a little about what Andrew was like?

A. He was very bright. He had a great sense of humour. He was always making jokes. We had a lot of sort of running jokes all through our marriage, silly catchphrases we would use. He was very kind and generous, loving, always ready with a hug.

Before he sounds too much of a paragon of virtue, he could be very stubborn and he didn't used to like helping with the housework and that sort of thing. He was brilliant with children. He would have made a great dad.

Excuse me.

He loved me unconditionally. He was my best friend. He was such a special person. I could never believe that such a lovely person would love someone as ordinary as me.

Q. Andrew suffered severe haemophilia A, diagnosed when he was very little, a toddler?

A. Yes, yes.

Q. We can see if we have up on screen, please, Henry, 1090003, and if we go, please -- this is an extract

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happy to be called Amanda.

MS RICHARDS: Yes.

SIR BRIAN LANGSTAFF: Amanda, please.

AMANDA JANE BEESLEY (sworn)

Questions by MS RICHARDS

MS RICHARDS: Amanda, you are here to talk about your late husband, Andrew, Andrew Michael Beesley.

A. That's right.

Q. We are going to put up three pictures and then leave one of them up.

Henry, could we have 1090024, please.

That's you and Andrew.

A. It is, yes.

Q. Then 1090023, please. That's a picture -- we cut off the rest of what he is doing. He is reading to two children.

A. Yes. He is reading to my friend's children and they are absolutely wrapped in the story with him.

Q. Then 1090025, please. We will leave this photo up other than we are looking at documents. Do you want to tell us when this photo was taken?

A. I am not sure what year it was. There was a concert going on. His friend had a large band called Anaconda. Andrew used to do the electronics, the technical side of it. I think there are some people

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from the National Haemophilia Database, the UKHCDO health records. If we go, please, Henry, to page 6, we will see a list of some of the many products that Andrew received over the years for his haemophilia. We can see there, picked up at the bottom, late 1969 and early 1970s, cryoprecipitate. Then from 1977 onwards we can see that Andrew received a full range of Factor products, all the different commercial products as well as occasionally BPL Factor VIII.

If we go to the next page, please, Henry, and we look at the bottom half of the page, we can see that pattern continuing through the 1980s, with Andrew receiving Factor VIII, Koate, Kryobulin, et cetera.

A. Yes.

Q. The medical records and documents that you have exhibited to your statement show as a child Andrew had to travel from his home in Crawley to Great Ormond Street frequently in order to receive the treatment.

A. Yes. I was quite shocked actually when I got his records after he died and I got his records from Great Ormond Street to see how often he was actually in hospital. His mum used to go with him and stay in hospital with him. They would be there for a fortnight together, have a couple of days at home and then be back at the hospital, which must have been

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1 so disruptive to family life. He has got a younger  
2 brother. So brother and dad still at home must have  
3 been awful for him.  
4 **Q.** Perhaps reflecting that, arrangements were made when  
5 he was 6 years old for him to receive cryoprecipitate  
6 on a prophylactic basis locally through his GP or  
7 local hospital, and then his mother learned to  
8 administer treatment to him at home. In 1977, at the  
9 age of 11, Andrew joined Lord Mayor Treloar's College,  
10 which I'll call Treloar's for shorthand, in Hampshire.

11 We see from other documents that you have  
12 exhibited to your witness statement from Andrew's  
13 records a number to references to surveys, trials and  
14 research projects. We will just look at a small  
15 number of those, if we may, Amanda.

16 Henry, can we have 1090008.

17 We can see there a letter dated 16th  
18 September 1977 from Dr Painter, who was the medical  
19 officer at Treloar's, to the local paediatrician. If  
20 we just go towards the bottom of the letter, please,  
21 Henry, we see a reference there in the last part of  
22 the main paragraph:

23 "As the hepatitis survey about which Dr Kirk wrote  
24 to you in the past is now finished, it would seem  
25 likely that there would be no restriction on material

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1 between the two.  
2 1090010, please, Henry. If we go to page 3, which  
3 is the next page, we can see here again it's just  
4 an example. It's a letter dated 2nd June 1980 to a Dr  
5 Han, "Re: Andrew Beesley".

6 It says:

7 "I have recently communicated with the parents of  
8 this patient in order to obtain their permission to  
9 approach their child for a study of the half life of  
10 a new preparation of Factor VIII."

11 He talks about having:

12 "... erroneously stated that the project was on  
13 behalf of the Haemophilia Centre directors of Great  
14 Britain. In fact, it is a project merely at the  
15 discussion stage in the working party on home therapy  
16 prophylaxis."

17 That's from Dr Aronstam.

18 Again, you don't know if that's the trial Andrew's  
19 mother had been asked to sign her agreement to or not?

20 **A.** No, I am sorry. I don't know.

21 **Q.** Then we have 1090012, please. We see here again  
22 a letter from Dr Aronstam. This is September 1980:

23 "Dear parent,

24 "I wrote to you last term and you very kindly  
25 agreed to the trial of a new product on your son.

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1 and that he could be treated with a concentrate or  
2 cryoprecipitate as available."

3 So a reference there to a hepatitis survey.

4 I don't think you know precisely what that refers to?

5 **A.** I have no idea what that is, I am sorry.

6 **Q.** That is before Andrew joined. This was roughly the  
7 time he was joining.

8 If we then have 1090009, please, we can see here  
9 Andrew's mother agreeing to Andrew taking part in  
10 a trial of a new Factor VIII product, "As explained by  
11 Dr Aronstam."

12 **A.** Uh-huh.

13 **Q.** Do you know from conversations you had either with  
14 Andrew or his mother what that related to?

15 **A.** No, I don't.

16 **SIR BRIAN LANGSTAFF:** Is that a date at the top of the  
17 page?

18 **MS RICHARDS:** It looks like February possibly. It says  
19 "Armour". I am not entirely clear what the rest of it  
20 says.

21 **SIR BRIAN LANGSTAFF:** Is there any link then with 003?

22 **MS RICHARDS:** I don't think so, sir. These are documents  
23 that are in Andrew's medical records. I should say  
24 there are a substantial number of Andrew's medical  
25 records, but it is not clear whether there's a link

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1 "The manufacturers were not able to produce stocks  
2 of the material in time for us to do the trial last  
3 term but there is a possibility that we may undertake  
4 the trial over the next two terms.

5 "I hope you will still agree to your son taking  
6 part in this study."

7 We can see someone has written:

8 "What??"

9 Do you know if that's Andrew's writing or his  
10 mother's?

11 **A.** It is not his writing. I don't know who wrote that.

12 **Q.** Lastly on this issue, 1090013, please, Henry: this is  
13 a letter, again September 1980, to Dr Aronstam from  
14 Andrew's local hospital, and it says:

15 "Clearly it is important that research should  
16 continue into the best treatment of haemophilia.  
17 I would support your request to the parents that  
18 Andrew be included in the anticipated double-blind  
19 controlled trial of the new preparation of Factor  
20 VIII."

21 Now, you have observed in your statement, based  
22 not only, I think, on your knowledge of Andrew's life,  
23 but the fact that you yourself worked at Treloar's --  
24 we will come on to that at a later stage of your  
25 evidence -- you have observed as follows:

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"I recall that boys with haemophilia were used for research at LMTC. To my understanding LMTC looked after the largest group of haemophiliacs in the world. They would have been an attractive group for researchers to target, being such a large group living in a relatively controlled environment with medics in a position to monitor them closely because they were seeing them regularly. I think I knew they were trying new treatments but I would never have thought they would come at such risks. I do not remember thinking Factor VIII was experimental."

A. No, that's right. I was working as a house parent, not involved in the Haemophilia Centre, which was a separate NHS centre on the school site or the college site, so my only involvement was travelling on the van. The boys used to go up and down from one site to the other on the van for their treatment. So occasionally they would be accompanied by one of the house parents for whatever reason, or we would be catching a lift on the van to get into town. So we didn't have much contact with the actual centre.

Occasionally the doctors would come and see us to try to tell us to stop the boys playing football and that sort of thing, but that was too hard to do, really. But, no.

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advice had been given to his parents or to him about any risks associated with the use of the Factor products?

A. His mum said they were not given any warning. There was no discussion about any risks.

Q. Now, you have provided to the Inquiry a document. It is quite a hefty document.

Henry, it is 1090021.

It is called "Factor VIII children's reference manual". If we look at the very bottom of that page, we can see "Copyright 1978, Armour Pharmaceutical Company."

I understand you found this amongst Andrew's belongings and records.

A. Yes. I came across it just a few weeks ago when I was asked to look something out for the Inquiry and, yes, just found it in -- I have got a huge plastic box that's full of things to do with Andrew, and found this in here, and I do sort of recall seeing it before, but I'd forgotten about it. But when I came across it and had a quick look at it, I thought actually you might be interested in seeing it. So I sent it to Collins.

Q. Your supposition is at some point it may have been given to Andrew during his childhood or his mother.

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The boys used to sometimes talk about things they were trying, but there wasn't any sign they were having anything that would be risky. It would be more like they might be trying different physio regimes or a different way of splinting or something like that, really. I wasn't aware that Factor VIII was experimental, no. No idea of the risks involved.

Q. Andrew remained at Treloar's until I think late 1980. Is that right?

A. That's about right, yes. I think he left in the December, Christmas, yes.

Q. He returned home because his parents realised Factor VIII could be a well managed home treatment by then and he didn't need to be so far from home.

A. No. His family missed him very much and wanted him to be home. As soon as that seemed to be a probability -- I think there was a new sort of special unit being opened up at the local secondary school and they thought that was an ideal opportunity for him to go back home. So that's what happened.

Q. Andrew had, as we have seen from the haemophilia database records, been receiving Factor VIII products certainly from 1977 onwards. Do you know from your discussions with Andrew or from your discussions with his mother whether any information or warning or

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A. Yes, I assume they were given that, perhaps when he was at Great Ormond Street, possibly when he was Treloar's. I don't know when, but yes.

Q. We will just look at a handful of passages, if we may. Henry, could we go to page 2, please, so we just see the contents.

We can see there in brightly coloured lines the chapter headings, as it were. As one flicks through it, there are lots of bright, engaging pictures and drawings.

A. Yes.

Q. And it's very much aimed at children and helping children understand haemophilia and the treatment they were receiving.

A. Yes.

Q. If we could go, please, Henry, to page 16.

I am just going to read out a handful of the passages in this document that you have found. This is in a section on the history of haemophilia and it goes through the history of treatments, and it says this:

"Doctors first made Factor VIII from the blood of cows (called bovine) and pig (called porcine) and used it to stop bleeding in haemophiliacs. But they found that proteins in animal blood were different than

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human blood proteins, and serious reactions resulted from repeated use. They needed to make human Factor VIII, but getting enough people to donate plasma for every haemophiliac seemed impossible. Many other people needed the plasma too."

