Friday, 10 May 2019

(9.59 am)

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

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

ANDREW EVANS, affirmed

Questioned by MS RICHARDS

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

A. Thank you.

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

A. That's right, yes.

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

A. Correct.

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

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

Q. Do you know if your parents were ever given any information or advice or warnings about any risk of infection associated with the use of those products?

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

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

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

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

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

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

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

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

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

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

A. Yes.

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

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

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

A. Yes. Yeah, I'm -- from what we've since discovered, it seemed that there was fairly common knowledge of at least hepatitis viruses in the blood and so it would be my suspicion that this kind of test was for that purpose.

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

A. Correct, yes.

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

It's 1213005 please, Paul.

It is the bottom of the page.

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

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

"American scientists are scouring the country for the first case of the bizarre new disease acquired immunodeficiency syndrome, AIDS, in patients who have undergone major surgery. The hunt for the cause of the disease which was first diagnosed among male homosexuals has now labelled as a prime suspect some unknown blood borne virus. In just one year the list of people at risk from AIDS has lengthened from male homosexuals, drug abusers and Haitians to include the entire population. In the last year, a task force under Dr Harold Jaffe at the Center for Disease Control in Atlanta, Georgia, has found seven cases of AIDS amongst haemophiliacs who do not fall into any of the other categories. Jaffe believes that the spread of the disease may be connected with new preparations of Factor VIII concentrate, the blood clotting agent given to haemophiliacs, which are made up from blood from large numbers of donors rather than one individual. If this is correct, any patient in hospital who is given a blood transfusion could be at risk if one of the donors of the blood carries the virus. No cases of AIDS among British haemophiliacs have been reported so far even though 50 per cent of the Factor VIII used in Britain comes from the US."

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

A. Yes.

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

A. Yes.

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

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

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

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

A. Correct, yes.

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

A. Correct, sir.

SIR BRIAN LANGSTAFF: Thank you.

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

A. Yes, that is right.

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

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

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

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

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

A. No.

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

A. Yes.

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

A. Correct, yes.

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

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

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

Q. In your witness statement, you put that you thought that was in 1985, but I understand from talking to your Mum that she thinks it might have been later. When does she think that conversation took place?

A. She -- her most recent recollection is that it was in around about 1987 when I was ten years old.

Q. You've described understandably that this was news that put your parents into a state of shock. Again, from subsequent conversations you've had with them, what was the impact of finding out that information about their ten year old son on them?

A. My parents were really good parents and I think they very much tried to shield me from the turmoil that must have been going on in their mind, but from what they've told me they were absolutely beside themselves. They didn't know what to do, they didn't know what my prognosis was. All they knew was that they had to try and give me the best life I possibly could before I inevitably died in quite short order, really.

Q. As far as you know, were they ever given, for example, any written material that they could take away and consider in less stressful circumstances about the condition or about the prognosis?

A. No, I don't recall that they were given anything. There was a fair amount of public information circulating, if you want to call it that, about AIDS, mainly quite graphic and scary commercials with falling tombstones and, you know, the sparse news that there was about it was that it was fatal, that you were quite dirty for having such a thing, that your lifestyle was not the norm, and that really for your safety you shouldn't tell anyone about it and they didn't. They didn't tell anybody.

Q. Now, they told you, not straight away --

A. No.

Q. -- but in 1989 when you were about 12 years old your Mum told you. What can you tell us about how that happened?

A. Yes, she told me. The reason that she told me was because, and I'm not sure that she would have told me if it hadn't been for this, but my blood results, my CD4 counts or T cell counts as they were back then T4s, were showing a decline and the hospital told her that I would probably need to go on medication very soon.

So they made the decision, the very difficult decision, to tell me and it was left to my Mum. My Dad was at work. So she took me out in the car and we drove out to a country lane. I'm not sure where it was. It wasn't very far away but it was a nice peaceful spot. We pulled up into the entrance to a field. There was a closed gate in front of us I recall, possibly some sheep milling around, and I thought to myself what's going on? This is not the norm. We don't normally do this. And she turned to me and with a very red face, and you could see that her eyes were welling up as well, she said, "I've got something to tell you", and then she told me. She said, "The Factor VIII that you've had was infected with HIV". She said, "Do you know what that means?" I said, "Well, yes, I know about HIV, a little anyway", and she said, "Well, do you know what it does?" And I said, "Well, yes, it eventually kills you", and she said, "Yes".

I don't know whether it was because I was trying to help her. I could see she was in obvious distress but I decided to be the strong person and I said to her, flippantly almost, I said, "I'll just have to become a researcher or a scientist and I'll have to cure myself then, so don't worry about it. It will all be fine", and that was that. We, I guess, hugged and then went home and went about our normal business as much as we possibly could.

Q. I am going to ask you in a few minutes about the treatment and how things progressed from then on but, just pausing there in 1989 and having been given that information, how did that affect family life from then onwards when you had this knowledge? You, I think, have a sister?

A. Yes.

Q. Was it something that was discussed? Did it affect the way in which family life was conducted?

A. My sister is a fair bit younger than me. She's almost four years younger than me; so the time I was told she would only have been about eight, at the most nine. I honestly do not know when she was told about it but it certainly wasn't then. It was something that we couldn't discuss, obviously, as a family when she was around and, as I recall, we didn't discuss it at all really. We almost ignored the fact that it was there and tried to get on with living a normal life.

And I think in retrospect that was my parents' trying to give me a normal childhood as much as they could when they knew that everything else would be stacked up against that, really, and the only time we really ever talked about it is when I had to go for clinic appointments and spoke to the doctors.

Q. You have some recollection in relation to your sister being told not to share your toothbrush --

A. Yes.

Q. -- and matters such as that.

A. Yes, yeah. I think as the illness progressed and it started to manifest itself, there were certain -- I think I remember certain sort of skin conditions and, you know, being a haemophiliac I'd probably have a few mouth bleeds and what not and I do remember that she or I was told to keep my toothbrush and my towel separate. But I'm not sure whether it was down to the HIV or just down to the sort of hygiene facts really, but I do recall that quite vividly.

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

A. Yes.

Q. But you learnt that a number of years later. What can you recall about the circumstances in which you discovered that you had also been infected with hepatitis C?

