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

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?

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

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.

A. No, nothing at all.

Q. You have also I think a recollection of being told by Dr Hill that the products were sourced from the United States.

A. Yes, I do, yes.

Q. We can see a list of the products that you received. Henry, can we have 1387002, please? We can see here particulars of blood products, batch numbers by month and year, and we won't obviously go through the detail of all the batch numbers, but we can see here the vast majority of the products that you received, with very few exceptions, were Armour Factor VIII?

A. Yes, that is correct.

Q. If we just look at the next page as well, please, Henry, we can see that continuing through 1981, through the 1980s.

In 1981 you fell ill after you had injected yourself with Factor VIII. What can you remember about that?

A. Not a great deal, really. This isn't the glandular fever incident?

Q. No. You said in your statement you subsequently learned that you were infected with hepatitis B at this time.

A. Yes. I don't actually remember a lot about that, to

be honest, other than I was ill and that was it.

Q. There are in your records, and you have recorded this in your statement, positive tests for hepatitis B surface and core antibodies, May 1981.

A. It turned out to be, yes.

Q. Do you know whether you or your parents were told at the time you were being tested for hepatitis B?

A. No. I have asked them this question and no.

Q. Were you told or your parents told that you had, in fact, tested positive for hepatitis B?

A. No.

Q. So in about early 1984 you fell ill with glandular fever.

A. Yes.

Q. Can we just have up on screen, please, Henry 1387010. We can see it's a letter from Dr Hill dated 20th January 1984 to you:

"I am sorry to hear that you have glandular fever and hope that you are beginning to improve. I presume this is why you could not come to my clinic today."

He offers further clinic dates.

What do you recall about that episode of glandular fever?

A. It was quite worrying, because I was planning to get married in the not too distant future. It was

a horrendous illness. Although I have got severe haemophilia, I am not ill usually and I was bedridden with this.

I do remember that our local village doctor came out, our family doctor came out to see us, and he said to me, "I am diagnosing you with glandular fever, but I think you should see a specialist in haemophilia". I genuinely believe he knew more than he was letting on, or wanted to let on professionally.

Q. The way you have put it in your statement is that the GP said that this fever would have been triggered by something --

A. Uh-huh.

Q. -- and that there were some things that were above his knowledge, or words to that effect.

A. That's correct, yes.

Q. With the benefit of hindsight --

A. Yes.

Q. -- you now think that's around the time that you were seroconverting.

A. Yes, yes, because that just ties in with everything that we found out. The amount of people who have had glandular fever when they were seroconverting is almost 100%, so ...

Q. I think you didn't, in fact, go and see

the Haemophilia Centre.

A. I didn't, no. Certainly not Frank Hill, but there you go.

Q. In 1984, you married.

A. Yes.

Q. And your former wife will be giving evidence after you --

A. Yes.

Q. -- this morning. Up to this point, apart from the illnesses you have described and apart from the obvious effects of the haemophilia that you have described, you were leading a busy, normal life?

A. Yes, yes.

Q. Working, good social life.

A. Yes, very good.

Q. Looking forward to marriage.

A. Very good, yes. The haemophilia didn't really -- it was just one of those things, you know. I just treated myself when I did and that was it, so ...

Q. I think you and your partner had bought a house together.

A. Yes, we did, yes.

Q. At some point in the early part of 1985, you had a urinary infection and passed out.

A. Yes.

Q. Can you tell us what you remember about that and what happened immediately afterwards?

A. Yes. We had only been married about a year, so *[redacted]* couldn't drive. My father picked me up. I was taken to A&E at the Queen Elizabeth Hospital, the Old Queen Elizabeth Hospital. I was on a trolley and a junior doctor came to see me. He was stood there to my left, flicking through the notes, and he just turned round and said, "This looks like HIV developing into full-blown AIDS", and that was it. I was -- well, I was already lying down, but I was floored, because I just -- I didn't even though what AIDS was anyway, really, and to be tested for it and then to be told I was positive as such a casual thing, I didn't know what to do or what to say, so ...

Q. As I understand it, you are not sure whether he used the words HIV or not or HTLV-III.

A. No, but I remember the word "AIDS" and "full-blown". That's how ...

Q. Now, there is no record of this in your medical records.

A. Apparently not, no.

Q. But I think it is right to say that the records you have got do not appear to be complete in any event.

A. No, no, they are not.

Q. You don't, I think, have your GP records either.

A. No. Mysteriously they vanished in 1985, 1984 or 1985.

Q. The only record that we have -- if we have up on screen, please, Henry, 1387013 -- prior to August 1985 is the UKHCDO records. We will just look at that briefly. We can see there it says "Date first positive: 28th April 1985". That would be consistent --

A. Yes.

Q. -- with your recollection of being given some information --

A. Yes.

Q. -- in the way you have described in the first part of 1985.

A. Yes.

Q. But it is right, I should point out, if we go to the next page, please, Henry, there is an obvious error on this page, because it says "Date condition diagnosed: 1st January 1999". You have no idea, I think, where that date comes from.

A. No, no.

Q. So the first reference in your actual medical records to HTLV-III appears to be August of 1985, 1st August 1985.

A. Yes.

Q. We will just again look at a record in relation to that. 1387008, please. If we look down the very bottom of the page, we can see an entry for *[redacted]*. It says:

"Married for 1 year. Wife pregnant."

Then it says this:

"HTLV-III status not known."

Then there appears to be a further line under that, but this is the only form in which you have a copy of your records.

A. Yes.

Q. So we don't know what that further line might say.

A. No, no.

Q. As I understand your evidence, you and your wife did go to see Dr Franklin on 1st August 1985.

A. Yes.

Q. You went to see him in part, at least, because your wife was pregnant.

A. Yes.

Q. And because you had this information --

A. Yes.

Q. -- from the accident and emergency admission that you might have AIDS.

A. Yes, yes.

Q. And you wanted to talk about that with Dr Franklin.

A. Yes.

Q. Could we have up on screen, please -- it's a document with a reference number for the next witness, Henry. So it is 1388002.

So we can see the date is 1st August 1985, the date of that entry in your records, the date you went to see Dr Franklin. It is a letter from Dr Franklin -- we can just about see that at the bottom -- to Dr Jones, who was your wife's GP, not yours.

A. Yes. He refused to have me.

Q. It says this:

"This 19-year-old girl who is the wife of a patient of mine who has severe haemophilia A came together with her husband to see me today. As you know, she is 3 to 4 months pregnant and would prefer to terminate the pregnancy. Any child of this union would be a haemophilia carrier if female, but haemostatically normal if a male. There would therefore appear to be no grounds for a termination from the haemophilia point of view.

"However, the current concern amongst the haemophiliacs regarding the acquired immune deficiency syndrome (AIDS) has been causing us to modify our advice to haemophiliac patients who wish to undertake 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 positon to be a signatory,

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.

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?

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 doctors in the autumn of 1985 or indeed at any later stage about whether you should tell other people or not about your infection?

A. Yes. It was pretty much, "Don't tell anybody". He knew that we were a young married couple and -- yes, it was "Just don't tell anybody". Not that we were going to anyway, because we still didn't know what this was. So, yes.

Q. *[Redacted]* is going to be giving evidence about this, but you were, as you describe in your statement, very young, very frightened.

A. Yes.

Q. And bombarded with information about the risks of AIDS.

A. Yes.

Q. And that really continued for the following years.

A. Oh, yes, yes.

Q. You said in your statement that it was around this time that there was a change, a shift, in the atmosphere and workings of the Haemophilia Centre.