Then it documents in the rest of this page the discovery by Dr Judith Poole in California in 1965 of what became cryoprecipitate. If we go over the page to page 17, please, the booklet says this:

"The discovery of cryoprecipitate was very important to the history of haemophilia. But doctors already had new ideas that could make the treatment of haemophilia even better. When the doctors began talking about their ideas, companies like Armour listened to them and then took on the big job of making their ideas really happen.

"They worked very hard to find a way to concentrate the Factor VIII in cryoprecipitate and dry it into a powder so that it could be easily stored in the refrigerator. They found special ways to draw only the plasma from blood donors, giving them back the rest of the blood. This way, people could give plasma more often and could make enough Factor VIII for all the haemophiliacs who needed it. Haemophiliacs could even learn to treat themselves at

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"It is as safe as we can make it, but it must be remembered that Factorate comes from human blood and that viral hepatitis can be passed from one person to another through the blood. There is no laboratory test known that is absolutely certain for the hepatitis virus, so it cannot be said for certain that there is no risk of transmitting viral hepatitis when a medication like Factorate is used."

If the hypothetical child reading this got to page 37, they would read that, but you are not aware of that information having been given to Andrew or his parents in any direct form by his clinicians?

A. No.

Q. You met Andrew when you were working at LMTC at Treloar's. You were 18 and you were doing a summer job as a house parent.

A. Well, it was actually like a gap year and my intention was to go to university. I went to a very stayed grammar school and it was just like a factory, almost, that you were just going to go straight into university, and I wanted to buck the trend a bit and said I was going to have a year out, which then changed into two years, because I changed my career path. But yes, I went to work there to have some time out of education.

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home!"

Then it says this:

"Today haemophiliacs can do almost all the things other boys their age can do. You probably think that treatment cannot get any better, but many people are still working very hard and learning many new things about haemophilia today. Rabbi Simeon ben Gamliel would be surprised to know how wise he had been about haemophilia many years ago, and even Alexis would never have dreamed that boys with haemophilia could have so much fun today. No-one knows what treatment will be like ten years from now, but it's nice to have the Factor VIII to use while we wait and see!"

Then if we turn, please, to page 36, Henry, we see this:

"The plasma that Factorate is made from comes from blood. It is not blood that is donated by just one person. It is blood that is donated by many different people. It represents many different blood types. So it is normal blood."

Then it goes on to explain how Factorate is better than plasma.

Then finally next page, please, Henry, page 37, the question is posed:

"Is Factorate safe for me to use?"

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- Q. You didn't have much contact with him at that time. As you have explained, you didn't have many direct dealings with the boys who had haemophilia. But you did talk to him from time to time and enjoyed chatting with him.
- A. Oh, definitely, yes. We knew all the children within the house, but haemophiliac boys generally didn't need any personal care, so we were dealing with the other children more. It would be occasionally if they had like an elbow bleed, they might need some help doing their tie up or doing their shoelaces and so on. But they were very lively and bright. We all ate together in the school dining room. There was a lot of noise, a lot of people eating together. So often I would sit with Andrew at the dining table and I used to enjoy his company. He was always -- always had a very good sense of humour. So, yes, he was fun to be with.
- Q. Now, it was a number of years later, in 1986, I think, that you met Andrew again. You were back working at Treloar's. Andrew was 19 and he turned up at Treloar's one day I think to see a friend of his.
- A. One of his previous dorm mates had gone on to Treloar's college, just down the road, and had just finished his exams and had nothing to do, so they quite often used to send the older students that had

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1 finished their exams down to the lower school, where  
2 I worked, to help out with lessons and things and just  
3 I suppose in part be a role model for the younger  
4 children. So his dorm mate Alexis came to school. So  
5 I enjoyed having a catch-up chat with him. We both  
6 sort of speculated on how Andrew was, because we  
7 hadn't seen him for some years then. I said, "I will  
8 write to him and see how he is". I did that, and not  
9 very long after, he turned up -- he just turned up one  
10 day to come and see us.

11 Q. Towards the end of that year, 1986, you started going  
12 out, you and Andrew. You have said in your statement  
13 that:

14 "We [I think you mean by that at Treloar's] had  
15 heard about boys being infected with HIV by that stage  
16 but Andrew didn't know whether he had been infected or  
17 not."

18 A. No. That's one of the things -- that day that he  
19 turned up, I think in retrospect particularly that  
20 he'd -- he needed someone to talk to, and actually  
21 when my letter came through, he thought, you know, it  
22 was a chance to go back to Treloar's and be able to  
23 talk to me and just, you know, about his worry that he  
24 might be infected. So he didn't know at that point.  
25 He just needed to be able to talk about the

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1 refer to a positive HIV test on 13th December 1984,  
2 but there's no contemporary record of such a test or  
3 of any consultation that refers to that specific  
4 issue. You believe that Andrew didn't learn that he  
5 was indeed HIV positive until a date in early 1987,  
6 when you and he went to St Thomas'.

7 A. Yes, that's when he knew.

8 Q. Can you tell us about that?

9 A. Do you want me to tell you about us going to St  
10 Thomas'?

11 Q. Yes, please?

12 A. We started going out in the November and we talked  
13 about whether he was infected or not. At that time we  
14 had no idea that the majority of haemophiliacs had  
15 been infected, so we still thought there was, you  
16 know, some chance that he hadn't been, but we thought,  
17 you know, he did need to go and get tested. So we  
18 went up to St Thomas' together for him to have the  
19 test, and it seemed very strange, because as we were  
20 coming away, the nurse said, "Don't forget to come  
21 back for the results this time". We didn't take it up  
22 with the nurse at the time, but we thought, "Well, why  
23 has she said that? You know, he hasn't been tested  
24 before. What does she mean?" We didn't give it any  
25 thought. Obviously years later we realised what had

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1 possibility that he was.

2 Q. You have spoken to Andrew's mother, your statement  
3 explains, and she has given you a recollection of hers  
4 of seeing a documentary on TV and then phoning  
5 Dr Savidge and St Thomas', where Andrew's care had  
6 been transferred, and having a conversation with him.  
7 What can you recall Andrew's mum telling you?

8 A. Well, a slight -- not exactly discrepancy, but slight  
9 difference in remembrances from what she told me  
10 a long time ago to what she said more recently. But  
11 piecing it together, what I believe happened is  
12 I think the family watched the World in Action  
13 programme and actually saw Andrew's consultant from St  
14 Thomas' telling the world, ostensibly, that  
15 haemophiliacs had been infected with HIV. That was  
16 the first they had heard of it. Obviously, as  
17 a family, it was devastating. Andrew's mother has  
18 described to me how they all cried together.

19 Then I think the following day his mum phoned the  
20 hospital and was told over the phone that yes, he was  
21 infected, but from what she told me years ago and what  
22 I know from what Andrew said, she couldn't bring  
23 herself to tell him. So yes, he was left unknowing  
24 for sure.

25 Q. There is in Andrew's records much later documents that

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1 gone on.

2 We went back two weeks later because you had to  
3 wait two weeks in those days for the test results to  
4 come through. Obviously very anxious about what we  
5 were going to be told. We had to walk across the  
6 hospital from the new building into a really old  
7 building, and I remember going up these really big  
8 wooden stairs that were reminiscent of some of the  
9 stairs at Treloar's, which some of the audience here  
10 will remember, the stairs in Gaston House, up these  
11 big wooden stairs into this what I can only describe  
12 as a really horrible dark room. I remember there was  
13 a window to the room but there was a brick wall  
14 literally inches from the window, so it was just  
15 an awful room, with an old gas fire, which was lit.

16 I remember us sitting next to the fire, facing  
17 each other, with the nurse to one side of us, with our  
18 faces getting increasingly heated -- you know those  
19 old fires where you used to just get really hot next  
20 to them but they didn't really heat the room? So we  
21 just sat next to it. I just remember that very  
22 clearly. The nurse told us -- I think there was a bit  
23 of preamble -- she told us he was infected, which  
24 obviously was absolutely devastating.

25 I think she talked at some length to us, but

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1 I can't remember anything of what she said, because to  
2 me it was just like, "Let us go". I just wanted to  
3 get out of that horrible room. There had been no  
4 attempt to make it friendly, welcoming, a pleasant  
5 room in any way as far as I could see. I just thought  
6 "I've got to get out of here".

7 We had to walk all the way back through this  
8 hospital to the Haemophilia Centre and wait for  
9 a while before they got his supply of Factor VIII to  
10 take home ready. I just remember waiting in that  
11 corridor, staring at -- it was a Monet print on the  
12 wall, just staring at the print. I don't know why  
13 I was staring at the print particularly. I suppose  
14 there was nothing else really to look at to take my  
15 mind off things, and just having this thought, "There  
16 goes our hope of a family", you know. That dream has  
17 gone.

18 Q. What was the impact of that news on Andrew as far as  
19 you can recall at that time?

20 A. Oh, it was devastating for him. You know, we were  
21 told that he had only got a couple of years to live.  
22 I don't know how anybody has managed to live with  
23 that. You know, obviously there's a number of people  
24 in this room who have had that same sentence spoken to  
25 them and they have had to live with that.

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1 came to work at Treloar's as a computer technician.

2 Q. And in 1988 the two of you moved into a tied flat at  
3 Treloar's.

4 A. Yes, yes.

5 Q. You have said in your statement you were aware of the  
6 risk that you might become infected. You were very  
7 fearful not so much for yourself but for Andrew, who  
8 would have been devastated that he had infected you or  
9 any child.

10 A. Yes. We were, if you want to say, fortunate. I know  
11 there are many people who didn't know about their  
12 partner or husband's status before they were in  
13 a relationship, a sexual relationship. So, you know,  
14 they became infected. We were in a different position  
15 where we knew from the outset firstly that Andrew  
16 might be infected, and then we knew for sure that he  
17 was, and so we were able to take precautions.

18 But, you know, I think there was a stage where  
19 staff within haemophilia centres were very almost  
20 overcautious about things, you know, they just became  
21 very scared that people would become infected and it  
22 was sort of belt and braces. You really had to be  
23 absolutely certain there was no risk of you passing on  
24 the infection, so we always took precautions. But  
25 I was aware that it wasn't just about saving my

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1 He didn't talk about things an awful lot. You  
2 know, he used to keep things to himself. But I know  
3 he had wanted a family. We had talked about that,  
4 because soon after we started going out together it  
5 was quite clear we wanted to get married and spend our  
6 lives together. We used to talk about children and  
7 sometimes we would allude to names we might call them  
8 and everything. That was part of what we were looking  
9 forward to. So yes, that was all just swept away.

10 Q. You became engaged in May of that year and married in  
11 August of that year.

12 A. Yes.

13 Q. You started looking for jobs, the two of you, so that  
14 you could be in the same area. Andrew got a job in  
15 an IT position at Treloar's.