A. I was at a -- I'd transferred to the Queen Elizabeth by this appointed I was under the care of Dr Wilde and I had just seen him in a consultation, and we'd spoken about the HIV, we'd spoken about the haemophilia, and the consultation was over, and I went to the treatment room next to have my bloods taken, which was a routine thing, and he popped his head round the door and he said, "Oh, we must remember to do a genotype for your

hepatitis C as well", and that was the first I'd heard about it, and I think he assumed that I had known about it all along but it was the very first I'd heard about it.

Q. Do you recall what your reaction was?

A. I think I immediately turned to the nurse, because he popped his head in and just as quickly popped it out again, and said, "What's this about the hepatitis C?" I think she seemed to think that I ought to have known as well, so I didn't push it any further. I went home and I asked my parents about it and they didn't have any clue. So I did a bit of research and that was it really. I just I kind of assimilated it into my consciousness that way.

But you kind of have to understand that for me in particular and my circumstances was that the HIV was the be all and end all. There was nothing else and whatever hepatitis C was for me at that time wasn't important because it wouldn't have a chance to get at me. It would be the HIV that killed me.

So, to be honest, I wasn't, at that point, I wasn't too worried about it.

Q. Just so that we can establish the dates in relation to the hepatitis C --

A. Yes.

Q. -- you have gathered from your records that the first positive test for hepatitis C that you found is 8 March 1994.

A. Yes.

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

A. No, not as yet, no.

Q. Your clear recollection is being told in the way you've described by Dr Wilde?

A. Yes.

Q. You transferred from the care of Dr Hill at the Children's Hospital to Dr Wilde at the Queen Elizabeth Hospital some time in late 1996?

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

Q. Because we have the transfer summary and that is dated 26 November 1996; so that gives us some kind of idea.

A. Yes.

Q. So if those dates and your recollection is correct there was a significant gap between the test and you being told?

A. Significant, yes. I think I'd been at the Queen Elizabeth by that point for at least a couple of years. When I transferred over to the Queen Elizabeth, I was extremely ill. I mean, extremely ill. They didn't realise -- they didn't understand

whether or not I was going to survive at that point and I recall being relatively stable and well when the hepatitis C question came up, and so that would place it about two years after I transferred or around '98/99, yes.

Q. You have recorded in your witness statement some surprise shall we say given what was known about hepatitis C at least from the early 1990s --

A. Yes.

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

A. Yes, especially given the transmissibility of hepatitis C through blood to blood contact and, you know, HIV was all generally about sexual transmission but hepatitis C seemed to be more easily transferred. I think it's something about being non-lipid envelope virus or something like that, it stays alive outside of the body for longer than HIV does, and so it could linger outside the body and then be passed on to somebody else.

Well, I had no idea about the fact that I'd got it and, therefore, I wasn't taking precautions for it and any person in my family could have become infected because of that, and I thought that that was terrible. How could they not have told me that this was a risk so that I could guard against it?

Q. It's right I should point out that the transfer summary from Dr Hill to Dr Wilde in November 1996 states that you were told about the hepatitis C result in March 1995 but you don't think that's right.

A. I don't recall being told about it at all and my parents don't recall being told about it either.

Q. You have what you've described as a very vivid memory of Dr Wilde telling you in the particular way that you've described.

A. Yeah. I can close my eyes and imagine that room right now and I can tell you where I was sitting and I can tell, you know, tell you -- I can see his head coming round the door and making that comment, yes.

Q. Now, your Mum having told you about the HIV in 1989, you started treatment for that pretty quickly after that, in about August 1989?

A. Yes.

Q. You started on AZT?

A. Yes, I did, yes.

Q. What can you tell us about how that was and how it made you feel and any side effects?

A. I can tell you that it was absolutely horrifying. I late learned that I was on I think they'd given me 800 milligrammes a day or something like that. I was 13 years old. I was a slip of a lad. I didn't weigh

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

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

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

I guess, what the reaction to that would have been from, you know, from my school mates. It was a really difficult time because I couldn't explain what was going on either.

Q. Because you didn't tell people?

A. I couldn't tell people, I couldn't. It was something that, as a kid, it was something that dirty people had. That was what we were taught. I know that's not the case and, you know, everybody can get it but at that time the stigma was such that if you had HIV or AIDS you were a dirty person. It wasn't like a disease like cancer or something that you could tell people about and get sympathy. This was something you had to keep absolutely secret.

Q. There did come a point whilst you were still at school when you did tell a couple of people. You told a girl that you were going out with.

A. Yes.

Q. What was the reaction?

A. She initially seemed to take it well and then very quickly I got a phone call saying she couldn't do it anymore and she decided to break it off, and it was my first sort of serious relationship, I guess. I felt that I had to tell her because we were getting towards sort of 16 years old at that point and there was

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

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

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

A. Yes.

Q. What happened there?

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

Q. You'd -- the AZT medication eventually was adjusted and other therapies added in.

A. Yes.

Q. You were able to get through school --

A. Yes.

Q. -- and your GCSEs?

A. Yes. I managed to get through school up until -- well, I was starting to become ill during my GCSEs but I managed to get them all done. At that point I think they had lowered the dose of AZT and added in one called DDI. I don't know if anyone remembers DDI but it came in two forms. You either had to drink -- it was a sachet of powder which you dissolved in water and it was like a sweet salty mixture. You know, I had to drink that twice a day or three times a day or it came in pills roughly the size of -- no, even bigger I think than extra strong mints which you were told to chew and swallow, that tasted a little bit like the chemical Germolene, so it was not a nice thing to take. I think that the adherence to that pill was very low.

But whatever, you know, I managed to make it through to the age of 16 and got my GCSEs.

Q. But there's no doubt in your mind that you would have been able to do a lot better at school if you hadn't been having to cope with at such a young age with all

these infections and treatment?

A. It is hard to say but I can't see it having helped. Yeah, I really think that had I not had all this going on, both mentally and physically, then I would have been able to concentrate a lot more on schoolwork.

Q. You were planning to stay on for sixth form. There's a detail that someone has told you about some kind of school assembly.

A. Yes.

Q. What was that?

A. I was told this after everybody had left school. I went to a gathering of old school friends and I had no idea about what people knew about my illness. They obviously knew that I hadn't been there for sixth form for most of the time, and so it came as a bit of a surprise to me when she said, "Oh, we had an assembly at school" and the headmaster stood up in front of at least our year, possibly the whole school, and said that I'd got AIDS and I wasn't expected to survive.