A. Very much so. I didn't go -- after this diagnosis, I very rarely went to the haemophilia unit, but what was very, very noticeable is you used to go into the waiting room and there were many, many, many chairs and it was full, always full. The clinic appointments

that I had afterwards, there was just one or two people or *[redacted]* and myself on our own, and that really struck out at us, you know, what's gone on? It was just so odd. Very, very odd. So ...

But I basically stopped going to the clinic appointments. The arrogance of the doctors I was seeing, you couldn't ask them questions, really. They just told you what they wanted to tell you and that was it, so ...

Q. It was some ten years later in 1995 that you found out that you had been infected also with hepatitis C.

A. Apparently, yes.

Q. Again, we will have a document up on screen. It is 1387006. It helps us date this. So it is 31st March 1995. It is from Dr Wilde, who by this time was your consultant, and it says this:

"[You] attended the clinic this morning requesting hepatitis C serological testing, having been prompted to do so by a communication from the Haemophilia Society. The blood test was duly performed and he will be informed of his result."

Now, the blood test was performed and you were informed of the result and it was positive.

A. Yes.

Q. But I think you don't believe this is a correct --

A. No, I don't.

Q. -- record of what triggered testing.

A. No. I don't. Anybody in the room that knows me knows that I have little regard for the Haemophilia Society. I would not have taken -- well, we would not have had any literature come through to us from the Haemophilia Society, full stop. If by any chance we did, it would have gone straight in the bin. So that does not ring true.

Also, 1995, that's a very, very, very late date for hep C. I just think that is a letter of convenience, as far as I'm concerned. It ties everything up nicely for the records. So ...

Q. And you don't know why you weren't called in for testing in relation to hepatitis C earlier than 1995.

A. No.

Q. So precisely what triggered the test, it hadn't been done prior to this year?

A. I don't know, but I hadn't sanctioned it, if it was.

Q. And you have said in your statement that having received the hepatitis C diagnosis, at that time it was the bottom of your list of things for you to worry about.

A. Very much so. I did get on with Dr Wilde, my haematologist. I went there for the -- I think it was

a clinic appoint. It wasn't just for the results, but he actually said, "I have the results of your hep C". He said something like, "Do you really need to ask?" I just shrugged my shoulders and said, "No, not really". A bit further on in the consultation I said, "About this hep C". He said, "I wouldn't worry about it. You have to prioritise things. Your haemophilia is going to come above the hep C and HIV and AIDS is top of your list". That was it. He really didn't speak much about it then.

Q. In 2000, so five years after the hepatitis C diagnosis, you went on a treatment strike, because you wanted to be on recombinant. Again, we will just look at a letter to help put this in context. It is 1387005, please, Henry. It is dated 19th May 2000. It is a letter from you to Dr Wilde and it says this:

"As you are aware, recently I sent a batch of Factor VIII back to the unit as I was not happy with its appearance. I read the letter from Grifols, the manufacturer, but I am afraid I was not convinced.

"In their opinion it may be within the colour ranges allowed, but there seems to have been no specific testing of this batch other than when it was packed for distribution.

"I know that you as a doctor cannot comment and

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

Then you say this:

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

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

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

What can you recall about that?

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

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

A. Yes.

Q. If you can explain who that was.

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

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

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

A. Yes.

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

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

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

A. Yes.

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

A. Yes, so somewhat proved a point.

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

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

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

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

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

A. Yes.

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

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

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

A. From -- initially, not much. A lot of mental anguish, but initially not much physical. I had a lot of sort of little opportune infections that were all put down to being related to HIV. It wasn't until 1999 that I had to go and see Dr Wilde because I had fell seriously ill. That's when we had the conversation about antiretrovirals, et cetera, so ...

Q. Just before we get to that, you had declined treatment with AZT.

A. Yes, I had.

Q. Why was that?

A. Because some of the haemophiliacs I had seen, to me they just looked worse than the ones that weren't on AZT. I asked -- I am pretty sure it was Frank Hill -- I asked about AZT, what it was. I was told, "There is no need for you to know, you just take it". That's the sort of attitude, which is why I stopped going. But I am glad I didn't take AZT. That's my personal choice, and I still think, you know, in some cases it should never have been given, but ...

Q. As you were just saying, it was around the late 1990s --

A. Yes.

Q. -- that Dr Wilde said to you, "Get treatment now or you will be dead within three months".

A. Yes. I went to see him. I was very weak at the time. I had oesophageal candida, which is a typical

HIV-related illness. He did some bloods on me. We had a chat. I always asked him to be straight with me. He said, "Look, you have never taken antiretrovirals. In my opinion, you have got about three months to live. So go home. Don't take too long to think about it, but have a think what you want to do". So I had to go home and have a think about it, so ...

Q. You have described in your statement you were still unsure whether you wanted to start the medication or just let nature take its course.

A. Yes.

Q. But you had a home visit from one of the haemophilia nurses, Sam.

A. Yes, Sam, yes, yes. She was a rod to many of us. She basically convinced me to give it a go. I think she said something like, "You can die later if you really want to". It's very flippant, but that's the sort of relationship we had with her, so ...

Q. You did start the antiretrovirals, but the first set of drugs that you had caused significant problems.

A. Yes.

Q. What were those?

A. I believe it was Nevirapine. I had -- I was burning up, but I had massive rashes on the inside of my

thighs, and I actually -- once I had started it, I thought, "Right, well, I am going to carry on". Sam came round and asked me how I was getting on. I think I had been on them for a matter of weeks. I said, "Oh, okay apart from this rash". I showed her the rash and she went ballistic and said, "You should have told me about it. Your body is rejecting it". So I was a little bit annoyed because I just thought it was one of those things. But I then got put on another drug, Delavirdine, which was named patient at the time. I was on that for years.

Q. You also said in your statement you think that first drug regime led to you having a duodenal ulcer.

A. Yes, yes.

Q. Since that time, what have been the side effects of the medications as they have changed over the years?

A. Multiple ulcers, which I have been in and out of hospital. Touch wood, I hope that this has now been sorted.

It is hard to put your finger on it, really, because you just live with it every day. But appetites, tiredness. I was forever going to see the doctor about why am I so -- why do I feel so lethargic and tired and can't concentrate? I was always told, "Well, it could be the hep C, it could be the HIV, it

could be the meds for the HIV. We don't know". It has just been an ongoing thing, really. So ...

Q. One of the concerns you voiced in your statement about your medical care is that your HIV care remained in the hands of haematologists.

A. Yes. It was a concern, because they weren't HIV specialist doctors. However, with Dr Wilde, I preferred it that way, because I could have an open chat with him about things and we literally did muddle through together. That was a sentence when he retired that he came out with. And I am still here. So, you know, he did all right by me.

Q. You have said in your statement, in relation to HIV, this:

"It is true that today HIV is a treatable disease. This has not always been the case and being diagnosed with HIV today is not the same as being diagnosed back in the 1980s, when there was either no treatment or only experimental treatment available. Some of the medications given at that time did as much harm, if not more, than the virus itself."

A. That's correct, and also this is happening now. Truvada, which I was put on, which was named as the wonder drug only last year, there is now a legal action in America for fatalities of people who have been taken it. I have been taken off it because of kidney results that started to fail, and numerous other people have in this country. This was held up as a wonder drug only last year. So it carries on.

Q. Hepatitis C treatment. You have said in your statement that some time after 2005 you were referred to see a Dr Mutimer.