16 A. It was actually before we got married that we started  
17 looking for jobs. I am a qualified occupational  
18 therapist and started looking for OT jobs in the  
19 Crawley area. Andrew was looking for IT jobs. It was  
20 a question of who found something suitable first. The  
21 IT job at Treloar's came up and that just seemed  
22 absolutely ideal. There were certain people involved  
23 in interviewing and so on that remembered him from  
24 when he was just a little boy, so there was  
25 a favourable response to his application. So, yes, he

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1 health; it would have been devastating for him if, in  
2 our situation, where we knew that he was infected, you  
3 know, he had passed that on.

4 Q. You describe having very happy times punctuated by  
5 sadness and the fear of losing him.

6 A. I think -- because we were just told it was a couple  
7 of years, if -- and we had almost 12 years together.  
8 If at the beginning of our marriage we had been told  
9 we had got the best part of 12 years, then maybe the  
10 first few years we could have enjoyed more, but I was  
11 just so frightened of losing him that anything that  
12 was really happy I would immediately think, "But I am  
13 going to lose him". So even in a happy moment, my  
14 brain would flip to this, "But you are going to lose  
15 him". I feel that I grieved all my marriage, even  
16 before I lost him.

17 Q. Now that Andrew was living at Treloar's, he received  
18 his haemophilia care from the haemophilia unit there.

19 A. Yes, yes.

20 Q. And if we just have up on screen, please, Henry,  
21 1090018, we can see that in 1990 there was  
22 a notification from BPL to Dr Wasseff at Treloar's  
23 that a plasma donation sent for fractionation and  
24 included in this batch of Factor VIII could  
25 potentially be infected -- this was with hepatitis

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B -- and therefore there was a withdrawal from issue of any remaining stocks of this batch of product.

Then if we have 1090019, please, we have a letter dated 16th May 1990 from Dr Trowell to Dr Wasseff, and it refers to including a brief note on each patient to document the discussion. If we look at the bottom of the page we have the extract that relates to Andrew, and you refer to this in your statement:

"Although I did not see this young man, we discussed his situation and results. He is a hepatitis B surface antigen negative patient who has titres of anti hep B core and hep B surface antigen. He has recently received treatment with a large quantity of hepatitis B positive Factor VIII, and we agreed it would be interesting to follow the titres of his anti hepatitis B antibodies."

So that is a discussion taking place between doctors in May of 1990 in relation to hepatitis B.

Do you know whether Andrew was informed of that at the time?

A. I have no memory of him being informed.

Q. Andrew was also infected with hepatitis C and your statement explains that he was tested for hepatitis C in June 1990 with the first generation test, confirmed in 1995 with a second generation test, and you think

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our GP had referred us to James Pringle House and we saw a really lovely doctor there. She was so sweet, but she basically said to us that -- because I had had that idea that if some sperm could be frozen, then maybe at a later date it would be possible for me to have that safely, that we would be able to go ahead and have a child safely or they could test that sperm to see if it was infected or not. I thought this was a way of buying some time. That is why our very helpful GP had referred us.

So she was a lovely doctor and talked to us about the basics of it all, and then just said she couldn't freeze his sperm because they might mix it up with other donations somehow and it might be given to the wrong person, which I found -- well, I mean, you just think, well, surely they have to be extremely careful with their labelling of samples, because otherwise how would they give anybody the right sample to fit in with, you know, their ethnic group or whatever? But because it was infected, then no, they couldn't help.

Q. You then read about a sperm washing treatment programme available in Italy.

A. Yes. A colleague at Treloar's had seen a little snippet in a Sunday magazine and brought that into work for me. It was included in an article by I think

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he was told he was hepatitis C positive in late 1995.

A. I don't know. I don't remember exactly when he was told, but I believe that he had been tested without his consent, because all I have is a vague memory of -- I think it was someone from the Haemophilia Society or been funded by the society or connected with them, somebody doing research, so it might have been a student doing some medical research. Actually, I don't think it was medical research. I think it was social -- psychosocial research. But anyway, she'd come to talk to adult haemophilia patients who were hep C positive, and I remember her coming to talk to Andrew and myself and we just said, "Well, it doesn't apply to us, you know, there is no point in talking to us because Andrew is not positive, not hep C positive", because we hadn't been told he was and just thought he wasn't, and then later on, at some point in one of his appointments at the haemophilia unit, we were told that he was.

Q. You and Andrew, as you have told us, both very much wanted to have children. You said in your statement that you were told that his sperm couldn't be frozen.

A. Yes.

Q. And what was the reason that was given for that?

A. Because it might be mixed up with other people's. So

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it was Mark Porter, the doctor, television doctor. So yes, there was this little snippet about HIV discordant couples being able to have children safely at this clinic in Italy.

Q. You were referred by your GP to a hospital in Basingstoke where you discussed sperm washing with his consultant there. What was his view?

A. I have to say the clinic there were lovely, all very welcoming and kind, and he went through a very detailed discussion of how sperm washing would work, so we could see very clearly it was quite a safe way of having children and felt quite buoyed up at the beginning of the consultation, but then towards the end of it -- he didn't put it in these words, because he was a very kind man, but he said, "I wouldn't touch it with a barge-pole". He obviously just couldn't take the risk of the infections and so on, so he couldn't help.

To give him his due, he then went on to help us have all the tests we needed to be able to go to Italy. So he did what he was able to do. So I am grateful to him for that.

Q. And you did go to Italy, you and Andrew, for the sperm washing treatment. What can you recall about that experience?

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A. We were very nervous about going. So my mum suggested we went for sort of a preliminary journey, you know, just go and see the hospital, go and see where you would be staying, you know, stay in the hotel, go and meet the doctor, and, you know, to not just go ahead with it but just see what it would be like to start with. So we did that.

The hospital weren't terribly helpful in some respects, because I found them all a bit dismissive, but they said they would treat us and explained about some of the procedures and so on. So we decided to go ahead with it. It was a pretty awful experience.

So we went over to Milan. I was told to arrive at the hospital at a certain time, which I did, and reported to wherever I was supposed to report. But without any explanation they said to me I had to wait outside -- I don't know what number it was, but say room 57 or something.

So I went out and waited outside this room. I had no idea what I was waiting for. There were other women in the queue, but they were all speaking Italian, and although I tried to learn enough to be polite in shops and so on whilst we were there, I couldn't sort of say, you know, "What are we standing here for?" Then when I went into the room,

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for him to sit, nothing. He wasn't allowed to come close to me. Then there was some discussion going on when they had examined me about something or other and I didn't understand what they were saying. Then they just went ahead with the procedure and we were just sent on our way. We had to go -- our flight was going pretty soon after that, so we had to rush off for that.

So it was all quite traumatic, and then obviously I was very hopeful that I was going to have a baby, kept willing that to happen, you know, imagining what might be happening inside me, willing this baby, and then my period arrived when I was at work one day. So that was that.

Q. You were then told when you were back in the United Kingdom that sperm washing would become available I think at the Chelsea & Westminster hospital --

A. Yes.

Q. -- in the not too distant future.

A. Yes.

Q. So rather than go back to Milan for a second attempt there, you decided to wait for the programme to commence, which you thought was going to be fairly quickly.

A. 12 weeks. They said it was going to be up and running

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it turned out I was going to have an internal examination. So that was without any warning whatsoever, that's what was happening.

That was all quite brutal. The doctors were not very gentle. They didn't explain what they were doing and so on either. They didn't explain why I had to have that done, because I had had all my tests and everything done in England before I went. So that was all pretty awful.

I then had to have injections of hormones to bring me into ovulation and so on and I was told I had to test -- do a test to be sure that I was ovulating and then would go back to have -- I think I had to have an injection as well. That's all a bit vague.

Anyway, we then had to go back for the actual insemination, and I can't believe the contrast with the clinic in Basingstoke, where it was obvious that they were all set up to help couples in difficult circumstances to go through procedures to have a child, you know. So it was all made very welcoming and kind. This was just awful, just a very bare room, and I just had to, you know, lie on the trolley for the insemination, and Andrew just stood in the corner just holding our coats, basically. They didn't even give us somewhere to put our coats. There was nowhere

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in 12 weeks' time.

Q. You I think were told in April 1996 it would be about 12 weeks' time, but it didn't happen in 12 weeks.

A. No.

Q. You eventually saw someone at the clinic in August of 1997.

A. Uh-huh.

Q. And you were told it still wasn't going ahead and there was some concern that had been expressed by the hospital's ethics committee arising out of an article in the Sunday Times.

A. Yes.

Q. But you still understood it was going to go ahead soon.

A. Yes.

Q. I think you chased the following year, April 1998, and waited. Then what finally happened in terms of when you received the details of the programme?

A. I actually got a letter -- I put in my statement it was two days but I have found out since it was three days, not that it makes much difference -- three days after Andrew died I had the letter inviting us for our appointment.

Q. That was nearly three years after you had approached the hospital.

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1 A. Yes, and it was just like -- it was always just the  
 2 other side of the horizon, but -- because had we been  
 3 told, you know, it wasn't anywhere close to being put  
 4 into place, we would have gone back to Italy until  
 5 Andrew became a bit too poorly for us to contemplate  
 6 that, but yes, there was a window of time when we  
 7 would have gone back to Milan.  
 8 Q. You had applied to the MacFarlane Trust --  
 9 A. Uh-huh.  
 10 Q. -- for funding to help you go to Milan.  
 11 A. Yes.  
 12 Q. We are just going to look at some of the  
 13 correspondence between you and the MacFarlane Trust in  
 14 relation to that.  
 15 Henry, could we have, please, 1090026? This is  
 16 a letter from you dated 9th October 1995 and it starts  
 17 with:  
 18 "I am writing to question the decision of your  
 19 committee not to give grant aid towards the costs of  
 20 assisted conception programmes."  
 21 So there had been some form of earlier refusal  
 22 before we pick up this correspondence.  
 23 A. Yes.  
 24 Q. You say this:  
 25 "I understood that the sole purpose of the trust

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1 "I am sorry to be so slow in writing again to you  
 2 but the trustees were unable to come to a final  
 3 decision at their meeting in November pending some  
 4 further inquiries by our medical trustee, Dr Elizabeth  
 5 Mayne.  
 6 "The trustees saw your letter (anonymised) but  
 7 this was in the context of re-examining the whole  
 8 subject of assistance with conception on which their  
 9 previous decision had been not to give any financial  
 10 assistance. Although every request to the trust (of  
 11 any kind) is looked at individually, there has to be  
 12 some underlying policy or guideline on the matter to  
 13 ensure consistency and fairness."  
 14 The next paragraph refers to there's going to be  
 15 the potential of a further decision and says this:  
 16 "I believe that they [that's the trustees] are  
 17 likely to make some change to their earlier exclusion,  
 18 but I also feel that this is unlikely to include any  
 19 treatments not fully recognised and approved by UK  
 20 medicals authorities or any treatment outside the UK.  
 21 At present I'm afraid this exclusion would apply to  
 22 Dr Semprini's treatment, whether done by him in Italy  
 23 or by an associate in the UK."  
 24 If we go then to page 4, we can see that by  
 25 mid-February you are still waiting for a response.