Q. You started around this point, around the age of 16, having planned to be able to continue studying and do your A levels, you became very ill.

A. Yes.

Q. You tell us, Andy, how your health was at that time.

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

So I had -- I remember one occasion they did

a sinus wash-out because I couldn't breathe through my nose at all. My nose was just streaming as if I'd got a really bad cold, so they took me down to the operating theatre and they did this sinus wash-out under anaesthetic and when I came to in the -- it was one of the side wards, the oncology ward where we were all kept, there was nobody in the room and all I could feel that was that there was some kind of packaging, packing, around my nose. So I groggily went to the bathroom, still half asleep from the anaesthetic and took this off and started tugging at what was up my nose and it was long pieces of gauze and I got it all out, and then the blood came and it was everywhere and nobody was there and I was pushing my buzzer and it was in a side room, I was on my own, nobody was coming to see what was going on.

So, eventually, to get someone's attention, because I thought I'm going to bleed to death, I had to pull the cardiac arrest button and then they came kind of rushing down telling me I shouldn't have pushed the cardiac arrest button, but eventually got me kind of stable, you know. The nose bleeds were stopped and I was okay but -- and then they had to do sinus wash-outs again a couple of times in the future but at least I knew what to expect and didn't pull the stuff out of my nose. But that was one such occasion.

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

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

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

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

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

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

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

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

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

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

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

A. Yes.

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

A. Correct, yes.

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

A. Yes.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

A. Yes.

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

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

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

A. Correct, yes, yeah.

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

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

A. Yes.

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

A. Yes, also known as lamivudine.

Q. You began to see some improvements?

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

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

A. Yes.

Q. What can you recall about that?

A. They'd just changed my combination therapy and I think they'd put me on to one called indinavir (Crixivan, I think it was called), and I had only been taking it a day, two days, something like that. My Mum had had a friend over so she was quite preoccupied. The friend lived quite a long way away so she was staying over and they were doing whatever they were doing and I was kind of left to my own devices and I started to feel very strange. I started to feel tingly down my left-hand side. Whenever I stood up, I would -- it was like the blood had all rushed from my head and I got dizzy, and that kind of -- those feelings progressed throughout the day until I stood up at one point and completely fainted. I collapsed. I don't know what had happened. I guess I'd just fainted.

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

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

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

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

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

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

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

A. Yes.

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

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

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

So, yes, it was an interesting time.

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

A. Yes.

Q. But you said this in your statement:

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

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

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

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

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

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

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

Q. But you found that very isolating?

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

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

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

A. Yes.

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

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

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

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

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

A. Yes.

Q. How did that come about?

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

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

visit her, which I did in February of 2002.

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

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

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

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

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

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

A. Yes.

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

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

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

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

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

A. Yes.

Q. What do you recall being told?

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

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

Q. If we just put up own screen, please, Paul, 1213006.

We can see this is a letter from 24 September 2004, Andy, from your doctor to you.

A. Yes.

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

A. Yes.

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

A. Yes.

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

A. Mm-hm.

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

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

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

A. Yes, yes.

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

A. Yes.

Q. What can you recall about that?

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

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

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

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

A. Yes.

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

A. Yes.

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

A. Yes, that was directly --

Q. Can you tell us about that.

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

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

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

So Tainted Blood as a website came about and

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

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

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

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

A. Yes.

Q. It's Michelle.

A. Yes.

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

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

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

a normal relationship, and it was amazing.

Q. You married in 2007?

A. Yes.

Q. And you've got three kids?

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

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

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

So Michelle had to undergo egg harvesting, which meant lots of hormone drugs beforehand and a little bit of an operation to harvest in eggs and then we had the sperm washing for that and then the foetuses were created and some were frozen and then it was a case of how many viable ones have you got. Everything was kind of fingers crossed, fingers crossed right up until the last moment and the first IVF cycle also failed, and so we decided to pay then for transplantation of one of the frozen embryos and it was a miracle but it worked and we had our daughter through it.

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

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

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

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

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

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

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

A. Yes.

Q. It was triple therapy?

A. Yes.

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

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

Q. What was that treatment like?

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

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

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

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

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

But then the interferon and the ribavirin over 48 weeks and it had to be 48 weeks because I'm HIV positive apparently. Had I just had hep C it would have been six months but in their wisdom 48 weeks. By the I time I came out of it I was absolutely wrecked. From the very early days, I was so tired that even the thought of looking after the kids on my own would send me -- I'd just burst into tears. I didn't think I could be left alone with them. I wasn't safe to be left alone with them because I couldn't help them if they needed anything and, at one point, I seem to remember they put it down to migraine caused by the drugs but I completely lost my vision and had to be rushed into A&E. Luckily that came back fairly quickly but just such a scary, horrible life-altering time really and it had an impact not just on me but everybody around me.

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

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

A. Yes.

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

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

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

Q. The treatment did clear the hep c virus?

A. Yes, thank goodness.

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

A. Yes.

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

A. Yes.

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

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

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

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

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

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

A. Yes.

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

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

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

apart --

A. Yes.

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

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

A. Yes.

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

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

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

Q. The employment and the financial repercussions of your illnesses have been that you've not been able to establish the career that you would have wanted to establish.

A. Correct, yes.

Q. You do some work, I think, still?

A. Yes. The only way that I've been able to come up with to -- to normalise my working life is to create my own business and the only way I've been able to do that is with the help of somebody else who is in very similar circumstances to me.

I taught myself web development. He taught himself and at university how to draw, how to illustrate and together we set up a web development company and it's -- it's what we could do. It's not a career. We understand each other. We know that we're going to be ill. We know that we're going to have time off. We know we can be flexible. We know we have to go to the hospital appointments that we've got to go to.

But it's something to tell people as well, "What do you do?"

"Oh, I'm a web developer."

Not, "What do you do?"

"Oh I sit at home and feel sorry for myself."

I had to have that in my life. I couldn't be

somebody who, just for outward purposes I had to have it. I had to be somebody who was contributing to society in some way and so that's what we do. We're never going to make a lot of money out of it but I at least feel like we're doing something.