A. Yes.

Q. And you underwent a fibre scan and blood tests.

A. Yes.

Q. You were offered pegylated interferon and Ribavirin.

A. Yes.

Q. What was your decision in relation to that?

A. No. At that time I had been involved with Birchgrove. We were receiving numerous letters from people who had been on this. I asked him -- it was a loaded question. I asked him what the side effects were. I knew what the side effects were because I had spoken to these people and it was horrific. He came out with, "Oh, well, it is mild flu". I challenged him about this and the meeting did not go very well.

Q. You also, I think, raised concerns about the interaction --

A. Yes.

Q. -- with your HIV medication --

A. Yes.

Q. -- and didn't get very clear answers.

A. No, didn't get very far with that either.

Q. So you declined the treatment. At the time you wrote your witness statement you were receiving reasonably regular liver function tests.

A. Yes.

Q. But the question of further treatment was left open. What's the current position?

A. Now, as of this year, I have got chronic liver disease. There is scarring and fatty tissue. I am going back to see Mutimer in November, hopefully with a view to going on the latest medication, if we manage to have a decent talk about it, so ...

Q. How have the events that you have described affected your trust in medical professionals?

A. I have no trust. I have no trust. As *[redacted]*, my partner, will bear out, it's getting worse in the health authorities, especially with haemophilia. My life has actually been literally threatened -- and that's not an exaggeration, is it? -- twice in the last three years by one doctor asking me when I contracted haemophilia, and at this time I was in accident and emergency with severe internal bleeding, and yes, it's just -- the list goes on. The list goes on.

Q. You have described in your statement an incident in which you were in an ambulance.

A. Yes.

Q. This was in 2016.

A. Yes.

Q. Can you tell us about that?

A. That was a burst ulcer. I had been vomiting and passing blood in large amounts. I felt very, very faint. *[Redacted]* called the ambulance. I thought I was going to pass out. So I automatically, as haemophiliacs do, you reach for your Factor VIII, because there is nobody else can have it. I had a large dose of Factor VIII and sat on the bed. The paramedics, two young ladies, turned up. We had a chat. They did blood pressures, et cetera. They wanted to take me to hospital. Took me down to the ambulance, and they were just sorting me out on the stretcher and everything and I asked, "Where are you taking me?" She said "Warwick". I said, "Well, I don't want to go to Warwick hospital, I won't come out of there alive, and also they won't want me". So she said, "Where do you want to go?" I said "Queen Elizabeth".

She put the radio, whatever it was, on hands free,

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

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

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

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

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

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

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

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

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

A. Yes.

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

A. Yes, yes.

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

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

A. Uh-huh.

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

A. Yes.

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

A. Yes.

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

A. Yes.

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

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

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

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

A. Yes.

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

A. Yes.

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

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

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

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

A. We never. We never discussed it again.

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

A. Yes, yes.

Q. You had to give up work.

A. Yes.

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

A. Yes.

Q. In the end, you separated.

A. Yes, yes.

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

A. She did, yes.

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

A. Yes.

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

A. Yes, yes.

Q. You had to turn that down.

A. I had to turn it down because I couldn't -- at that time it was difficult to get a travel visa, let alone a work visa. So we just -- again, we never spoke about it. I had the job offer and it literally got thrown in the bin.

Q. You say in your statement that you not only lost out on a career, but the feeling of being useful in life.

A. Yes, very much so, yes. You can never get that back. Yes. Whether it's the doctors or whatever, you are a disposable commodity that doesn't mean anything, and I think that's why a lot of haemophiliacs strive in whatever career they do to get to the top or be better than somebody who hasn't got haemophilia. I don't know. It is like a challenge. So it's worse to be knocked flat than if you hadn't had haemophilia, that's how I look at it, because we had the challenge of it anyway, so ...

Q. You threw yourself into campaigning work.

A. Yes.

Q. In particular your work with the Birchgrove Group.

A. Yes.

Q. You describe yourself in your statement as constantly in fear of the stigma attached to your infections, particularly in relation to the HIV.

A. Yes.

Q. I wondered if you could tell us about that.

A. Well, a lot of people say there is no stigma to HIV anymore, and in London, no, there isn't, and most big cities probably not. I live in a small *[redacted]* village. I tell you now, if I walked in the pub with a red ribbon on, I dread to think what would happen. It is still the same. There is still the same stigma. Maybe not as violent or as vicious, but there is a lot of stigma around HIV and AIDS, and a total misunderstanding of haemophilia and HIV, even today.

Q. You have referred in your statement to -- because of the known association between haemophilia and HIV and AIDS --

A. Yes.

Q. -- you began to downplay the fact of your haemophilia and not tell people you were a haemophiliac.

A. Yes. From my teenage years I rode scooters, and all my friends knew I was a haemophiliac in case I had an accident. I stopped telling anybody that I met, because haemophilia just equated to AIDS. I think I did put it in my witness statement, because again it is sort of gallows humour, but I was on a rally in I think it was Great Yarmouth and a friend of mine shouted across "Oh, you are one of those necrophiliacs, aren't you?" I actually preferred being called a necrophiliac to a haemophiliac. That's how bad it was.

Q. You say in the 1980s and 1990s, the fear about AIDS was overwhelming --

A. Yes.

Q. -- and there were horrible jokes --

A. Oh, yes.

Q. -- everywhere.

A. Yes, yes.

Q. You would pretend to laugh along.

A. Yes. You would be sat in a pub and, you know, even the crowd of my good friends would tell AIDS jokes and I would just have to sit and laugh, you know. You have to be the third person and remove yourself from that. Some quite horrific things when Rock Hudson died and all that sort of stuff. It was terrible. And I think a lot of this mentally has never been looked at. The attitude towards haemophiliacs and AIDS has never -- *[redacted]* and I closed the door and that was it. We shut the world out. We didn't buy newspapers, we didn't watch the news, because it was just terrifying, absolutely terrifying, and then I go out with my friends and it is reinforced that that attitude is there, so ...

Q. You are still to this day very selective about --

A. Very selective.

Q. -- who you tell.

A. Yes.

Q. You have said in your statement that the village you live in is not a place in which you would even say the word "HIV".

A. No, no.

Q. You also describe how there have been occasions where you have been in hospital and a ward sister might call-out in front of our patients --

A. Yes.

Q. -- "Your HIV meds are ready".

A. Yes. I think that was when I had my ankle done. They take your meds off you when you go in, which I have got a problem with to start with because you need to take them at set times, and these times never fall in line with when they come round with the medicine trolley. So that was one thing.

The other thing is that I was on a public ward and the nurse shouts, "I have your HIV meds for you". It shouldn't happen.

Q. Over the years from 1985 onwards, what support or counselling, psychological assistance has been offered to you?

A. None.

Q. You say in your statement there are no drop-in sessions, no support, no counselling made available, and the only assistance you have had are from individuals such as nurses at the haemophilia unit.

A. Yes.

Q. Mark Simmons, the social worker attached to the unit.

A. Yes.

Q. You have also referred to a benefits adviser from the MacFarlane Trust. Some individual pockets of assistance?

A. Yes. She was brilliant. She turned my life around. I was in a very dark place. I had no money coming in. I didn't want to fill out any forms or anything. I just couldn't cope. I don't think they do it now, but I was awarded a DS1500, which means sort of imminent death, I think it is death within 12 months or something. Obviously that didn't happen. But, yes, within a couple of days she turned it all around for me, so ...

Q. You were involved in the 1991 HIV litigation and you recall having to sign a waiver.

A. Yes.

Q. What were you told? What were the circumstances in which you signed that?

A. We were basically told, "If you don't sign it, nobody else will get the money", and that was it. That was basically -- I think it was at the office in *[redacted]*, the solicitors' office in *[redacted]*. We just signed it. That was it.