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1 was to help people with haemophilia and HIV deal with  
 2 the difficulties they face as a consequence of their  
 3 infection.  
 4 "One of the most distressing aspects of living  
 5 with HIV is the inability of couples to have a family  
 6 without risking wives and offspring becoming infected.  
 7 This is not simply about couples wanting a baby as  
 8 some sort of possession, but is about bringing a sense  
 9 of purpose to life, of seeing a continuation of self,  
 10 of keeping pace with peers."  
 11 Then you refer further down in the letter to the  
 12 treatment programme in Milan, and you say this:  
 13 "Before we can go to Milan, we have had to have  
 14 a number of tests, some of which we have had to pay  
 15 for. We will have to pay for our flights to Milan,  
 16 for accommodation and treatment. None of this would  
 17 have been necessary if my husband had not contracted  
 18 HIV from infected blood products. I therefore believe  
 19 that the trust should at the very least be prepared to  
 20 accept an application for a grant towards the costs  
 21 involved in this programme and should give it careful  
 22 consideration."  
 23 If we then turn on to page 3, please, Henry, we  
 24 can see the letter you received from the MacFarlane  
 25 Trust, 21st December 1995. It says:

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1 You say in the second paragraph of your letter:  
 2 "I continue to wait for a proper reply to my  
 3 request for a grant towards the cost of assisted  
 4 conception."  
 5 Then if we go on, please, Henry, to page 6, we see  
 6 a document from the MacFarlane Trust dated  
 7 3rd April 1996. This particular document is addressed  
 8 to Dr Wasseff and it says this:  
 9 "As you may be aware, the trust has made payments  
 10 in the past to couples wishing to have a child without  
 11 risk of infection to the mother. Typically these  
 12 payments have been a contribution towards the cost of  
 13 donor insemination treatment.  
 14 "Payments in this category were suspended last  
 15 year whilst trustees considered a fair and consistent  
 16 policy covering this form of assistance. Our trustees  
 17 also gave careful consideration to whether their  
 18 policy should make provision for payments to cover  
 19 treatment based on new reproductive technologically,  
 20 particularly sperm washing.  
 21 "The purpose of this letter is to let you know  
 22 that our trustees have settled on a policy which  
 23 allows the trust to contribute toward the cost of  
 24 private assisted reproduction treatment provided that  
 25 the treatment is approved by the Human Fertilisation

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Embryology Authority and available from the NHS. Applicants must first apply through the NHS and satisfy counselling criteria. If treatment is approved in principle but subject to delay, the trust will then contribute to the costs of private treatment."

So that was the decision communicated in April of 1996. We can see if we go on to page 8, please, the letter that was written to you. Picking it up in the second paragraph:

"I am sorry to say that (for the present at least) your request does not fall into of the trustees' criteria. For any type of medical treatment, for this or any other purpose, the trustees are concerned that to give financial support implies an acceptance/endorsement of the process, if not an actual recommendation, and they are therefore reluctant to be involved in anything experimental, particularly if it is not accepted by the National Health Service (or in this case by the Human Fertilisation Embryology Authority either)."

Then it says this in the next paragraph:

"We [the two individuals at the trust] admit your views are entirely tenable, even though they do not coincide with the present views of the trustees."

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important to us? Especially as it is something that would make so much difference to us, bringing great joy into lives that have been totally devastated by HIV."

Then if we go to page 12, please, Henry, you wrote again the next month setting out your understanding that the Human Fertilisation Embryology Authority's ethics committee had agreed to HIV discordant couples having IVF treatment and said this:

"The MacFarlane trustees have said they would not help to pay for sperm washing procedures because they were not approved by the HFEA, but surely they can no longer refuse to help now that the HFEA have approved a technique that carries far more risk of seroconversion than sperm washing does?"

Finally, page 13, the response that you received from the chairman of the MacFarlane Trust, 6th June 1996, second paragraph:

"I am sorry to tell you that the trustees did not agree to extend the terms under which they are prepared to assist with the costs of reduced-risk conception.

"The trustees had considerable sympathy for your views ..."

Then it goes on to say in the penultimate

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Then he says in the final paragraph he will raise the matter with the trustees again and see if we can persuade them to widen rather than move the goalposts.

You wrote back, Amanda. Just look at the terms of your letter. Page 9, please, Henry. 16th April 1996. Halfway down the page, you said this:

"We do not have the time available to wait for Dr Semprini's procedure to be adopted by the NHS. We have to proceed now whilst my husband is still alive. Why can the trustees not treat me as an adult capable of assessing risk to my health and support me in taking what I consider to be the safest option of conception?"

Then you suggest the possibility of asking couples to sign an agreement to show your understanding that the trustees would not be somehow endorsing the procedure.

Then over the page, please, Henry, page 10, second paragraph:

"It amazes me that the trustees will agree to helping us with expenses involved in moving house but will not help me to have a baby safely. People move house whether they are HIV positive or not. They do not have to go all the way to Milan to have a baby! Why not help us with the one thing that is most

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paragraph:

"The decision ultimately rests on what the trust could and can do with its limited resources. You make the point about other types of grant which you consider less important. We accept that as a very reasonable personal view but the choice before the trustees must take account of overall priorities for use of resources as well as each individual case. Deciding priorities is always difficult and sadly the decisions are never going to suit everyone.

"One call on trust resources that has never been accepted is for medical treatment of any kind, either for people registered or for members of their families. Likewise, we have not contributed to research or tests of any kind, either in abstract scientific terms or in clinical trials with individuals. If we are to make any departure at all from these exclusions, it could only be on a very limited basis and any decision must rest with the discretion of the trustees."

That was your attempt to ask the MacFarlane Trust to help you pay for what by then would have been a second trip to Milan.

A. Uh-huh.

Q. Do you have any observations on that issue and the

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1 stance taken by the MacFarlane Trust?

2 A. I think its just typical of their approach, really,

3 that they were just a paternalistic organisation and

4 they held so much control over what we could and could

5 not do with our lives.

6 I think if you look at it in terms of assessing

7 risk for people, I think that sort of attitude would

8 have pushed some people to have taken the risk to have

9 a baby, you know, naturally and taken the risk of

10 seroconversion of the wife and possibly the baby. We

11 wanted to go ahead with a procedure that had been

12 shown to be successful, and I can't remember the

13 numbers now, I think I put it in one of the letters,

14 you know, but there were very many people who had gone

15 through that procedure in Italy and there hadn't been

16 a single seroconversion, but they just wanted to play

17 God with us, you know, wouldn't allow us to make our

18 own decisions, you know, which we should have been

19 able to.

20 Q. You say in your statement that you were and you still

21 remain deeply saddened that you were never able to

22 have a baby with Andrew.

23 A. Uh-huh.

24 Q. Andrew began to be really unwell in the course of the

25 1990s?

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1 some Piriton. You know, it would have been helpful if

2 they had said before he took the Septrin that it would

3 be a good idea to have some Piriton just in case.

4 I don't know what they expected me to do, how they

5 expected me to get hold of Piriton just like that.

6 I would have had to drive four miles into town to get

7 some and leave him on his own to do that. As it

8 happened, the way things were in those days -- quite

9 different from now -- Treloar's had a medical centre.

10 Some of the men here would remember it as sick bay.

11 In those days you could actually go and ask the nurses

12 if you could have paracetamol if you had a headache or

13 something. I just went over to them in a panic and

14 said, "Have you got any Piriton I can have? Andrew is

15 very poorly". They kindly gave me some. I know these

16 days, the way everything is double checked and

17 controlled in any situation with anybody giving you

18 medication, they probably wouldn't be allowed to do

19 that, but then they could and I am so grateful that

20 they did, because that obviously did help to bring his

21 symptoms down, but that was the first instance.

22 He was on AZT, but it made him feel so ill and he

23 just said to me, "I am not taking this, you know,

24 I can't live like this. I am just not going to take

25 it".

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1 A. Uh-huh.

2 Q. He had started on AZT. He began what you have

3 described as a period of five years of illnesses and

4 reactions to drug regimes. What can you recall?

5 A. Until the illness that actually killed him, I believe

6 all the illnesses he had were related to the drugs

7 that he took. It started with him taking AZT and

8 Septrin. He was put on Septrin against pneumonia. We

9 weren't warned that there could be a really bad

10 reaction to that, and my understanding is that Septrin

11 actually often brings about severe reactions. Andrew

12 sadly seemed to just suffer with almost every side

13 effect you could have to any drug he took.

14 With Septrin, he became incredibly ill very, very

15 quickly. He was having hallucinations, covered in

16 a rash, high temperature. I was so panicked by it.

17 I remember I phoned the Haemophilia Centre. Bearing

18 in mind we lived within the complex of Treloar's, we

19 just lived over the road from the school. The

20 Haemophilia Centre was three miles down the road and

21 I very naively thought, you know, because he was so

22 poorly, that one of the nurses, who literally was, as

23 I say, three miles down the road, could have got in

24 the car and come to see what was in the matter with

25 him and helped us. But they just told me to get him

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1 Q. You and he became concerned that the haemophilia unit

2 at Treloar's wasn't specialist in HIV.

3 A. Uh-huh.

4 Q. And so you sought advice and support elsewhere in

5 terms of Andrew's HIV care. What can you recall about

6 that?

7 A. Well, just to put it in context, just before we got

8 married I went to see our GP, Andrew Sword, and told

9 him that I was getting married to a haemophiliac who

10 was positive. He was so kind and he just said to me

11 "Amanda, I don't know what you are going to need in

12 the future, but whatever you need, come and ask me and

13 I'll see what I can do". So that's what we did. He

14 stood by his word all through and was a tremendous

15 support.

16 So when we were going to the Haemophilia Centre

17 and having discussions and trying to ask questions

18 about the treatment and options and so on and getting

19 the response all the time that the Dr Wasseff would

20 have to consult with his colleagues in London, we just

21 thought, "Why are we talking to a doctor that doesn't

22 seem able to give us the information but can talk to a

23 doctor in London? Why don't we go and talk to the

24 doctor in London ourselves?"

25 We went back to Andrew Sword and said, "Please can

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1 you refer us somewhere for HIV help", and he referred  
2 us to the Chelsea & Westminster. I have to say, that  
3 was quite different. You know, when we got there and  
4 we met with the consultant, David Asboe, who was just  
5 a wonderful doctor -- I mean, he didn't know about  
6 haemophilia and there were some issues around that,  
7 but it was so easy to talk to him. He just knew so  
8 much. You could ask him anything about the drugs and  
9 he would have a reasoned discussion with you. It was  
10 very much -- he treated us as equals.