Q. You've, in terms of the practical financial arrangements of life, you've looked into the possibility of getting life insurance but, you've put it this way in your statement, nobody would touch you with a barge pole?

A. Quite right, yes, yes. I mean, "Can you tell us about any of your previous medical conditions?"

"Haemophilia."

"Oh, yes, okay, we can probably workaround that, yes."

"Hepatitis."

"Ah, mmm, we might have to take that to our specialist medical assessors and see what we can come back with."

"HIV."

"Right ... no, I'm not sure we're going to be able to help you on this occasion, Mr Evans."

Q. You used to be unable even to get travel insurance. Now you can but it's very expensive.

A. Yes, I'm hopefully off on holiday later this year. My

family have, the four of them, apart from me have managed to get travel insurance for about £30. Mine's come back at about £176.

Q. Can I just ask you next about your experiences in relation to the trusts and schemes, Macfarlane, et cetera. You have made some reference to them already.

Just starting with the litigation, the HIV litigation in 1991, you've explained in your statement how your parents had to sign a waiver. You wanted, I think, to share a little more information about that with us.

A. Yes. So from what I've been told -- and I was not involved in this in any way, this was one of the things I think they tried to protect me from -- they were offered as part of the litigation a financial settlement, a scaled financial settlement depending on the circumstances of the victim, and they were told that they would have to sign an undertaking which said that they would not take the Government back to court for any -- for the HIV infection or any future viral infections, and they were also told that this was a circumstance in which nobody would be given the settlement unless everybody agreed to it. It wasn't something they could check because nobody knew each

other at the time. She might have been -- my Mum might have been able to talk to other parents at the hospital and I think probably did, but certainly the wider community, we had no way of verifying this.

So they felt so pressured to sign it that that's what they did. They were absolutely desperate. They thought that people who were possibly in an even worse situation than I was, that they wouldn't get any money and they needed that money desperately and they couldn't be the ones to hold that back from them.

Q. This was in about 1991, as far as you know?

A. Yes, yes, 1991.

Q. Were your parents, as far as you know or based upon the discussions you have had with them subsequently, were they given any understanding or any information about the possible risks of infection with hepatitis C at the time they were being asked to sign that waiver?

A. No, none at all, as far as I'm aware. The hepatitis -- I think, was it mentioned on the waiver? I think it was mentioned on the waiver but I think that was the first they heard of that particular threat, and the circumstances were that they didn't expect me to live very much longer and so even so I don't know whether that would have been a factor in them, even if they'd known about it, a factor in them not signing because they didn't expect to have their son for much longer and they were just trying to do as much as they could.

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

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

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

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

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

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

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

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

A. No.

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

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

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

A. Yes.

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

A. They do.

Q. But you have a particular concern about those payments.

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

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

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

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

A. Yes.

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

A. Yes.

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

A. Correct.

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

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

Q. Now, a very important part of your life in recent years has been as you've described in part already, Tainted Blood and providing support for the community of people who have undergone experiences similar to your own.

A. Yes.

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

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

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

getting to hear what happened in this story.

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

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

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

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

A. Yes.

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

A. Yes.

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

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

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

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

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

add?

A. I did scribble something down.

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

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

My body's been changed by the viruses and all they bring, all the consequences of the treatments, all the damage treating the indirect damage causes and that's bad enough, but I've dealt with that for quite a long time. I've become good at being ill or disabled or in pain without relief but the one thing that I've been banking on all that time is this, my mantra, that you may not take -- you may take my body but you must not take my mind. I've maintained that all of my life and now it feels that since the hepatitis C treatment that I have even had that taken away from me and I feel like there's really very little left to take.

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

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

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

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

has anything else.

No. Thank you.

A. Thank you.

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

A. Thank you, sir.

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

A. Thank you, sir.

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

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

SIR BRIAN LANGSTAFF: Thank you very much.

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

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

(11.46 am)

(A short break)

(12.22 pm)

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

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

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

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

making a further order during the course of the Inquiry.

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

Mrs D.

MRS D, affirmed

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

A. I may do.

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

A. Thank you.

Question by MS FRASER BUTLIN

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

A. I did, yes.

Q. You were admitted into hospital?

A. Yes.

Q. And on 23 May you were told you had to have a transfusion?

A. That's right, yes.

Q. Before the transfusion was completed it was disconnected and you were sent for an ultrasound?

A. Yes.

Q. And you describe in your statement that it was all rather strange and you didn't really understand what was going on.

A. Yes, that's correct.

Q. Can you tell us a little more about that.

A. Well, I wasn't actually told why I'd got to have the transfusion in the first place. I was just told the doctors said that you're having it. They put the cannula in. They started the transfusion and -- but three-quarters of the way emptying, when the same sister came in and said, "You've got to have it out. You've got to go for a scan".

She disconnected me, gave me a cellular blanket to put over the gown that they'd given me, and told me to walk without help, without, you know, anybody else, to the scanning for an ultrasound.

That actually involved going down a corridor out of the building, past the workmen who had got scaffolding up, across the grounds to a small single storey building where I had to have the ultrasound.

Q. When you got to the place you needed to have the ultrasound, the radiographer was concerned that you were alone?

A. She was very, very concerned. She was shocked, and she said that she was going to call to complain and ask for a porter with a wheelchair to take me back.

Q. Somebody did that and you went back to the ward?

A. Yes, that's correct, yes.

Q. When you got back to the ward, you understood that there had been some raised voices amongst the staff?

A. Yes. The lady in the next bed, because I'd already been on the ward for three or four days so I'd made, you know, a relationship with the woman in the next bed and she said, in her words, there had been a bit of a hoo-ha, raised voices, it sounded somebody had been having a go so I thought, oh, the radiographer had phoned and made a complaint and it hadn't gone down too well.

Q. You were never sure whether the hoo-ha was whether you had gone to the ultrasound on your own or whether it was about the transfusion itself?

A. Yes, because I hadn't been told why I got -- there was no reason, as I knew then, why I should be having one. So I thought at the time when they took it out, part way through, was it meant for somebody else? Had they made a mistake? Was I that person, you know, and especially getting me out of the building. I mean, it did raise concerns.