Q. You spoke to a solicitor about seeking financial advice after the payment had been received?

A. Yes.

Q. What was the response?

A. Basically he turned round and said, "Why would you want to? You are going to die fairly quickly. Go out and enjoy it". Again, for the solicitor to be saying that, you know -- because I still didn't believe this was going to happen. I felt healthy. I was young, but obviously it was going to happen. So we did.

Q. You were also involved in US litigation --

A. Yes.

Q. -- against the pharmaceutical companies in the States.

A. Yes.

Q. You have a memory of flying out to the States and giving evidence.

A. Yes.

Q. Or giving a deposition.

A. Yes.

Q. We have got a record of some of what you said, but you have a recollection of being asked other questions.

A. Yes.

Q. Can you tell us what your memory is of the kind of things you were asked about?

A. If I had had gay relationships, was I an intravenous drug user. These were implied, that I was an intravenous drug user. When you read the deposition, I don't think it does justice to how we were treated over there. You were almost a guilty party. I also -- do you want me to say about the blood transfusion subject now?

Q. Yes.

A. That was after the gay sex and the intravenous drug use, apparently. There was an entry in my medical notes that said that I had had a blood transfusion. Well, ironically, I hadn't, and I know I hadn't, because I had only had one transfusion up until then, and that was when I was 12 months old. So my lawyer was trying to keep me quiet. She didn't want me to say anything. But I was just so disgusted, because it was a false statement that was entered into my records.

Q. And the purpose of the question, as you understood it at the time --

A. Yes.

Q. -- was to try to suggest that there was a source of infection --

A. Yes.

Q. -- other than the American pharmaceutical products.

A. Yes, yes.

Q. It is that memory that led you to say in your statement that you think there were things in your medical records --

A. Oh, definitely.

Q. -- that were not true.

A. Yes.

Q. You are not talking about the records that we have seen but records you have not been able to locate.

A. No, no.

Q. Can I ask you about the MacFarlane Trust. First of all, your direct experiences in making applications.

You applied after the break-up of your marriage --

A. Yes.

Q. -- for a grant to do some basic work to your house?

A. Yes.

Q. You were offered a loan.

A. Yes.

Q. And that was put as a charge on your house.

A. Yes.

Q. As a understand it, when you and your new partner then purchased a house, the charge was transferred over.

A. Yes.

Q. Is that right?

A. Yes.

Q. It was then, when the MacFarlane Trust ceased to exist, was wound up, that charge was transferred to the Terrence Higgins Trust, and we have heard that from other witnesses.

A. Yes, without my knowledge.

Q. Without your knowledge. Do you know what has happened to that charge now?

A. I believe that the charges have been dropped, for want of a better phrase. Yes, I think there were nine registrants altogether, and I believe now they have been removed.

Q. You have said in your statement that you were at some stage a trustee of the MacFarlane Trust.

A. Yes.

Q. What can you tell us about the trust from that perspective?

A. Not very good things. It seemed that they always wanted to bring people down to a level, not raise them up to a level. There's very little empathy with HIV or AIDS-related conditions, what people were going through. It was just not fit for purpose.

There were two of us that were infected haemophiliacs and worked as trustees. There was definitely a trustee board within a trustee board, and we weren't part of that. Some of the decisions that

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

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

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

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

activities, have had some knowledge of. One was about a member of your group, the Birchgrove Group, who was taken ill on holiday.

A. Oh, yes.

Q. What do you recall about that, without mentioning any names?

A. No. He will mention his own name. Yes. He was taken ill on holiday and there was a shortfall in holiday insurance, and they basically refused to pay. It was £100-odd, something like that. They refused to pay because it was HIV related. Again, it is all sorted now, that HIV thing. It's all gone away.

The other was a funeral grant. If you have got hep C, you can get a funeral grant, but HIV is nowhere on the list and people are still dying of HIV-related conditions.

Q. There's a passage in or a couple of passages in your witness statement I am just going to read out, with your agreement, where you try and describe what the effect overall has been on your life, of the events you have described. You say this:

"From that brief time in 1985, my life both physically and mentally have never been the same. How can it be? I can only speak from my perspective as a man of 20, just married, with my whole life ahead of

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

You say this:

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

Then you say this:

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

Those are the questions I have for you, but before I ask you what else you would like to add, I am just going to ask Mr Snowden if there's anything else he would like me to ask. No.

What else would you like to say?

A. Just a couple of sort of angry, bitter points that I usually bring up.

I think our community has been let down historically by the Haemophilia Society, who pushed Factor VIII at a time when haemophiliacs were dying in America. They carried on and carried on pushing the fact that we should use Factor VIII more and more and more.

After that time, they vanished from the community. There was token gestures, but they didn't want anything to do with the HIV community. It disgusts me. It really does.

When I worked on the Birchgrove, the individual that ran the society at the time used to pay us as Birchgrove to cover any HIV-related stories so the haemophilia magazine didn't have to cover it. That's what -- they didn't want to frighten off the newly diagnosed haemophiliac children, et cetera, et cetera, and also with the ties with the pharmaceutical companies.

That's one thing I really hope that this Inquiry brings out, the in-depth links with the society.

Also, the mattress(?) which we have spoken about. Again, I think all the trusts warrant their own Inquiry. Again, the thing we touched on is I do believe that haemophilia, whether it is infected, co-infected, whatever, people need more education through the hospitals about haemophilia. They haven't a clue, and in an emergency situation, haemophilia will kill you in a short amount of time. This knowledge seems to have vanished over the last ten years.

So I think, yes, I think that's about all I have got to rant on about really.

MS RICHARDS: Thank you. Sir Brian.

SIR BRIAN LANGSTAFF: Well, rant on you certainly haven't.

Can I just ask you a question? In one of the passages of your evidence you described how you were quite argumentative at times, and you added this:

"You have to be with the medical profession."

A. Yes.

SIR BRIAN LANGSTAFF: Can I just explore how far that goes, because you have said quite a lot of very positive things about nurses --

A. Yes.

SIR BRIAN LANGSTAFF: -- about social workers, about the professions allied to medicine.

A. Yes.

SIR BRIAN LANGSTAFF: So by medical people, you mean who? Doctors?

A. Yes. Clinicians and surgeons. Even to this day we found an air of arrogance to certain individuals -- not all, but certain ones. I mean, for example, all of my haemophilia nurses have retired and left because they couldn't take it anymore, and they helped me historically and many others in this room over the years beyond the pale, literally beyond the pale.

SIR BRIAN LANGSTAFF: So you saw tension between them and the medical staff?

A. Yes, very much so, and I believe that carries on now, without mentioning any names, because there are a couple of who are still in post. Yes. They try and do their best for us, and there's just no urgency for anything -- other than the nursing staff to do anything for us. And that's a haemophilia thing. That's not a HIV thing. That is a haemophilia problem.

SIR BRIAN LANGSTAFF: And do you have any insight from actual experience as opposed to from opinion as to why the medical staff relate to you in that way when others in the clinical field don't?

A. Again, I think it harps back to when I was young and you just feel like you are a disposable commodity. You are neither one thing or the other. You know, you are looked upon -- you can walk in, but you are a disabled person. I don't know what goes on in their mind, but we have certainly come across arrogance in the last few years beyond belief, and it should really stop. You know, we live in a different time now, which is probably going to be one of the argument for the doctors a few years ago that infected us. But there's a lot of education that needs bringing forward about haemophilia and that sort of illness really. I can only talk about haemophilia. No doubt other people are worried to death about thrombosis or whatever, how they are treated and the knowledge behind that, so ...