11 In fact, when we first started seeing him,  
12 I didn't even know he was a consultant. I thought he  
13 was a registrar. His manner was just so down to earth  
14 and friendly and welcoming. It was so easy to talk to  
15 him about things. But the doctors at the Treloar  
16 haemophilia unit never forgave me, and it was  
17 particularly me, because I think they thought I had  
18 marched Andrew off to London. It was a joint  
19 decision. I would never have done anything -- I was  
20 often his mouthpiece, because he found it quite  
21 difficult to assert himself, but, you know, I only  
22 ever did what he wanted me to do and, you know, it was  
23 our decision that we should go to London. But the  
24 doctors, as I say, at Treloar's never forgave me for  
25 that.

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1 drive, so he rang my mum, and she rushed him to the  
2 hospital, phoned me to say that that's what was  
3 happening.

4 So I rushed out of the hairdressers with wet hair,  
5 so frightened, because I didn't know what was  
6 happening. I just thought, "He could die before I get  
7 there". Days before satnav, so although I had been to  
8 Basingstoke several times, I had been to Guildford  
9 several times, but I was in Guildford and I didn't  
10 know how to get from Guildford to Basingstoke easily.  
11 It was just such a panic. But anyway, I got there.

12 But when Andrew arrived at the hospital, my mum  
13 dropped him off at the hospital door while she went to  
14 park. He was sick on the steps because he was so  
15 poorly with it. Thankfully -- once he was made  
16 comfortable at the hospital, and I think he passed the  
17 stone. I can't remember the treatment for that, to be  
18 honest with you.

19 The second time was when he had pancreatitis. We  
20 had actually been to the GP's the day before and he  
21 had reported his symptoms, sort of stomach pains and  
22 so on. I don't blame the GP at all for this. It  
23 wasn't Dr Sword, it was one of his colleagues, who  
24 were all brilliant with us, I have to say, but she was  
25 basing it on her GP knowledge that the symptoms he

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- 1 Q. You described in your statement a number of side  
2 effects and physical health problems that Andrew  
3 experienced. He had nightmares from one of his  
4 treatments.
- 5 A. That was a very, very scary time. He had very vivid  
6 nightmares and would wake up talking absolute rubbish.  
7 It was very scary.
- 8 Q. He had peripheral neuropathy, which he described as  
9 having red hot pokers forced up through his feet into  
10 his legs.
- 11 A. I think sometimes people think peripheral neuropathy  
12 is just something like pins and needles. The way he  
13 described it was just like excruciating pain.
- 14 Q. He suffered acutely with kidney stones and  
15 pancreatitis, and on one occasion was rushed into  
16 hospital in Basingstoke.
- 17 A. On two occasions. The kidney stones I think was the  
18 first one. I was actually out. I had gone to get my  
19 hair cut about 15 miles away from home. He suddenly  
20 became very poorly at home. He phoned the Haemophilia  
21 Centre and they just said to him to go to hospital.  
22 So I think what they should have done is phoned for  
23 an ambulance for him, because he was in dire straits,  
24 but they just said, you know, "You have got to get  
25 yourself to hospital". He wasn't well enough to

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1 presented with were typical of indigestion and so on,  
2 so she just said, "I think it is indigestion. Here is  
3 a prescription for something or other. Go home and  
4 see how you get on". But then he became rapidly ill  
5 and was rushed in and almost died of pancreatitis the  
6 next day, and he was in hospital for a month.

7 Q. You have said in your statement that his mental health  
8 deteriorated around this time.

9 A. Uh-huh.

10 Q. And in a confused state he attempted to swallow  
11 a knife in order to take his own life.

12 A. Yes. I mean, he must have been confused to have  
13 thought that that was a way of taking his life, but  
14 yes, I got a phone call, because I was staying with  
15 him in the hospital overnight and I had gone home to  
16 be able to have a shower and so on, and I got a phone  
17 call to say he had attempted suicide, so obviously  
18 I rushed back.

19 Then they told me that he needed to be watched  
20 24 hours a day, but they didn't have the staff to  
21 offer that care, so I basically had to live in the  
22 hospital. His mum -- I actually I think he was in for  
23 six weeks, because his mum said she had to have six  
24 weeks off work. She travelled from Crawley everyday  
25 to Basingstoke to be with him for part of the day when

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I went home to do home things and to be able to shower and get a meal, because there was nowhere in the hospital I could eat properly. So I was getting a meal and then bringing food back into the hospital with me. I mean, there wasn't proper accommodation in the hospital for me, I just had to sleep on the floor of his room to make sure that somebody was with him.

**Q.** You have said in your statement that after Andrew's attempt to take his life, he was offered psychological support in the form of sessions with an art therapist.

**A.** Uh-huh.

**Q.** He thought that was nonsense and wasn't going to help him.

**A.** No. I think he did have maybe two sessions, but no more than that probably. He didn't set much store by it.

**Q.** You also experienced difficulties in terms of staff understanding either the seriousness or the nature of his illnesses. Two occasions you have described in your witness statement, one at St Michael's Hospice in Basingstoke and another at Basingstoke General Hospital. What can you recall about those events?

**A.** The one in the hospital was he was in incredible pain with his elbow one night, I mean just off way off the scale from an elbow bleed, so we thought best to go to

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"monitoring". "Like what? You haven't got a doctor here who knows what's the matter with his elbow. You can't do anything for that. You are suggesting that he sleeps in a bed next to somebody who could give him an infection he could die of. You tell me what time you want me back in the morning. If you want me bringing Andrew back at 4.00 in the morning, 5.00 in the morning, whatever, I will bring him back, but he is not sleeping here overnight."

So we had to sign this form to say, you know, we had been advised he should stay in hospital and that we were refusing medical advice and going home, but, you know, it was just ridiculous, so we had to do that.

With the hospice, I think he had only been in the hospital for his pancreatitis. I think it must have been after that. I was a bit worried about how we were going to manage when we got back home because he still poorly, and we were told he could go over to the hospice, which seemed a reasonable idea. But very soon after we arrived there, we went over some time in the afternoon, later that afternoon Andrew went to the toilet and said to me he was urinating blood, passing blood. Unusually for a haemophiliac, he had not had that happen before. We were quite worried about it.

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the hospital. I think we may have phoned the on-call haemophilia doctor. I expect that's what we did, and were told to go to the hospital, so we did that. There was no haemophilia doctor to be seen, so we were just seen by I think it was a rheumatology doctor. They wanted to admit Andrew for the night, but it was just on a general ward and they were going to put him into a bed next to a gentleman who was coughing and coughing, you know, really coughing very badly. I said to the nursing staff, you know, "Is this gentleman -- has he got an infection?" They said to me he had got a chest infection of some sort. I said, "My husband can't stay in a bed next to somebody who's got an infection, because his CD4 count is very low and his viral load is really high". They just looked at me like, "Well, what are you talking about? What do you mean?" They didn't understand that what I was saying was Andrew doesn't have an immune system now. You can't put him next to somebody that's got an infection.

So I talked to Andrew about it and I said, "We are not staying here". They were really cross with me for that. I said, "Tell me what you are going to do overnight that I can't do for my husband at home", and there was nothing. You know this sort of generalised

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It is a new symptom. "Goodness, what's happening? What's going on?"

I said to the hospice staff, "Please can you or we phone someone from the Haemophilia Centre?" This was pre the days when everybody had a mobile phone, so I had no way of doing that for myself, otherwise I would have done it. I was reliant on them. They just kept saying to me things along -- I had got to accept that my husband was going to die, you know, he was poorly, he was going to die and I couldn't just keep looking for treatment for him sort of thing.

I was like, "This is an acute haemophilia problem that maybe he -- because we didn't know what was happening. Maybe he could die of this today. He doesn't need to die today of this. Get me the treatment. Get him the treatment. Get somebody here". I don't know quite how I managed it in the end, but we did actually see a haemophilia doctor, who then dealt with it and it was okay.

But the level of ignorance about haemophilia and HIV and what we were going through was just incredible, really, and just again this always having to fight, fight with the medical professionals to get treatment that you need and having to understand and know. I mean, you had to be knowledgeable yourself to

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1 try and get the treatment right, because nobody seemed  
2 to be joining up the dots and nobody seemed to be  
3 offering comprehensive care.

4 You know, I remember sometimes when Andrew was  
5 ill, I think there was one particular thing where he  
6 had something come up on his face. It always seemed  
7 to happen in the night. I was just beside myself  
8 because I just thought, "Who do I phone? Do I phone  
9 a GP? Do I phone a haemophilia doctor? Do I phone  
10 Chelsea & Westminster for a HIV doctor? What kind of  
11 problem is this? Who is going to advise me?" I think  
12 in the end I phoned the GP on call and they put me in  
13 touch with a doctor at the hospital. I could tell  
14 I was speaking with a very junior doctor who, bless  
15 her, was trying her hardest to help. She said,  
16 "I just don't know what to advise you".

17 We had to be our own experts in it because nobody  
18 else, as I say, seemed to be joining up the dots and  
19 offering comprehensive care. It felt sometimes as if  
20 you were just falling through the gaps.

21 Q. Can you tell us about Andrew's last illness and the  
22 events that led to his death?

23 A. I shall do my best to. So, as I say, he had a lot of  
24 side effects of the treatment. So we got to a point  
25 where Dr Asboe had taken him off all medication. We

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1 next". So he did take his antibiotics. He was  
2 compliant.

3 But he got worse over the weekend, so I said, you  
4 know, "We need to go to the hospital". We used to  
5 have a bag that was all packed ready to go to the  
6 hospital so if he had an emergency, another emergency  
7 admission, we didn't have to panic about things.  
8 There was just a bag ready with -- he had duplicate  
9 pyjamas and all of that. That was all there ready.  
10 I said to him, "I think we need to take your bag". He  
11 said to me, "I know, it is just in case, isn't it?"  
12 I said, "Yes, it is just in case. I won't let them  
13 admit you if you don't need to be admitted, but just  
14 in case, we will take your bag".

15 He wasn't well enough to sit up in the car, and  
16 I remember he -- we stopped at the garage to get some  
17 Opal Fruits for him because he was very dry and kept  
18 coughing and coughing. He wasn't well enough so he  
19 lay on the back seat of the car and I took him to  
20 Basingstoke Hospital. He was later admitted for  
21 pneumonia.

22 At the time I thought, "Well, people don't die of  
23 pneumonia anymore", you know. I realised it was  
24 an HIV-related illness, but I thought it was his first  
25 illness, he wasn't going to die of that, but they

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1 were not ready to try any salvage medication, because  
2 Andrew had been through so much. He couldn't cope  
3 with any more side effects.

4 We had a holiday. We were very fortunate that  
5 some teachers at Treloar's had a villa in Spain and  
6 they offered us the use of their villa over half term,  
7 and another very good friend came with us. Andrew  
8 suggested that this friend could come with us and he  
9 was able to drive us and help, because I was so  
10 frightened that something might happen to Andrew  
11 whilst we were away and I wouldn't be able to cope on  
12 our own. So our very good friend came with us. We  
13 had this holiday.