Q. Before you were given the transfusion, were you warned about any risks of having it?

A. I wasn't told anything about it at all, even to the point I didn't know why I was having it.

Q. As a result of that transfusion you were infected with hepatitis C.

A. Yes.

Q. About a year after the transfusion in June 1987 you didn't feel quite yourself.

A. No.

Q. Can you tell us what was wrong.

A. I just started feeling down, depressed, lacking in energy. I just wasn't me. Before I'd been full of life, you know, I did clubs, I was sporting. I'd got a young daughter who'd survived the pregnancy because I wasn't sure, and I should have been full of life. There was nothing wrong in my life, except for me. I felt just like there was -- I wasn't me anymore.

Q. You've described that you felt like you were carrying ten other people around with you?

A. That's it. I was just -- everything was exhausting.

Q. So you went to the doctor.

A. Yes.

Q. What did the doctor say?

A. You're a working Mum, because I was working, I was working full time, you're a working Mum, you're going to be tired. That was it, sort of go away because there's nothing more.

Q. Over the years you have had a number of physical conditions.

A. Yes.

Q. Thyroid cancer, several miscarriages, irritable bowel syndrome, fibromyalgia, an enlarged spleen, undifferentiated connective tissue disease, as well F3 liver disease.

A. Yes.

Q. You are not sure whether they are related to the hepatitis C but you often wonder whether they are?

A. I very much believe, and it has been said to me in the rheumatology department that it was probably the hepatitis C infection that trigger the autoimmune conditions, which in itself have put me on immune suppressants and that in itself causes you get a cold, you get sepsis, you don't -- and it makes you feel very ill.

Q. You believe that there's been a really a cycle of illness all arising from the hepatitis C?

A. I do, yes.

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

A. I hadn't felt any better from the time I was tired in, you know, years earlier, but I started getting more achey, I was exhausted, I was collapsing on the floor at work. I'd been really pushing myself because I had been doing really well at work, working up for promotion, and after collapsing a few times, I went to the doctors and they gave me sick notes at the time it was called for exhaustion, and it literally was the most awful exhaustion. I just couldn't stand anymore, which actually felt really embarrassing because it was just like saying, "I can't work anymore because I'm too tired", but it was far more than that, but that's how it felt and I think that's what other people thought as well. It's just like, you know, you're just tired.

Q. If we fast forward to 2016 because that continued and went on but by 2016 you were really very unwell.

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

Q. What can you tell us about your symptoms at that time, just before your diagnosis?

A. For months I had been being sick, physically sick. I couldn't eat anymore. I was losing weight. I went down to just over six stone, which was half my body weight, and there was just no reason. I couldn't find -- you know, I was having monthly blood tests for my autoimmune conditions but nothing was showing up, but I just literally, as my family said, I was dying in front of them.

Q. Eventually you were referred to a haematologist --

A. Yes.

Q. -- who did a series of tests.

A. Yes, quite a few.

Q. And you were then told that the test for hepatitis C had come back as a positive. With that first test what did the haematologist tell you?

A. Well, he actually phoned me up and told me this over the phone. He said not to worry everything else come back clear but this one had come back as a positive but he didn't believe it was a true positive. He thought it was a false positive because of my immune conditions and the medication I was on and he could see no reason why it would be positive, so he'd like to do a second test.

Q. So you had that second test?

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

Q. Then what happened?

A. Then I received a phone call from my GP's surgery saying they had received a letter and could I go in to discuss it, which I made an appointment and went in.

I was expecting this to be a letter from any one of the departments that I was going, either orthotics, rheumatology, anything like that, I went in and I sat down and the GP held up a Public Health England letter and said, "You're drug taking or a sex worker. You are at risk of infecting everybody. You've got HCV". I didn't even know what that was. They said, "You've probably passed it on to your kid and husband and you might die from this".

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

A. I said, "That's not right, no, no, no. That's a false positive. My haematologist told me 100 per cent. I've had a second test", and he said, "No, no, no", and he said, "No, it's definitely the second test has proved positive".

I mean, I was kind of freaked because all was going whizzing round my head was, "I am going to die but I've actually killed my kids and husband". That's all I could think, "That's it, we're all going to die". But it was -- I asked what it is and he didn't know. I said, "What can be done?" He said, "You'll be referred to somebody", and that was it.

I mean, I can still picture the room. I can picture the jumper he was wearing, the pen on the desk, everything, the letter, but it was just -- it was like he'd called me in to say, "You're a dirty disgusting person, a danger to society. I don't know what it is myself but that's what they're saying so go away. You'll get an appointment from somebody else", and I left.

Q. As you say, you can still remember vividly the details of that?

A. I can remember everything about the room. I won't go in that room. I can remember even the stitching. He'd got a hair on his jumper. The whole lot became stuck in my brain. I can still picture it now.

Q. And you still have flashbacks to that day?

A. I do have flashbacks and I was later diagnosed with PTSD from that point.

Q. You have described in your statement that you walked out of the surgery feeling suicidal.

A. I did. I left, I could not -- I could not compute or work out what I'd just heard, the consequence, I'd been given nothing to help me understand any of this and I just had the GP who'd known me a few years basically say I was a drug-taking prostitute and, you know, I'd put everybody at risk with something I didn't even understand, and I left and I drove which now thinking about it I really shouldn't have done, driven in that state, and all I could think of was there was a local viaduct which I was going to go and throw myself off.

Q. In order to get to that viaduct you had to drive past your own house.

A. Yes.

Q. As you passed by you realised you couldn't do that to the children?

A. Actually, my son was looking out of the window waiting for me because he knew I was desperately ill, he knew I'd gone to the doctors', and he was just, sort of, "Where's Mum? Is she going to know what it is", you know, and I just saw his face and I thought, "I can't, however bad it is, I can't leave them to deal with this without me", so I went into the house instead.

Q. It then took a month before you saw anybody again and on that occasion you saw the haematologist again?

A. Yes, I did.

Q. What was their reaction to how you'd been told about the hepatitis C?

A. They were horrified. They were furious. They were really, really angry, as he'd asked for the tests.

He'd asked me if I could -- you know, have the tests, he'd had the tests, he'd had the results, and he was so angry that the GP had told me because he was going to tell me in a situation where he could explain a little bit about it and he was just literally furious. He was going to explain about it he said.

Q. He was able to tell you a little more about what hepatitis C was.

A. Yes. He said, "I don't know. I'm a haematologist", because he had actually been checking for blood cancers, but he'd just screened me for that, for everything. He said it was a liver illness and there were treatments for it and he was going to refer me off to a hepatologist.