SIR BRIAN LANGSTAFF: Well, thank you very much for that, and thank you in particular for coming and giving your evidence. From what you have said, you have explained very clearly, as I see it, the tension between being very apprehensive about saying anything at all -- you put it that you are very selective about who you tell in those last few extracts that were read to you about how the stigma has affected your life. You have explained exactly why you wanted to keep everything quiet -- and yet you have got the desire to be useful, in particular to tell people, to communicate, to educate, and the two pull in different directions. Certainly your giving evidence has been much more of the latter than the former, although I know it has been a struggle for you to bring yourself here.

A. It has, yes.

SIR BRIAN LANGSTAFF: And I very much appreciate that.

A. I do believe that this has to be the end, this Inquiry. Many of us have campaigned for years and years and years in this room. We have come so close and we have had two Inquiries that have just been utter whitewashes. We have had to step up again and try and see justice this time. And that to me is what it's all about.

I have spoken to you, obviously, and I -- what I want to see is criminal charges. That's my goal, and that's Birchgrove's goal, but we will see. I know the Inquiry hasn't got the teeth to do that, but ...

SIR BRIAN LANGSTAFF: No. The Inquiry has no -- I have no power, no right to determine criminal liability. I am able, I think -- and if I find it, I will -- to say that fault occurred, but that's rather different.

A. Yes.

SIR BRIAN LANGSTAFF: Thank you very much.

A. Thank you.

(Witness withdrew)

SIR BRIAN LANGSTAFF: Well, we'll take a break until 11.40.

(11.09 am)

(Short break)

(11.43 am)

SIR BRIAN LANGSTAFF: Our next witness also is anonymous and there will also be no live streaming of her evidence. She is witness W1388, but in her case, rather than use letters, we are going to use the name Frankie: that's at her request.

The name and address of witness W1388 -- to you and me, Frankie -- and any other identifying information, such as the name of the witness's former partner, 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 W1388 must be referred to only as "Frankie".

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.

That is the order which protects Frankie and her

identity.

Could we have Frankie, please.

FRANKIE (sworn)

Questions by MS RICHARDS

MS RICHARDS: Frankie, as with the previous witness, who you were formerly married to, you may be using names in the course of your evidence, because it may be easier for you to refer to names, but that is covered, as with the previous witness's evidence, by the restriction order and those names cannot be repeated.

You were 15 years old, I think, when the two of you first met.

A. Yes.

Q. And you have described your former husband in this way:

"He lived a very normal life. You wouldn't have known he was a severe haemophiliac. He lived life to the extreme and then an extra 10%, to the annoyance of his parents."

A. Yes.

Q. You bought a property together at a very young age.

A. Yes.

Q. And you married at a very young age --

A. Yes.

Q. -- in 1984, when you were just 18.

A. Yes.

Q. We have already heard from him about the glandular fever that he had in 1984, early 1984. Can you recall anything about that?

A. Yes. At the time I was living with his parents, because we'd bought the house and it was just going through and I had to find a job in that area, so we moved in with his parents so I could work and find a job. I mean, it was pretty different times then. You know, we had 100% mortgage. We realistically had no idea what we were doing. We just knew what we wanted to do. I knew that I wanted to move forward with my life. I wanted, you know, to, dare I say it, have more than my parents. My father always said -- sorry.

Q. It is all right. Take your time.

A. Blimey. I have got no chance if I'm crying already, have I?

My father always said that we were cannon fodder, you know. As working class people, that's what we were. Well, I didn't want to be cannon fodder. So I met *[redacted]*. We both were very focused on doing the best we could, achieving the best we could. Yes, we had aspirations, but they weren't mad aspirations; they were just aspirations of being the very best we 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 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 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 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 discussing this about this thing, whatever this thing is. We don't really know about it and we are being taken along with the current, if that makes sense. So our sensible option is to do what it is that we chose to do, and, you know, as we carry on with this and other things happen, it's not even the virus anymore. It is about the support about how you kind of -- you are kind of in an arena, kind of like a gladiator, you know.

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

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

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

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

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

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

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

A. Uh-huh.

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

A. Yes.

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

A. Yes.

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

the test came back negative.

A. Correct.

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

A. Yes.

Q. You thought your husband was going to die.

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

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

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

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

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

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

A. Yes.

Q. You discovered that I think quite late.

A. Yes.

Q. And you went to see your GP.

A. Yes.

Q. What can you recall your GP saying to you?

A. I don't -- if I'm honest, I don't -- I think, if I look back on it now and if I'm perfectly truthful with you, probably since that day, which is, what, 30 years ago, 20 years ago -- no, 30 years ago, my two pregnancies have been one, because I can't actually cope mentally with one, let alone two. Okay? So I don't know what I said to that GP. I don't know the conversations that we had. I just know that if I'm not working and I've got a child and we are in this situation, truthfully, is that a good environment, bad environment, you know? I'm just scared and I don't know what to do, and I'm still scared, because I made that decision. The worst part about that decision is that 30 years later I'm having to justify that decision and I don't know that I can. Sorry.

Q. Would you like a break?

A. I'm so sorry.

Q. There's no need to apologise at all. Would you like a break?

A. No. I'm okay.

Q. There's some water beside you.

A. I'm not sure I can hold it, but yes, thank you.

Q. You have said in your statement -- and I will read a sentence from your statement, if I may -- about this time:

"I was a frightened young woman who went to my GP for help and I was made to feel like I had no other option than to terminate my pregnancy. I can no longer even comprehend what was said to me to make me agree with what they wanted."

A. No. I don't -- so we talk about, you know, having to recall what we went through and, you know, the more conversations that people have, the more this isn't virus-led at all, you know. I don't care. Virus-wise, I don't care about animosity. I don't care. All I care about is decisions that people had to make that are just beyond comprehension.

You know, every person in this room has got a story. Every person has got an individual story. People have lost people. People have grown up without their dads. Even grandchildren are involved in this. It is just so wrong. It is just so wrong that we are having to recall this stuff, and not only has it destroyed us then, but it is destroying us again and again and again. I hope this is an end to that, you know, because I don't want to wake up every morning and class myself as a murderer, because that is what I do.

Now, the worst part about being in this room is actually thinking that I am going to be judged, and that is so difficult, and that actually is a situation that I've been put into that is absolutely no fault of my own, you know. I cared for my husband. I loved my husband. You know, how much do you take away? You know, we are in a situation where we were at an age where, if we had had kids then, we would have done. We missed out on the sperm washing. We were too old for that.

Now, if I look back and think about the fact I am not a grandchild -- sorry -- grandmother, you know, I am bitter, and I am really sorry for everybody that I have hurt in that bitterness, but I cannot keep justifying and keeping our story told, because every time it gets told, it kills me a little bit more. And I don't want to die anymore, you know. I want to live. That's what I want, and that's all I want from this Inquiry.

I am sorry. I have gone off on a tangent again.

Q. You haven't at all.

You have in your statement described what happened on the day of the termination.

A. Yes.

Q. And I have heard you talk about that before.

A. Yes.

Q. It is entirely a matter for your decision as to whether you want to say anything about that now, whether you would like me to read that passage from your statement, or whether you would rather we did not talk about it further.

A. I think that you have to talk about it, because that is what happened. You know, we are in 1989. We are in a situation where celebrities are dying, you know. This is not underground anymore. This is massive, you know, and even I don't talk about *[redacted]* being a haemophiliac. We don't talk about *[redacted]* being a haemophiliac, even to people we have known for years, you know. We just do not talk about it.