14 Not long after that, Andrew started becoming  
15 poorly with a bad cough. I said, you know, we needed  
16 to tell the doctors about it. We went to the  
17 hospital. I do remember after a first appointment  
18 about that they had given him some antibiotics and he  
19 actually did say, "No more tablets". I remember he  
20 said, "No more tablets, no more Lindsay". Lindsay was  
21 the art therapist, so it was like saying to me,  
22 "I don't want any more of this rubbish, anything".  
23 I said, "You have got to take your antibiotics. This  
24 is probably something that's just treatable. Take  
25 your antibiotics and we will just see what happens

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1 couldn't get a sputum sample from him. His cough,  
2 although really bad, wasn't productive. So they were  
3 not getting a sample from him. Because of that they  
4 couldn't grow anything to know how to pinpoint the  
5 infection. The doctors at Basingstoke, the  
6 haematologists there refused to phone Dr Asboe in  
7 London, as I say, because of this ongoing -- well, in  
8 their arrogance of thinking, you know, they knew  
9 everything and that I'd been really naughty in going  
10 to a doctor in London. They refused to phone  
11 Dr Asboe. And, again, because I didn't have a phone,  
12 I couldn't just phone him myself.

13 I was feeling very run down. I had many, many  
14 nights with very little sleep before that. I didn't  
15 feel very strong and didn't -- something in me was  
16 thinking, "Stop arguing with everybody, Amanda, you  
17 have got to just let them try to do their job". So  
18 I didn't phone David Asboe myself at that point.

19 The doctors said to me, "It won't be pneumocystis  
20 because Andrew has been on Pentamidine", which was  
21 an inhaled drug, which he used to have once  
22 a fortnight. So they made this assumption that there  
23 was no point in treating him for pneumocystis because  
24 it wouldn't be that.

25 I later learned that, actually, with Pentamidine,

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1 you are lucky if it actually does get right to the  
2 bottom of the lungs, and that's where the infection  
3 was, at the bottom of the lungs. So it could well  
4 have been pneumocystis. He didn't have a post mortem,  
5 because I refused that, so I don't know if he died of  
6 pneumocystis in the end. But there is a good chance  
7 that's what it was.

8 So they didn't know how to treat his pneumonia.  
9 Obviously he did have some medication. But I think he  
10 was in for about a fortnight and then, on the second  
11 Friday, he was, you know -- he wasn't any better and  
12 his -- I think it was -- there was a Dr Roy, who was  
13 one of the haematology doctors. I think he was  
14 a registrar. I am not sure. Anyway, somebody came  
15 into Andrew's room and said to me could I go down to  
16 see Dr Roy, he wanted to speak to me. They told me  
17 where I'd got to go. I had to go to the other side of  
18 the hospital, basically, down -- I don't know -- about  
19 four floors, walk through like a rabbit warren of  
20 hospital. There was lots of work going on in the  
21 hospital. I remember there being lots of polythene  
22 sheeting and scaffolding and stuff. It was just kind  
23 of a nightmare journey trying to find where I was  
24 going to.

25 Eventually I found Dr Roy's office and went in.

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1 He didn't ask me. I did get tearful, because  
2 obviously I was very frightened. His actual words  
3 were -- this might sound a bit funny but it is one of  
4 the phrases we used, "Are you having a sad?" I said,  
5 "Yes, I am. I am frightened of losing you". Trying  
6 to make light of it really, he said, "I suppose you  
7 would rather lose me somewhere like Sainsbury's where  
8 you would be sure to find me again", and I said, "Yes,  
9 I would".

10 So his parents came in to see him on the Saturday.  
11 His mum came back on her own on the Sunday, and on the  
12 Sunday night he deteriorated. He kept insisting on  
13 putting on the oximeter to see what his oxygen levels  
14 were and we could see they were falling. You know, it  
15 was obvious he wasn't going to last very long. He had  
16 said -- I think at some point earlier in the weekend  
17 he had said to me, "I am very ill, aren't I?" I had  
18 said, "Well, you know, yes, you are, but Dr Roy is  
19 going to see you on Monday to see what they can do".

20 I believe he kind of held on to see what Dr Roy  
21 might be able to do on Monday, but he was very, very  
22 poorly through the night on Sunday and had to have  
23 morphine and so on. He did get very distressed not  
24 being able to breathe properly.

25 That night there was -- a strange thing happened

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1 He said to me, "There's a possibility that Andrew  
2 might die over the weekend and we need your permission  
3 not to resuscitate him", and he explained to me  
4 that -- excuse me -- if they had to give him a blow to  
5 the chest to resuscitate him, that would probably  
6 cause a massive bleed and that he could die of that  
7 anyway, and he was very, very poorly, so there  
8 probably wasn't an awful lot of value in resuscitating  
9 him, because it would just -- you know, it would just  
10 happen again. So I felt I had no choice really but to  
11 say that I gave my permission.

12 Andrew knew that I was going to see Dr Roy, that  
13 I had been called to see him. I had to walk all the  
14 way through the hospital -- excuse me -- on my own  
15 back to his room with this knowledge that they were  
16 expecting him to die over the next couple of days.

17 We had a policy between us that we were always  
18 honest about everything, but I had made my decision as  
19 I walked through the hospital, through that filthy pit  
20 that's Basingstoke Hospital. I knew, as I say, that  
21 Andrew had known I had been called to see Dr Roy and  
22 I thought, "If he wants to know what that conversation  
23 was about, then he will ask me, and if he asks me,  
24 I will be honest and I will tell him, but if he  
25 doesn't ask me, I am not going to tell him".

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1 where he had been sort of sitting up and he slumped  
2 forwards and then kind of -- and his mum and I looked  
3 at each other across the bed like, you know, "Is that  
4 it?" Then he just came back up and he said, "I've  
5 died, haven't I?" and we said, "No, you haven't died,  
6 you are still with us".

7 Later he said to me, "I wish I could open the door  
8 and go into the cool garden" -- excuse me -- "the cool  
9 garden". I got the sense when he had slumped forward  
10 that time he had had some sort of a vision of a garden  
11 or something, because I couldn't understand why he was  
12 saying that, you know. Why would he just suddenly say  
13 "I wish I could open the door and go into the cool  
14 garden"?

15 Then on the Monday morning Dr Roy came to see him.  
16 It was obvious that Andrew was dying. There was  
17 nothing more he could do for him. He didn't actually  
18 put it in those words or anything, you know, but  
19 Andrew was slipping in and out of consciousness at  
20 that point and he was gasping for breath.

21 I had heard from other people and read, you know,  
22 that sometimes when people are dying, they hold on for  
23 permission. Excuse me. I understood sometimes people  
24 needed permission to die, permission from their loved  
25 ones. So I spent a few minutes just saying to him how

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1 much I loved him.

2 Actually, I do want to say before I say this bit,  
3 a little bit before that Andrew had looked at me and  
4 said "I have loved you so very much, goodbye". So he  
5 obviously had known at that point that he was going to  
6 die. And then, as I say, as he was just struggling at  
7 the end, I said to him, "Why don't you open the door  
8 and go into that cool garden?" I wanted to give him  
9 permission to die, and he died soon after that. It  
10 was peaceful in the end, and I just hope that he's in  
11 that cool garden, and that one day I will be there  
12 too.

13 Q. You held a small but beautiful funeral for Andrew --

14 A. Yes.

15 Q. -- in the church near Treloar's.

16 A. Yes. It was such a lovely service. I think I was --  
17 sorry -- I was very fortunate, because -- it sounds  
18 an awful thing to say in some ways actually -- in  
19 a school like Treloar's, it's inevitable that some of  
20 the children there who have got conditions that are  
21 life-threatening, sometimes there's a loss of  
22 a child's life. We had a school chaplain, because,  
23 you know, of the pastoral care. So the way that they  
24 prepared for the funerals for children, which weren't  
25 usually held within Treloar's, it would be wherever

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1 as we walked into the church with Andrew's coffin,  
2 Mark was playing acoustic guitar, and it was  
3 beautiful, and again as we went out and in part of the  
4 service.

5 The church was very full. He was very loved by  
6 a lot of people. I had very much wanted it not to be  
7 a celebration of his life, because I thought he's been  
8 through such an awful time, but I did want it to be  
9 a huge thanksgiving, because we were so privileged to  
10 have had him in our lives, and that's what it was. It  
11 was beautiful.

12 He wanted to be buried, not cremated, so we walked  
13 from the church up to the church annex, just like  
14 a churchyard annex just up the road in Froyle. It is  
15 so peaceful. It is surrounded by fields. I think  
16 some people who loved him found it very difficult that  
17 I asked for it just to be family at his interment.  
18 But he never wanted his friends to see him when he was  
19 poorly, and I felt he wouldn't have wanted them to see  
20 him being lowered into the ground, so I asked for it  
21 just to be family, which I think actually did hurt one  
22 of his friends, and I am sorry for that, but I wanted  
23 to carry out what I felt his wishes were. But it was  
24 just so -- he is buried in a very peaceful, beautiful  
25 place.

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1 the child was from, but the chaplain would ask for  
2 people to contribute memories of the child to be put  
3 forward for the funeral service. So that was my  
4 immediate thought, you know, to ask -- to have people  
5 asked for their memories.

6 So it was really lovely that there were so many  
7 lovely memories of Andrew put forward for his service.  
8 So although -- it was a Methodist minister that took  
9 the service, although it was in an Anglican church,  
10 because I was a Methodist. The minister had not known  
11 Andrew, but rather than it being a very impersonal  
12 service, because she had all this input of all these  
13 lovely memories, that made it very personal.

14 Andrew had -- he didn't want to talk about what he  
15 wanted for his funeral and everything really, but  
16 there were just a couple of times he said small things  
17 to me about pieces of music he would like. He said he  
18 wondered if his friend Thomas, who had the band, would  
19 play at his funeral. I said, "I'm sure he would do".  
20 He said, "I don't suppose my friend Jerry could take  
21 the service but I would like him to be involved". So  
22 I asked Jerry if he would do a reading. Poor Mark.  
23 I asked him if he could play a couple of pieces of  
24 guitar music, which he had to learn very quickly, but  
25 he did and did it so proud. It was just so beautiful

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1 Q. It was March 1999 when Andrew died. He was, I think,  
2 32 years old.

3 A. Yes.

4 Q. You say in your statement that you have never stopped  
5 grieving for him.

6 A. No. I mean, he was my best friend. As I said at the  
7 beginning, he loved me unconditionally. That is such  
8 a gift. I couldn't believe that he would love me.  
9 I was very in love with him, and when we were both  
10 working at Treloar's, I remember one day  
11 particularly -- because I worked at the Froyle site at  
12 the lower school and he worked primarily at the  
13 Holybourne site down the road. One day he had come to  
14 do something at Froyle, and I didn't know he was  
15 working at the Froyle site, and I was just walking  
16 across the car park and he came out of a door, and it  
17 was just as if I had seen him for the first time ever.  
18 I literally felt weak at the knees. I loved him so  
19 much.