Q. You then had to wait for a few more weeks to see the liver specialist?

A. Yes.

Q. You saw the specialist nurse?

A. Yes, I did.

Q. What happened at that appointment?

A. She was actually brilliant. She was really, really helpful. She discussed what it was that I'd got, where I'd, you know, just talked to me to find out about me and we worked back and found out. Then she asked if I'd had a transfusion and I said, yes, I'd

had this transfusion in 1986, and she said that that was more than likely the reason that I'd caught this, and she also gave me the numbers for the Hepatitis C Trust and mentioned the online support groups.

Q. You then had a liver scan and established the extent of the damage?

A. Yes.

Q. Did any of the doctors explain to you the ways in which hepatitis C can be transmitted?

A. Well, no. I mean, obviously, first off I had the letter saying it was through drugs and sex, and then my hepatologist nurse said, you know, it's a blood-borne thing, but no -- but even she didn't give me any leaflets, information, or anything to tell me how you get it really or what precautions you should take or anything. There was just no advice at all. It was just HCV actually means hepatitis C. That's about what I learned but there was nothing, no. I got given no advice.

Q. You didn't have any leaflets or anything to take with you?

A. There was nothing at all, absolutely nothing.

Q. You have two very particular concerns about your infection. Firstly, you have questioned why the infection wasn't identified earlier, given that you

were receiving treatment for a number of conditions over the 30 years between the transfusion and the diagnosis.

A. Yes, I mean, through every pregnancy you get, randomly really, just checked for HIV and Hep B and it wasn't picked up on. I mean, rheumatology, all that, all the tests I had, all the diagnosis, and I know now that if you get -- if somebody is going to be started on treatment for rheumatoid arthritis, they test for HCV now. But that was after they'd started me on treatment; so they didn't test me. They didn't think, "Oh, why has this woman got all these conditions? We can't find out why".

I was put on a ward in the early 2000s through rheumatology for a whole week to see if they could find out what was wrong with me and all they -- well, they came up with a diagnosis of fibromyalgia with the thought there might be something else. But, no, even through thyroid cancer, on the immune suppressant, 4-weekly tests, nobody ever found out until they thought I had got blood cancer as haematology will screen for everything.

I mean, I was at the hospital, yes, my notes were that thick *(indicated)*, endless tests, endless medications: all the time, never tested.

Q. Your other particular concern is why you were given the transfusion and you've said that you were never told why you needed it?

A. I wasn't at the time.

Q. There's also no record of the transfusion in your medical records, is there?

A. There isn't.

Q. When you applied to The Skipton Fund you requested your medical records.

A. That's correct.

Q. Can you tell us a little bit more about what happened then.

A. Well, I had trouble asking for them and they seemed to delay in sending them. When I did receive them, there's some notes. I was actually admitted on to the ward on 19 May. There's a page of notes for the 19th, the 20th, the 21st, the 22nd, then it is goes to the 24th, the 25th, all the way up to the 29th when I was discharged having given birth.

The 23rd was missing. There's no notes for the transfusion. There's no notes for the ultrasound. There are no notes at all for that date, nothing, you know, not temperature, not foetal, there's nothing. So I questioned them on this and said, you know, "This is -- not only have you not got the bit I know I need,

but where is all the supporting notes, all the nurses' notes", and it was a very lengthy process which ended up with me putting in a complaint which was ignored.

I sent in a letter recorded delivery to the hospital saying, "This is my complaint. I need you to find these notes", to which they said they hadn't received it, even though it was signed as their mail room.

I actually went up to the hospital in person, went to the reception desk and asked them to bring somebody down from the office to hand them my complaint letter and all a sudden they instantly found everything, except for the notes.

It took, all in all, about ten months from initial request for them to supply me with notes that they said they'd got and a letter to say that they thought that, due to the timescale and the building moves, that any letters from that time, except for the ones that I got either side of that, had been destroyed or lost and they've never come up with the day of the 23rd.

Q. So there's no record of 23 May?

A. No.

Q. Also you have noted in your statement that the discharge letter from your admission has a tick in the

box to say that you didn't have anaemia?

A. That's correct, which is a surprise because I was anaemic from a child. I've always been anaemic and I'm still anaemic now. I was anaemic before I was admitted but, miraculously, I suddenly became non-anaemic through the time I was there and then ever since I've been anaemic with transfusion level anaemia with the other three pregnancies I had. So it was just like somebody decided to wipe that day, my transfusion, my anaemia, for whatever reason.

Q. You've said that that's what worries you most, that they have hidden the fact of the transfusion?

A. They have hidden the fact because part of me is should I have had the transfusion? Did I need it? It may have been for anaemia, it probably was -- you know, they would have found I was anaemic anyway. But obviously since looking at things and learning, it's like was I -- and because of the arguments when I was at the ultrasound, you know, I personally think was I given the transfusion on -- was I infected on purpose?

Q. You've said in your statement that the whole situation around the notes and the lack of the records makes you question whether you were deliberately infected because you were young and healthy and you say maybe

they wanted to see what would happen.

A. That's correct. That still stands today because I have some across through support groups other women who were exactly the same age because I was 19, I was young, and they were 19 and they were given a transfusion for anaemia and there just seems to be a few cases and it's why did they do it? Why was there not notes there on that day? Why has nobody ever followed me up? Why did they leave me for 30 years, and why does there seem to be such a cover-up over it?

If it just been, you know, a regular, "Well, we gave to have a transfusion. We admit you had a transfusion and unfortunately people got infections from them", but it seems to have been deliberately hidden.

Q. You are worried that there continues to be a cover up because of something that happened when you attended the hospital in April of this year?

A. That's correct, yes.

Q. Tell us what happened.

A. Well, I'm always at the hospital, I'm always having appointments and, as Andy said before, my notes are quite thick, from obviously regular -- so I notice them coming when the receptionist gets them out. So

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

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

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

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

Q. Can you remember a little more clearly what you recall the doctor saying about the notes.

A. He said that it looked like somebody had messed them up and that he couldn't, therefore, find -- and if he tried to look through it could take maybe half-an-hour to an hour or whatever. You know, he thought it would take too long to even look through them all because they were in such a mess. It looked liked somebody had messed them up. "I don't know what somebody's been doing with these", is what he said.