When I went in, I was put in a room on my own, and there were not only biohazard stickers everywhere but everybody -- you know, when you get people coming back from Ebola, that's all I can liken it to, and you saw them being wheeled across with all their stuff in. That's the situation that I was in.

I was treated by the nurses like I was a murderer, like what I was doing was completely and utterly wrong. I wasn't allowed to leave the room. I had to use the commode. *[Redacted]* was asked to leave. He couldn't be there, couldn't be by my side. Nobody spoke to me during the whole time that I was there. They were just rude. And at the end of it, when the doctor came in to see me the day afterwards -- because you have to remember that I had to give birth to that child, you know. I don't -- and when you have to completely shut that out in your mind, because on Monday you have got to go back to work and keep the house over your head, it becomes something rather -- an out of body experience, you know. It didn't happen to me. It wasn't me. I didn't do that. But I did. And then at the end, you know, when I am being checked out, whatever it is, the doctor said to me, "Women like you should be sterilised". What do I say to that, you know? But that's what she said on her parting shot.

Q. You said in your statement you went home. The two of you never discussed it again, and then you have no idea how you made it through the weekend, and on Monday you had to go back to work as if nothing had happened.

A. Yes.

Q. You were offered at that time no counselling and no support.

A. No. I wouldn't even know what that was, if I am

honest. What is that? You know, at the time I wasn't aware -- I know it sounds ridiculous -- that counselling even existed. What is that? I don't know. I didn't know at the time.

Q. You have said in your statement that the fact that you had two terminations as a result of the Contaminated Blood Scandal is something you struggle to live with on a daily basis. You don't know how you made those decisions and you have been unable to forgive yourself.

A. I can't. How can I, you know? How can I? And how can you move forward, because time and time and time again, when you think that you can settle, that you can get on, it comes back. It comes back and we are here again talking about it.

Realistically, did I want to come in and give this statement? No, not a cat in hell's chance. I don't want to be here. Do I want to put my life on the line and what people think of me? No, I absolutely do not. Because I hate me. So why would I want to give other people that benefit? I wouldn't, but I have to. I have to. Who knows how many Positive Women died? I am not even sure there are any figures. We cared and we loved our husband, and for that, some of us became infected and some of us died. So please

recognise us, because we are here.

Q. We will come back to your reference to Positive Women and some of the complaining work you have done in a little while.

A. Yes, yes.

Q. Following 1989, you and *[redacted]* increasingly lived separate lives. You have described how you were working multiple jobs. You felt isolated in a private world in which you had no-one else to talk to, and you have said in your statement that seeing each other was a constant reminder.

A. Yes. So realistically I guess that 1989 was my turning point of intelligence, for want of a better word, and I thought about me for once, you know. In all that time I thought about me and the need to protect me, you know, and then I guess that is where the disconnect began, because how can you love someone, marry someone and take away that intense love that you have without destroying it, without destroying the marriage? You can't. They can't exist side by side. They don't. They can't, you know. Not for us, because we were passionate people. We were believers. But the belief was going and the passion was going too.

So I lived a separate life, you know. I didn't

tell people about *[redacted]*. People didn't even know I was married. I took my ring off, you know. I completely and utterly blocked myself off from it, and I used to go home and look after *[redacted]*. I used to go to the hospital. He wouldn't go to the hospital. He wouldn't have medication. He wouldn't eat properly. You know, all this stuff just mounts and mounts and mounts and mounts, and you become so oppressed by this as a person, taking away what we have already been through, because by this point I am like, "Right, that's it now", because I have to be strong. I have to forget that, because that's gone, that's done. Okay? Then you become strong.

So your compassion is gone, because all you've got is fear, hate, regret, resentment, and that builds and builds and builds and builds, and you build a barrier, and the barrier you build is so strong, it is so forceful, because it is not only protecting people around you, because you might hurt them seriously with either your words or your actions, but it's protecting me. It is protecting my soul, because if I lose a bit of it more, I am not sure what I am going to do, and each time this happens, that little bit of soul goes, you know.

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

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

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

A. Yes.

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

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

Q. Don't worry.

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

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

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

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

Q. And you had been tested in 1985 --

A. Yes.

Q. -- and in 1989.

A. Yes.

Q. Those tests were negative.

A. Yes.

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

A. Yes.

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

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

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

A. Yes.

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

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

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

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

A. Yes.

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

A. Yes.

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

"To whom it may concern."

It explains you have:

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

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

A. Yes.

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

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

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

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

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

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

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

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

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

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

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

A. Yes.

Q. -- from a clinical psychologist.

A. Yes.

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

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

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

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

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

Q. Not at all. You were talking about the counselling. That has been funded through the EIBSS.

A. So I had to obviously jump through a large amount of hoops in order to get this, but I believe that I need to heal and I'm passionate enough that I can put this together to get this healing, because it is the right time for me. It might not be the right time for everybody else, but I feel it is the right time for me, and EIBSS, although they are a pain in the arse, compared to the MFT, my God, they are kittens.

So I guess we are all hardened to that aggressive, matter of fact, throwaway of us, because we've put up with it for so long, but, you know, we are human and we do want to be treated that way. So no support system, no matter what support system they put in place, will ever recognise that because it is just a support system. That is not what we want and not what we deserve.

Q. You heard the evidence that *[redacted]* gave about the American litigation.

A. Yes.

Q. I think you too went to the States for the purposes of that litigation.

A. Yes.

Q. And you have a recollection of the questions that you

were asked.

A. Yes. Well, first and foremost, when I went in to give my evidence, I was told not to look like a woman. Does that make sense? As in sexual, as in as a woman, as in, you know, that you would prefer to dress, that you would -- does that make sense?

Q. Yes.

A. So I had to change my dress. That was the very first thing, because I had a shift dress on, and at the time I was very, very slim, so I guess -- you know. That was number 1.

So you go into a room and I think there were five attorneys there, and they were so aggressive you would not believe. So I am here as -- I don't know how old I was at the time. So it would be 15 -- I was probably early 30s. So I was a little bit more savvy by then, a little bit more. So I went into a room with these five solicitors and basically you were made to feel like a prostitute, a drug user, and when they talked about my terminations, they basically just made me feel the way I feel in this room today, you know.

So I guess that kind of sticks with you, and we went through all that, for what? Another disappointment, another cast-off, you know. You keep going through this stuff to be cast aside again.

Do you know how hard it is to walk into that room and sit in front of five people who are cross-examining you? It is horrendous, absolutely horrendous. Not only did they cross-examine you, they were so aggressive that I thought to myself, "Who am I doing this for? Because this is not for me", you know. But I just think, "I am just going to do it".

Q. Can I ask you a little bit about the MacFarlane Trust. One of the observations you've made in your statement about the recent dissolution of the MacFarlane Trust was the transfer of its funds to the Terrence Higgins Trust.

A. Yes.

Q. And the point you have made in your statement was that that was undertaken with no consultation with the community.

A. No. So I didn't find out about the THT until it was all done. I don't think any of us found out about the THT until it was all done. I don't have a problem with THT, but THT, really they are about a homosexual environment, you know, not -- and everybody needs support in a different way. We all need support in a different way.

So your first aspect of that is: why would somebody do that, because what is our association with

that, you know? It is difficult enough that we are in MFT when you have got male, female -- you know, you have already got a division of men, you have different aspects of it, you have already got a bit of a melting pot, and then you have introduced another bit of a melting pot. So I don't know why they did that, you know. It was another way of the MFT saying, "You mean nothing. We are not going to consult you. We are just going to do whatever it is we are going to do". The complete arrogance of these people is beyond reproach.