20 You know, we shared so much in the way we used to  
21 talk about things. We used to sing in the car  
22 together. The stupid jokes we had together, like  
23 a shared language that nobody else would understand  
24 now. They would just think I was bonkers. I mean,  
25 some of his friends might get some of the references,

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1 but generally nobody would know. I miss him so much.  
 2 I do continue to grieve for him. I probably always  
 3 will, because he was my soulmate. There's a Roger  
 4 McGough poem that is called "The Way Things Are".  
 5 There's a line in it that says, "When one glove is  
 6 missing, both are lost." To me that was us, because  
 7 it was like we were a pair, and with one of us  
 8 missing, the other one is lost. I am just completely  
 9 lost in life without him.

10 Q. I want to ask you, finally, if I may, more generally  
 11 about your experiences and knowledge of Treloar's,  
 12 because you have a family connection with Treloar's  
 13 that goes back to your childhood --

14 A. Uh-huh.

15 Q. -- and to your father. Could you just tell us  
 16 a little about that, please.

17 A. Yes. Treloar's has been a huge part of my life  
 18 really. So I first knew about Treloar's when my  
 19 parents fostered a girl from Vietnam who had a spinal  
 20 injury. She was sponsored by Lady Sainsbury. I won't  
 21 go into all of that, but she was sponsored by Lady  
 22 Sainsbury to come -- she had treatment and so on and  
 23 then came to England for her education, with the idea  
 24 that she would be at Treloar's until she was 19. That  
 25 didn't work out and I won't go into that. So my first

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1 a week and I used to go along with him.

2 My brother worked there for I think a year as what  
 3 they called a medical orderly then, when they had the  
 4 boys' college and the girls' school, I think in days  
 5 when things were quite rough and ready and a bit  
 6 brutal really there. When I wanted to have my time  
 7 out from education, it seemed quite natural then to me  
 8 that I could perhaps go and do a year at Treloar's.  
 9 So yes.

10 Q. So you did the gap year -- I think you stayed longer  
 11 than that in the end --

12 A. Yes.

13 Q. -- as a house parent at what was now a co-educational,  
 14 Lord Mayor Treloar College. It was whilst you were  
 15 working there you have told us about meeting Andrew  
 16 for the first time. But you were inspired to train as  
 17 an occupational therapist.

18 A. Yes. Not actually from the OT that was at Treloar's,  
 19 from somebody else I met. My dad used to run summer  
 20 schools for visually impaired people. It was an OT  
 21 there, Josie Harrop, who has sadly passed away. She  
 22 was hugely inspirational and I wanted to be like  
 23 Josie, so I wanted to go and train to be an OT. I had  
 24 to wait an extra year to apply to OT college and do  
 25 that.

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1 contact was her going to Florence Treloar's School,  
 2 and we have used to come up -- we lived in Dorset at  
 3 the time, so we would come up to Hampshire to take her  
 4 to school and then collect her for school holidays,  
 5 just over the couple of years that she was with us as  
 6 a family. I just thought it was this amazing place,  
 7 really. I read too much Enid Blyton so I thought  
 8 boarding schools were all about midnight feasts and  
 9 things, and my sister did nothing to take that image  
 10 away, because she did used to tell me about them  
 11 getting up to jinks in the night and having midnight  
 12 feasts and things. I just thought Treloar's was this  
 13 magical place.

14 After my sister returned to Vietnam, my father  
 15 kept the contact with Treloar's. He ran a youth  
 16 activity centre in Weymouth and used to have parties  
 17 for the girls to come to go canoeing. I don't know  
 18 how it all worked out. I was very young at the time,  
 19 probably about eight or nine years old, but the  
 20 physiotherapist from Treloar's, Mrs Bell, would bring  
 21 these girls down to have a holiday of some sort and  
 22 learn to canoe.

23 Then my dad got a job in Hampshire, as it  
 24 happened, as an education adviser, and taught canoeing  
 25 at Treloar's on a voluntary basis. He used to go once

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1 Q. For the reasons you have already given us, you didn't  
 2 in that capacity have a huge amount of contact with  
 3 the haemophilia boys, but you said they were a lively  
 4 bunch and often up to mischief.

5 A. Oh, yes, they were just like the life and soul of the  
 6 school in so many ways. All the children at Treloar's  
 7 were valued. It was very much a can-do school,  
 8 a can-do attitude to everything. The things that were  
 9 done then, the trips that children were taken on and  
 10 the activities that were done, you know, just opened  
 11 them up to all sorts of opportunities. You know, we  
 12 believed in them, believed in their potential, all of  
 13 them, but the boys, you know, were such a lively  
 14 bunch.

15 I still have these images, because Treloar's was  
 16 set up like one of the old TB hospitals, with the open  
 17 cloisters. I can see them running round there and  
 18 jumping over the walls and up to high jinks. Yes,  
 19 they were just -- they were a huge part of the school,  
 20 much loved by us all, yes.

21 Q. You wanted to make the point and make it clear that  
 22 the Haemophilia Centre where Dr Aronstam worked from  
 23 and later Dr Wasseff and others was not part of the  
 24 Lord Mayor Treloar trust, but an NHS facility, albeit  
 25 an NHS facility based physically at the school.

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1 A. Yes. I think it would be very sad if references to  
2 Treloar's within this Inquiry were to paint the school  
3 and college in a poor light. I know there were some  
4 experiences that some of the boys had whilst at the  
5 school and college that, you know, perhaps weren't  
6 favourable and, you know, that's another thing, but  
7 the treatment with the Factor VIII, the infected  
8 Factor VIII, was not part of what the school were  
9 doing; that was the NHS treatment centre that was  
10 based at the school for the convenience of everybody,  
11 really, but the boys then didn't have to go to  
12 hospital every time they had a bleed. They could just  
13 go -- if they were at the college site, it was just  
14 literally there, and if they were at the school site,  
15 it was just, as I say, three miles down the road.  
16 They could get a bus there and be treated very quickly  
17 and monitored appropriately.

18 Q. You qualified as an occupational therapist in  
19 July 1984.

20 A. Uh-huh.

21 Q. In the subsequent year, 1985, you returned to  
22 Treloar's as a unit leader.

23 A. Yes. When I qualified as an OT, I didn't feel very  
24 confident about my therapy abilities, really.  
25 I didn't want to work in a hospital anyway. I had

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1 What we didn't have was any help to know how to  
2 support the boys. So boys that had been diagnosed  
3 with infections and would come back to the house and  
4 talk to us about it, we had no training for how to  
5 talk with them about that, how to help them come to  
6 terms with it -- anything, really, how to support  
7 them. We did our best, but I was very young at the  
8 time. What did I have really to offer them other than  
9 a listening ear?

10 Q. Then you returned to work as an occupational therapist  
11 at Treloar's from January of 1991 through to July of  
12 2008.

13 A. Yes.

14 Q. By that time there were very few boys with haemophilia  
15 left at the school.

16 A. Yes. We had two boys with haemophilia at the school,  
17 but they were quite a lot younger than the cohort that  
18 had been infected. I think, yes, there were perhaps  
19 a few still at the college just finishing their  
20 education. But no, I didn't have any on my case load  
21 as such as an OT.

22 Q. You started to hear about former pupils dying from  
23 AIDS.

24 A. Yes, yes. That was obviously very scary, because, you  
25 know, being married to Andrew and there just, yes,

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1 done a couple of short-term OT jobs, because I knew  
2 the district OT and she had got a couple of vacancies,  
3 short-term. So I had done three months paediatrics,  
4 three months geriatrics, and I just didn't like  
5 working in a hospital, and I missed the care work,  
6 because I have to say my first two years at Treloar's  
7 as a house parent were probably the happiest years of  
8 my life. I just loved it. I loved the care work. So  
9 I went back to that, yes.

10 I worked -- the unit leader meant I was just sort  
11 of promoted to where I worked exclusively on one --  
12 I will not say exclusively -- mostly on one unit.  
13 I had nine boys that were under my care, including  
14 some haemophiliacs. So, yes.

15 Q. You stayed there in that capacity until 1988. You  
16 don't I think remember when you first started to learn  
17 about boys having been infected with HIV. Can you  
18 recall any advice or information being given by  
19 Dr Aronstam or others in that regard?

20 A. I do remember we used to have updates from Dr Aronstam  
21 at sort of annual staff meetings. We had generalised  
22 advice on how to treat blood spillage in school. So  
23 there were sort of guidelines for that that we should  
24 follow. So there was -- yes, there was sort of  
25 generalised advice on that.

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1 being a number of announcements that boys had died.

2 Q. I think you have a memory of at one point receiving  
3 a document or a list from the pupils' association  
4 which listed the past haemophiliac students who had  
5 died. You saw on that list the names of boys you had  
6 known.

7 A. Oh, yes, there were. It was just heart wrenching to  
8 get this list. It was just in everybody's pigeonhole  
9 that morning. I can't remember what reason. The  
10 former pupils' association must have been wanting to  
11 bring that to people's attention for some reason.  
12 I just remember reading through the list and being  
13 devastated, you know, because I remembered the boys so  
14 clearly, all the ones that had been through the school  
15 anyway. I didn't know the boys at the college when I  
16 was working at the school. There were a few --  
17 I didn't know the names, didn't know them, but there  
18 are men in this audience who were at Treloar's at the  
19 time who are grown men in their 40s probably now, but  
20 I still if you ask me to picture them, I would be  
21 picturing them as these vibrant young lads that they  
22 were, and to just read this list of so many that had  
23 died, you know, it was a huge, huge blow, a huge blow.

24 Q. Do you have any other observations based upon your  
25 knowledge of Treloar's generally, your time working

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1 there, about the workings of the haemophilia medical  
 2 centre, the unit there?  
 3 A. I suppose the thing is that other than educating us  
 4 about the infection and making sure that, you know,  
 5 any blood spillage was dealt with appropriately, they  
 6 didn't -- as I say, we weren't helped to know how to  
 7 support those boys, and I think that there could have  
 8 been a lot more -- the unit was -- they were so  
 9 paternalistic. They were their boys. So although  
 10 they lived with us in the boarding houses and ate  
 11 their meals with us and they went to school and into  
 12 the classrooms and everything, so they spent the  
 13 majority of their days with the school staff, they  
 14 belonged to the haemophilia doctors. So that's where  
 15 everything -- I suppose they thought they were dealing  
 16 with it all and, as I say, they just didn't appear to  
 17 have done anything proactively to ensure -- I mean,  
 18 the most important thing is we weren't able to give  
 19 the boys the support we could have done if we had  
 20 known more and understood more and had the skills, but  
 21 also how we should deal with this devastating news.