Q. You're worried that someone's gone through your notes because you're giving evidence to the Inquiry?

A. Yes, because it wasn't -- nobody was aware that I was going to be giving evidence before, at my rheumatology appointment my notes were fine, and since then, you know, all of a sudden, my notes are a mess, they're not in order, there's pages hanging out which there weren't at the previous appointment and there's no reason for anybody to have done anything with those notes between one appointment and the next.

Q. You are represented by solicitors and the solicitor's contacted the trust?

A. Yes.

Q. They have denied that that is what was said by the doctor?

A. Yes.

Q. And denied that the notes had been accessed by anyone inappropriately.

What's your response to that?

A. I say that they -- that it is a further cover-up because the notes were in a terrible mess, the doctor did say that to me, I could see that they were a mess, and the fact that they used the word "inappropriately" means that somebody had looked at them but they had presumably thought it was appropriate to look through them, but they haven't given me any reason as to why they were in a mess. I mean, there is no answer to that at all. They've just, you know, got back to the solicitor and I've seen that letter and it doesn't explain it.

Q. I want to move on from that.

A. That's fine.

Q. You had been diagnosed with hepatitis C in the autumn of 2016?

A. Yes.

Q. And in January 2017 you were told you would be put forward for treatment with Epclusa?

A. That's right.

Q. You then had to wait to start that treatment until August in 2017?

A. Yes.

Q. Why did you have to wait?

A. I was told I would have to wait until the NHS funding was available. I was told it was done on a month to month basis, that who could have their treatment funded that month and that you wouldn't know who it was going to be until they'd had the meeting that month and decided who was going to get the treatment, so that if somebody suddenly became a really bad case -- you know, it was you didn't know when you were going to get treatment. The nurse said that she was retiring in five years' time and I may have had the treatment funded by then.

Q. You feel you shouldn't have waited for treatment.

A. No, I didn't see why on earth I should wait for the treatment, especially as I'd found out that it was the NHS that had actually given me the infection and caused so many medical problems associated with that and the fact I needed the treatment, they should have just made it available there and then.

Q. While you waited for the treatment to start, did you have any support?

A. No. I had no support. Literally, there was just --

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

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

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

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

cancer.

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

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

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

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

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

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

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

A. That's right, yes.

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

A. Yes.

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

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

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

Q. While you were on the treatment with Epclusa can you tell us how you were?

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

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

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

It was horrible. I felt out of control and it went on and it went on and I started getting dizzier and I felt more down and -- from being able to cope in a way, I hate to refer to Andy but he said you learn to deal with the thing, and I dealt with the cancer, I'd stayed confident, looked after my kids. It really knocked me sideways and I haven't been the same since, since that.

I mean, I was having the tests while I was having it as well and I'd heard great things about people's numbers dropping. Mine took to after 12 weeks to drop, so I was scared it wasn't going to work and actually the nurse didn't think it was going to work, but the test four weeks after I'd finished showed it had actually cleared, which was a bonus. But I've never felt the same since having it.

Q. Your hair turned a different colour as well?

A. Yes, I had -- if you imagine that I'd been ill, I couldn't be the fit, healthy, happy person already, then having gone down to 6 stone, I was skeletal and I felt horrible. The one thing I had left was waist-length hair, a lot of it.

The treatment, it started changing colour as it was growing out and each month my hairdresser said

it's like looking at the rings on a tree, the time-lines, it went yellow, it went a funny colour and it all started breaking off and falling out.

I ended up with just horrible stubble and I know it sounds stupid because everything, everybody goes through in the illness, but that's just hit me so hard. It was just the last little bit of you, it was me, it was just that last bit of nothing to do with the illness. I'd still got my hair, stupid and vain, but it was just that one thing that kept me going.

Q. You said in your statement:

"My hair was the last thing I had and that destroyed my self-confidence."

A. I just didn't feel like a woman anymore. I didn't feel like a person. I was just this ill, skeletal thing that ... you know.

Q. You have continued to feel really quite unwell, even after the treatment?

A. Yes, I have not felt well since. I just felt -- I've never felt well. I haven't felt well since 1987 but I've been through everything else and gone through everything else and I've just felt worse and worse and worse, and I was so hoping the treatment would make me better.

All it did was get rid of the hep c -- all it

did, that sounds like it's belittling it because it's a big thing to get rid of it, but that's it, it's done that. It hasn't changed my life. It hasn't changed my health. It hasn't given me that I'm okay now.

Q. Mrs D, I'm conscious we've been talking for a little bit more than half-an-hour. Do you want to take a break at this point?

A. No, I'm fine. I'll carry on. I'll just keep crying in my tissue.

Q. As you say, you've cleared the virus.

A. Yes.

Q. And you have now been discharged from the liver team?

A. Yes.

Q. But that in itself is making you anxious. Can you explain why?

A. Because it was, "You've cleared it, goodbye". I was told I'd got, you know, F3 nearly F4, you know, I'd got severe fibrosis, it was obvious, it was nearly cirrhosis, and I am on a lot of other things and there's no follow up. There was no, well, you know, I mean, I've already had cancer. I'm on immune suppressants which makes you more likely of cancer and having had hepatitis C there's another high risk of liver cancer and I hoped or I think I should be checked every six months or so to catch something

early.

You know, it was 30 years before they found that. I'd like them to catch something like that a bit quicker but it's not the case. It's, "No, you've cleared it, you no longer need" -- from a mental okay, for just the knowledge that every six months they could check there's nothing else going to rear its ugly head would be at least helpful but they don't want to do that.

Q. Since your diagnosis, your rheumatology team has changed?

A. Yes, it has.

Q. As has your oncology team?

A. Yes.

Q. And you think that is because of your hepatitis diagnosis?

A. I do. I found a change in an awful lot of people as soon as I got that diagnosis. I wouldn't see the consultant I'd been seeing for ten years. I'd suddenly have to see somebody else.

The four-weekly blood tests which became almost like a community day because you would go and you'd see the same people, you would see the same phlebotomists, they would be chatty. They stopped being chatty. Where I have to have my blood tests it's lots of little cubicles with curtains, and they always leave all the curtains open, so it's like five or six people having blood tests and, of course, it said special precautions on every test after that, so they'd get the gloves, and then you'd see other people looking and you are thinking they're going, "They're getting gloves for that person. They've got something".