So I think all of us -- I say all of us -- a few of us who obviously knew about that contacted THT. So you have got a massive organisation here, THT, which gets a lot of publicity, which has got processes an procedures in place that have been in place for years and years and years, and they have got this little -- it is not even a lot of money, you know. They have got this tiny little fund.

So we get somebody allocated to us initially that we talk to. You know, obviously people had real worries, you know. There were loans that they didn't know what was happening to these loans. People had been held back for 30-odd years, not being able to move, not being able to live their lives because of a decision they made when they were on the floor. So this has been transferred to somebody else, who has no face, that's part of an organisation that is in place for years. It is like going into a door and saying, you know, "We are here".

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

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

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

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

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

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

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

A. Yes.

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

A. Yes.

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

A. Yes.

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

A. Yes. Since 2005.

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

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

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

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

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

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

A. Yes. Haemophilia Society. The term doesn't -- they have taken some of the deed -- I mean, I don't even know what this deed was or what was in it or what we signed -- I have no idea. They have taken some parts of this deed to EIBSS and they have taken away some parts of this deed. So they pick and choose what they want. So we have an antiquated system on EIBSS of ridiculous stages of payment depending on whether you were a child, depending on whether you were married, depending on whether you had children. Ridiculous, you know. That should be gone. It should be sorted out, rectified, and everything with the other -- as far as hepatitis stage 2 is concerned, you get 20,000 at stage 1, you get 50,000 at stage 2. You are not judged on whether you have children or no children, or like us, you are an infected intimate, where you are down here. You are even below.

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

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

A. That's correct.

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

A. Yes, that's correct.

Q. -- have been the concerns you raised.

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

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

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

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

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

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

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

too. That's all.

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

Is there anything further you want to say?

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

MS RICHARDS: Thank you. Sir Brian.

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

Can I be very clear. In this room, you are not being judged for what you did, but valued for what you 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 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 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 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 so disruptive to family life. He has got a younger brother. So brother and dad still at home must have been awful for him.

Q. Perhaps reflecting that, arrangements were made when he was 6 years old for him to receive cryoprecipitate on a prophylactic basis locally through his GP or local hospital, and then his mother learned to administer treatment to him at home. In 1977, at the age of 11, Andrew joined Lord Mayor Treloar's College, which I'll call Treloar's for shorthand, in Hampshire.

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

Henry, can we have 1090008.

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

"As the hepatitis survey about which Dr Kirk wrote to you in the past is now finished, it would seem likely that there would be no restriction on material and that he could be treated with a concentrate or cryoprecipitate as available."

So a reference there to a hepatitis survey. I don't think you know precisely what that refers to?

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

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

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

A. Uh-huh.

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

A. No, I don't.

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

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

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

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

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

It says:

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

He talks about having:

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

That's from Dr Aronstam.

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

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

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

"Dear parent,

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

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

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

We can see someone has written:

"What??!"

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

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

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

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

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

"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.

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 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.

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 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

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?

"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.

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

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

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

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

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

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

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

Q. There is in Andrew's records much later documents that refer to a positive HIV test on 13th December 1984, but there's no contemporary record of such a test or of any consultation that refers to that specific issue. You believe that Andrew didn't learn that he was indeed HIV positive until a date in early 1987, when you and he went to St Thomas'.

A. Yes, that's when he knew.

Q. Can you tell us about that?

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

Q. Yes, please?

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

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

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

I think she talked at some length to us, but

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

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

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

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

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

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

A. Yes.

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

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

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

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

A. Yes, yes.

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

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

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

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

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

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

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

A. Yes, yes.

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

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

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

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

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?

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,

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

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

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.

A. Yes, and it was just like -- it was always just the other side of the horizon, but -- because had we been told, you know, it wasn't anywhere close to being put into place, we would have gone back to Italy until Andrew became a bit too poorly for us to contemplate that, but yes, there was a window of time when we would have gone back to Milan.

Q. You had applied to the MacFarlane Trust --

A. Uh-huh.

Q. -- for funding to help you go to Milan.

A. Yes.

Q. We are just going to look at some of the correspondence between you and the MacFarlane Trust in relation to that.

Henry, could we have, please, 1090026? This is a letter from you dated 9th October 1995 and it starts with:

"I am writing to question the decision of your committee not to give grant aid towards the costs of assisted conception programmes."

So there had been some form of earlier refusal before we pick up this correspondence.

A. Yes.

Q. You say this:

"I understood that the sole purpose of the trust

was to help people with haemophilia and HIV deal with the difficulties they face as a consequence of their infection.

"One of the most distressing aspects of living with HIV is the inability of couples to have a family without risking wives and offspring becoming infected. This is not simply about couples wanting a baby as some sort of possession, but is about bringing a sense of purpose to life, of seeing a continuation of self, of keeping pace with peers."

Then you refer further down in the letter to the treatment programme in Milan, and you say this:

"Before we can go to Milan, we have had to have a number of tests, some of which we have had to pay for. We will have to pay for our flights to Milan, for accommodation and treatment. None of this would have been necessary if my husband had not contracted HIV from infected blood products. I therefore believe that the trust should at the very least be prepared to accept an application for a grant towards the costs involved in this programme and should give it careful consideration."

If we then turn on to page 3, please, Henry, we can see the letter you received from the MacFarlane Trust, 21st December 1995. It says:

"I am sorry to be so slow in writing again to you but the trustees were unable to come to a final decision at their meeting in November pending some further inquiries by our medical trustee, Dr Elizabeth Mayne.

"The trustees saw your letter (anonymised) but this was in the context of re-examining the whole subject of assistance with conception on which their previous decision had been not to give any financial assistance. Although every request to the trust (of any kind) is looked at individually, there has to be some underlying policy or guideline on the matter to ensure consistency and fairness."

The next paragraph refers to there's going to be the potential of a further decision and says this:

"I believe that they [that's the trustees] are likely to make some change to their earlier exclusion, but I also feel that this is unlikely to include any treatments not fully recognised and approved by UK medicals authorities or any treatment outside the UK. At present I'm afraid this exclusion would apply to Dr Semprini's treatment, whether done by him in Italy or by an associate in the UK."

If we go then to page 4, we can see that by mid-February you are still waiting for a response.

You say in the second paragraph of your letter:

"I continue to wait for a proper reply to my request for a grant towards the cost of assisted conception."

Then if we go on, please, Henry, to page 6, we see a document from the MacFarlane Trust dated 3rd April 1996. This particular document is addressed to Dr Wasseff and it says this:

"As you may be aware, the trust has made payments in the past to couples wishing to have a child without risk of infection to the mother. Typically these payments have been a contribution towards the cost of donor insemination treatment.

"Payments in this category were suspended last year whilst trustees considered a fair and consistent policy covering this form of assistance. Our trustees also gave careful consideration to whether their policy should make provision for payments to cover treatment based on new reproductive technologically, particularly sperm washing.

"The purpose of this letter is to let you know that our trustees have settled on a policy which allows the trust to contribute toward the cost of private assisted reproduction treatment provided that the treatment is approved by the Human Fertilisation

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."

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 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

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 stance taken by the MacFarlane Trust?

A. I think its just typical of their approach, really, that they were just a paternalistic organisation and they held so much control over what we could and could not do with our lives.