22 When a boy that you are caring for, that you are  
 23 parenting in some respects -- obviously you don't take  
 24 the place of their parents, but, you know, you are  
 25 caring for them on a day-to-day basis, and they come

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1 I wrote then:  
 2 "I have been feeling all sorts of emotions which  
 3 I feel unable to accurately pinpoint and label and  
 4 unable to express. I feel them bubbling up under the  
 5 surface, messing up my thought processes, interrupting  
 6 my intentions and my focus, exhausting me. It feels  
 7 like something growing inside, preparing to burst out.  
 8 I want it to burst, to release this terrible tension.  
 9 I feel a need to cry, to sob, to howl, but only a few  
 10 teardrops make their way out. Sometimes I want to  
 11 shout, to rage, throw something, kick something, beat  
 12 my hands against something.

13 "I know there is a depth of terrifying sadness,  
 14 not just for Andrew and for me, but for all those who  
 15 also have their stories of loss, of pain, of lives  
 16 ruined, of babies aborted, the lives lived as  
 17 reclusives, lives lived in fear and emotional pain,  
 18 layered up on physical illness, encounters with death.  
 19 There are people out there somewhere who caused this.  
 20 Who are they? Where are they? Escaping justice."

21 I would like to say a public thank you to Jason  
 22 Evans for his tireless work fighting for justice and  
 23 bringing to light the evidence showing that the  
 24 infection of the haemophiliacs with deadly viruses was  
 25 no accident. My husband, Andrew, was one of many with

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1 back and tell you they have been given this  
 2 devastating news, you know, there's feelings in  
 3 yourself as well to deal with. It is minor in  
 4 comparison to what the boys are going through, but  
 5 there was very little for us, to support us either.  
 6 We are losing this community of boys who we loved, you  
 7 know. We loved the children at Treloar's. It was  
 8 a loving environment, you know, and to think that  
 9 a huge group of them had been given this infection  
 10 just -- yes, devastating.  
 11 Q. Amanda, those are my questions. I'm just going to ask  
 12 Mr Snowden if he has anything else. Nothing further  
 13 from Mr Snowden.

14 Is there anything further you'd like to say?

15 A. There is, yes. I would like, if I may, so read  
 16 an extract which is -- it is like a sort of diary  
 17 extract and then I would like to make a short  
 18 statement after that.

19 This is something I wrote a few days after I had  
 20 been to the Leeds Inquiry and felt very moved by some  
 21 of the evidence that I heard there, some from people  
 22 that I knew before and some people I didn't. I was  
 23 really struggling to cope with my emotions afterwards,  
 24 so I just thought, "I am going to put something down  
 25 on paper to get this out". This is unedited from what

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1 haemophilia who were not just considered worthless,  
 2 expendable, cheaper than chimpanzees to experiment on,  
 3 but were considered to be an unnecessary drain on  
 4 public resources, so could be given treatment that was  
 5 expected to drastically reduce their numbers.

6 I know this Inquiry does not have the power to  
 7 bring about criminal prosecutions, but I sincerely  
 8 hope it will be allowed to run its course and will  
 9 expose the attitudes and actions of politicians, civil  
 10 servants and medics with such clarity that those who  
 11 do have the power to prosecute will have no option but  
 12 to do so, and thereby bring about the justice deserved  
 13 by the haemophiliacs, those they unintentionally  
 14 infected and their families.

15 As they face the possibility of being called to  
 16 give account for their actions, may those involved in  
 17 the chain of decisions and events that caused the  
 18 pain, suffering and deaths of so many now take their  
 19 turn at being the ones to lie awake in the night  
 20 fearing what the future may hold.

21 That's all.

22 MS RICHARDS: Thank you. Sir Brian.

23 SIR BRIAN LANGSTAFF: Your way of telling it so gently, so  
 24 calmly and so caringly at the start I think threatened  
 25 to hide from us the frustrating and distressing times

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1 that you have had, but it didn't in the end. It came  
 2 through, in my view, very clearly.  
 3 But underpinning it all and shining through it all  
 4 was and is your great affection for the man you lost.  
 5 A truly memorable piece of evidence altogether. Thank  
 6 you very much.  
 7 **A.** Thank you.  
 8 **(Witness withdrew)**  
 9 **SIR BRIAN LANGSTAFF:** Well, after that it seems somewhat  
 10 banal to ask about tomorrow.  
 11 **MS RICHARDS:** Sir, we have tomorrow a number of witnesses,  
 12 none of them tomorrow anonymous. First we are hearing  
 13 from Stuart Mclean, then from Mark Ward and Richard  
 14 Dudley-Smith, and then from Androulia Andreou.  
 15 **SIR BRIAN LANGSTAFF:** 10 o'clock. 10 o'clock, please.  
 16 **(Adjourned until 10.00 am on Thursday, 17th October 2019)**

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(69) ulcer - washing

<b>W</b>	27/25 29/20 29/21 31/20 32/18 34/13 37/24 43/12 46/12 50/14 52/16 54/2 56/21 60/6 63/25 76/20 78/25 82/13 86/2 93/23 94/5 94/14 94/25 100/9 106/13 111/17 114/8 115/22 122/13 123/15 123/16 126/14 136/8 140/7 142/25 146/16 151/15 151/18 151/22 152/7 153/3 155/18 170/3 173/9	7/23 8/19 14/20 16/25 20/23 23/6 23/14 24/6 24/16 25/4 28/10 28/18 30/22 32/18 34/12 35/16 39/12 40/10 40/11 40/14 43/3 43/14 44/21 45/1 46/15 49/8 49/16 51/23 51/25 55/11 55/25 58/10 59/22 63/25 68/16 68/18 69/3 69/6 69/12 70/13 73/20 75/2 75/9 75/10 77/19 80/8 80/9 81/4 84/18 86/2 86/19 88/2 89/1 97/2 97/3 97/4 98/21 99/3 99/21 100/19 101/4 107/15 107/20 108/1 108/2 108/3 109/13 111/7 111/14 113/21 115/6 115/7 118/24 122/2 125/25 127/3 127/13 127/15 128/17 129/6 140/16 141/3 141/11 143/12 143/19 144/25 147/18 148/5 149/4 156/9 156/22 159/18 160/1 160/9 161/5 161/18 163/3 163/5 163/6 165/23 166/16 168/15 169/22	46/10 50/1 52/8 54/25 65/6 71/9 76/20 78/4 78/5 78/14 80/25 81/12 84/3 88/14 88/15 89/18 91/7 100/25 101/10 101/23 103/2 105/13 111/22 116/9 116/15 116/23 123/15 125/14 127/23 130/14 131/8 132/22 135/20 136/4 137/18 142/8 147/20 152/20 152/21 157/24 158/24 159/21 168/4 170/16 171/2	<b>widen</b> [1] 134/3 <b>wife</b> [11] 8/6 11/5 11/14 11/18 12/13 13/13 13/21 14/3 34/8 48/1 137/10 <b>wife's</b> [2] 12/9 24/11 <b>Wilde</b> [6] 18/15 19/24 20/16 25/3 25/22 28/7 <b>will</b> [60] 1/8 2/2 8/6 10/5 11/1 13/14 14/1 15/4 16/13 18/13 18/21 20/13 25/23 30/18 32/23 34/8 35/21 36/12 41/23 46/5 47/7 48/12 50/8 53/17 53/21 54/8 66/1 71/2 73/7 79/25 84/10 85/16 97/25 98/19 99/1 100/3 101/14 104/5 104/24 108/4 110/12 113/7 116/10 130/15 133/5 134/1 134/20 134/22 147/8 150/25 151/14 154/23 154/24 154/24 157/11 161/3 166/12 172/8 172/8 172/11 <b>willing</b> [2] 127/11 127/12 <b>window</b> [4] 46/9 116/13 116/14 129/6 <b>windows</b> [2] 46/8 46/11 <b>Winter</b> [3] 22/11 22/14 23/1 <b>wise</b> [2] 66/13 110/8 <b>wish</b> [4] 12/25 97/2 156/7 156/13 <b>wishes</b> [1] 159/23 <b>wishing</b> [1] 132/10 <b>with</b> [275] <b>withdrawal</b> [1] 121/1 <b>withdrew</b> [3] 54/1 97/19 173/8 <b>within</b> [13] 20/21 25/23 41/13 41/15 45/24 77/22 78/14 91/24 112/6 119/19 138/18 157/25 165/2 <b>without</b> [14] 45/5 45/6 46/3 47/5 51/14 66/18 71/19 71/19 122/3 125/16 126/2 130/6 132/10 161/9 <b>witness</b> [26] 1/3 1/7 1/8 1/14 2/3 3/5 12/3 15/19 15/22 30/5 34/12 35/6 38/18 47/18 54/1 54/7 54/9 54/12 54/18 55/5 62/7 97/19 97/25 101/12 145/20 173/8	<b>witness's</b> [4] 1/11 54/14 54/15 55/9 <b>witnesses</b> [3] 1/5 45/4 173/11 <b>wives</b> [1] 130/6 <b>woman</b> [3] 66/4 86/3 86/4 <b>women</b> [6] 69/13 70/22 71/2 91/12 94/23 125/21 <b>women's</b> [1] 95/4 <b>won't</b> [7] 5/9 31/21 31/22 151/12 152/19 161/20 161/25 <b>wonder</b> [2] 28/24 29/4 <b>wondered</b> [2] 37/23 158/18 <b>wonderful</b> [2] 34/24 141/5 <b>wood</b> [1] 27/18 <b>wooden</b> [2] 116/8 116/11 <b>Worcester</b> [1] 22/20 <b>word</b> [6] 9/18 33/15 40/3 60/5 71/14 140/14 <b>words</b> [10] 7/15 9/17 72/20 95/14 96/22 97/10 97/12 124/14 155/2 156/18 <b>work</b> [25] 32/7 36/5 36/25 37/15 37/17 44/15 56/8 63/20 69/8 69/20 71/3 74/4 111/24 119/1 123/25 124/10 127/13 144/24 153/20 161/25 165/25 166/5 166/8 167/10 171/22 <b>worked</b> [12] 45/23 49/16 104/23 109/17 113/2 160/11 160/12 162/18 163/2 164/22 166/10 166/11 <b>worker</b> [1] 41/3 <b>workers</b> [1] 50/24 <b>working</b> [17] 8/14 56/20 63/13 64/15 65/12 71/8 103/15 105/12 110/6 111/14 112/19 160/10 160/15 163/15 166/5 168/16 168/25 <b>workings</b> [2] 17/20 169/1 <b>world</b> [7] 39/17 59/21 71/9 93/6 105/3 114/12 114/14 <b>worried</b> [3] 52/13 147/17 147/25 <b>worries</b> [2] 23/20 88/22
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(70) washing... - worries

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(71) worry - youth