I think if you look at it in terms of assessing risk for people, I think that sort of attitude would have pushed some people to have taken the risk to have a baby, you know, naturally and taken the risk of seroconversion of the wife and possibly the baby. We wanted to go ahead with a procedure that had been shown to be successful, and I can't remember the numbers now, I think I put it in one of the letters, you know, but there were very many people who had gone through that procedure in Italy and there hadn't been a single seroconversion, but they just wanted to play God with us, you know, wouldn't allow us to make our own decisions, you know, which we should have been able to.

Q. You say in your statement that you were and you still remain deeply saddened that you were never able to have a baby with Andrew.

A. Uh-huh.

Q. Andrew began to be really unwell in the course of the 1990s?

A. Uh-huh.

Q. He had started on AZT. He began what you have described as a period of five years of illnesses and reactions to drug regimes. What can you recall?

A. Until the illness that actually killed him, I believe all the illnesses he had were related to the drugs that he took. It started with him taking AZT and Septrin. He was put on Septrin against pneumonia. We weren't warned that there could be a really bad reaction to that, and my understanding is that Septrin actually often brings about severe reactions. Andrew sadly seemed to just suffer with almost every side effect you could have to any drug he took.

With Septrin, he became incredibly ill very, very quickly. He was having hallucinations, covered in a rash, high temperature. I was so panicked by it. I remember I phoned the Haemophilia Centre. Bearing in mind we lived within the complex of Treloar's, we just lived over the road from the school. The Haemophilia Centre was three miles down the road and I very naively thought, you know, because he was so poorly, that one of the nurses, who literally was, as I say, three miles down the road, could have got in the car and come to see what was in the matter with him and helped us. But they just told me to get him

some Piriton. You know, it would have been helpful if they had said before he took the Septrin that it would be a good idea to have some Piriton just in case.

I don't know what they expected me to do, how they expected me to get hold of Piriton just like that. I would have had to drive four miles into town to get some and leave him on his own to do that. As it happened, the way things were in those days -- quite different from now -- Treloar's had a medical centre. Some of the men here would remember it as sick bay. In those days you could actually go and ask the nurses if you could have paracetamol if you had a headache or something. I just went over to them in a panic and said, "Have you got any Piriton I can have? Andrew is very poorly". They kindly gave me some. I know these days, the way everything is double checked and controlled in any situation with anybody giving you medication, they probably wouldn't be allowed to do that, but then they could and I am so grateful that they did, because that obviously did help to bring his symptoms down, but that was the first instance.

He was on AZT, but it made him feel so ill and he just said to me, "I am not taking this, you know, I can't live like this. I am just not going to take it".

Q. You and he became concerned that the haemophilia unit at Treloar's wasn't specialist in HIV.

A. Uh-huh.

Q. And so you sought advice and support elsewhere in terms of Andrew's HIV care. What can you recall about that?

A. Well, just to put it in context, just before we got married I went to see our GP, Andrew Sword, and told him that I was getting married to a haemophiliac who was positive. He was so kind and he just said to me "Amanda, I don't know what you are going to need in the future, but whatever you need, come and ask me and I'll see what I can do". So that's what we did. He stood by his word all through and was a tremendous support.

So when we were going to the Haemophilia Centre and having discussions and trying to ask questions about the treatment and options and so on and getting the response all the time that the Dr Wasseff would have to consult with his colleagues in London, we just thought, "Why are we talking to a doctor that doesn't seem able to give us the information but can talk to a doctor in London? Why don't we go and talk to the doctor in London ourselves?"

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

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

Q. You described in your statement a number of side effects and physical health problems that Andrew experienced. He had nightmares from one of his treatments.

A. That was a very, very scary time. He had very vivid nightmares and would wake up talking absolute rubbish. It was very scary.

Q. He had peripheral neuropathy, which he described as having red hot pokers forced up through his feet into his legs.

A. I think sometimes people think peripheral neuropathy is just something like pins and needles. The way he described it was just like excruciating pain.

Q. He suffered acutely with kidney stones and pancreatitis, and on one occasion was rushed into hospital in Basingstoke.

A. On two occasions. The kidney stones I think was the first one. I was actually out. I had gone to get my hair cut about 15 miles away from home. He suddenly became very poorly at home. He phoned the Haemophilia Centre and they just said to him to go to hospital. So I think what they should have done is phoned for an ambulance for him, because he was in dire straits, but they just said, you know, "You have got to get yourself to hospital". He wasn't well enough to drive, so he rang my mum, and she rushed him to the hospital, phoned me to say that that's what was happening.

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

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

The second time was when he had pancreatitis. We had actually been to the GP's the day before and he had reported his symptoms, sort of stomach pains and so on. I don't blame the GP at all for this. It wasn't Dr Sword, it was one of his colleagues, who were all brilliant with us, I have to say, but she was basing it on her GP knowledge that the symptoms he presented with were typical of indigestion and so on, so she just said, "I think it is indigestion. Here is a prescription for something or other. Go home and see how you get on". But then he became rapidly ill and was rushed in and almost died of pancreatitis the next day, and he was in hospital for a month.

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

A. Uh-huh.

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

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

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

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

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

"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.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

That night there was -- a strange thing happened

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

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

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

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

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

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

A. Yes.

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

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

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

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

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

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

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

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

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

A. Yes.

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

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

You know, we shared so much in the way we used to talk about things. We used to sing in the car together. The stupid jokes we had together, like a shared language that nobody else would understand now. They would just think I was bonkers. I mean, some of his friends might get some of the references, but generally nobody would know. I miss him so much. I do continue to grieve for him. I probably always will, because he was my soulmate. There's a Roger McGough poem that is called "The Way Things Are". Theres a line in it that says, "When one glove is missing, both are lost." To me that was us, because it was like we were a pair, and with one of us missing, the other one is lost. I am just completely lost in life without him.

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

A. Uh-huh.

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

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

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

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

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

a week and I used to go along with him.

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

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

A. Yes.

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

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

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

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

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

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

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

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

A. Uh-huh.

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

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

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

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

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

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

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

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

A. Yes.

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

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

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

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

being a number of announcements that boys had died.

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

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

Q. Do you have any other observations based upon your knowledge of Treloar's generally, your time working there, about the workings of the haemophilia medical centre, the unit there?

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

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

back and tell you they have been given this devastating news, you know, there's feelings in yourself as well to deal with. It is minor in comparison to what the boys are going through, but there was very little for us, to support us either. We are losing this community of boys who we loved, you know. We loved the children at Treloar's. It was a loving environment, you know, and to think that a huge group of them had been given this infection just -- yes, devastating.

Q. Amanda, those are my questions. I'm just going to ask Mr Snowden if he has anything else. Nothing further from Mr Snowden.

Is there anything further you'd like to say?

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

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

I wrote then:

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

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

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

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

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

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

That's all.

MS RICHARDS: Thank you. Sir Brian.

SIR BRIAN LANGSTAFF: Your way of telling it so gently, so calmly and so caringly at the start I think threatened to hide from us the frustrating and distressing times that you have had, but it didn't in the end. It came through, in my view, very clearly.

But underpinning it all and shining through it all was and is your great affection for the man you lost. A truly memorable piece of evidence altogether. Thank you very much.

A. Thank you.

(Witness withdrew)

SIR BRIAN LANGSTAFF: Well, after that it seems somewhat banal to ask about tomorrow.

MS RICHARDS: Sir, we have tomorrow a number of witnesses, none of them tomorrow anonymous. First we are hearing from Stuart Mclean, then from Mark Ward and Richard Dudley-Smith, and then from Androulia Andreou.

SIR BRIAN LANGSTAFF: 10 o'clock. 10 o'clock, please.

(Adjourned until 10.00 am on Thursday, 17th October 2019)

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