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

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

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

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

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

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

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

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

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

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

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

A. Yes, if you would please.

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

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

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

A. I wanted it destroyed, yes.

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

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

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

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

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

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

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

A. We did. It just made it very clear that it was, like, leave or die. And I was petrified. I mean, I had to make my children aware that there was a threat. I had to say "don't go outside the door" because I didn't want them to have to see these things we had to clear up. My children became desperately, desperately miserable. They stopped seeing all their friends, they had to go under CAMS, the mental health service, but then they didn't trust to tell them just how bad it was or what was going on in case, in their minds, maybe they might not want -- you know, they might think the same things of them, to the point that my one son wouldn't go to college anymore. My other son was at school. He wouldn't go to school. He's meant to be doing his GCSEs now. He hasn't been to school in months. It destroyed him. He didn't want to live anymore. He didn't trust anybody. He said if this is what life is like and how people are in the world, what's the point?

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

A. Yes.

Q. Move house?

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

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

A. Yes.

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

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

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

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

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

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

A. Yes.

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

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

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

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

A. Yes.

Q. What have you asked them to do now?

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

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

A. Yes.

Q. In your statement you've put it like this:

"It's put pressure on all of us. It's caused stress in my relationship with my husband. It's put stress on my children. I have lost friends and there are family members that I no longer see. We don't have a social life. We don't see anyone. I've hated myself for years. This in itself has had an impact. If the kids want to do something I am too ill, too tired, or can't afford it. I haven't been the wife, the Mum, the sister or the daughter that I could have been. All of these things have been taken from me and from my family."

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

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

A. Yes, that's fine.

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

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

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

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

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

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

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

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

A. Yes.

Q. And that was turned down.

A. It was, yes.

Q. What your observations about that?

A. I phoned them up and I explained the problems that I'd got and they said, "Yes, you can apply". The one big problem I have is the inconsistency of the information you get from them because you'll speak to one person, they'll say one thing, and the next time they'll say -- they said I need a letter from the doctor. I went to the GP and they said, yes, they'd write a letter supporting saying I suffered from these conditions and they thought that a specialist bed would help me. That I'd been diagnosed hepatitis C, I'd got all this, which I phoned them up I said, "I got this letter", and they said, "That will be fine", and it phoned up 30 days later saying, "I haven't had a decision. Is it going to happen". I'd had to go round getting quotes, because you have to get quotes for the bed, and they said, no, it's not good enough because she said they, can't -- haven't actually said it's the hepatitis C that causes the pain, and I said, "Oh right, okay, well it's difficult to say that", and I went back to the doctor and she says, "Well, no, hepatitis C itself doesn't cause the pain. It can cause conditions that cause pain", but she wouldn't directly say the hepatitis C caused pain, so even though I was having all those problems they constantly kept saying no, to the point I didn't bother going back, because there was no way my GP said, "We don't know enough about it really anyway to write these letters but we've said we support you", and they've turned round and said no.

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

Q. You have just given up?

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

Q. Mrs D, those are the questions I have for you. Before I ask Mr Lock whether there are points he wishes for me to raise is there anything else you would like to say?

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

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

A. That's fine. *(Pause)*

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

A. Yes.

Q. Why did that come to an end?

A. Because I was going through the -- it was just -- I'd just started that when we started getting all the death threats, I'd had the letter, the stress, the house move, and they said that it was getting in the way of my treatment, because obviously my anxiety and everything just went up a level.

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

MS FRASER BUTLIN: Thank you.

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

We'll take a break until 2.30.

(1.19 pm)

(Luncheon Adjournment)

(2.31 pm)

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

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

COLETTE WINTLE, affirmed

Questioned by MS RICHARDS

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

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

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

A. Yes.

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

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

I am one of twins. I have a brother and an older sister.

So in 1962, Professor Douglas as he was known tested both my sister and myself, didn't expect to find it in my brother and, of course, did not but we were found to be carrying haemophilia A.

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

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

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

A. Yes.

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

A. Yes, that's right.

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

A. Mm-hm.

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

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

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

My parents were never counselled by the doctors on what type of clotting products that they would use if I bled so there was no informed consent on what they would use, and it's interesting that laterally, years after this has happened, and I sought to get my records from the Glasgow trusts, which it was a hell of a fight to get them, I discovered a slip of paper demonstrating clearly that the intention from the haematologist at the time was that I would be given cryoprecipitate.

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

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

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

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

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

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

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

Q. You have said you don't think your parents received proper counselling about the nature of the products?

A. Mmm.

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

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

You know, why on earth would you go to the United States where people, the wrong type of person is attracted because they are paid for their blood, when you have a system in the UK here where that -- it's a gift, you know. So, yes, it blows my mind that any doctor, you know, would be happy to take that risk and I'm afraid to say that I know that by 1976 it was quite evident that the knowledge of that had been there for some years of what those risks were but they most certainly were not imparted to my parents and, of course, I was a minor so I had no opportunity of discussion at all.

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

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

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

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

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

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

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

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

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

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

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

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

A. Yes.

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

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

The cover for that would be DDAVP. The advice,

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

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

A. I was given Factor VIII.

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

A. Yes.

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

A. No.

Q. -- with the doctor about different products?

A. No. In fact, what actually happened was, as often happens with mild haemophiliacs because they are not treated prophylactically, they don't have bottles in front of them with warnings or labels or anything. What you are presented with is the syringe with the already made-up product ready to inject into your arm. So there's nothing, you know, to say that there's any risk there, so there was nothing evident for me, and most certainly there was no discussion. You simply turned up and said this is your clotting products, and they were injected and that was it.

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

A. Yes.

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

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

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

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

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

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

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

A. Yes.

Q. -- as a nurse.

A. Mm-hm.

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

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

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

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

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

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

So I then had to phone up and discuss this with my training tutor and as soon as the hospital found out they couldn't wait to get rid of me, and I asked about, "If I get over this and I'm well enough, can I come back and finish my training", and I was told, "No".

Q. Can you recall what, if any, treatment you received for the hepatitis B at that point in time?

A. None.

Q. What impact did that attack of hepatitis B have on you at the time? Obviously, you weren't able or weren't permitted to go back to work. How else generally do you recall feeling?

A. Desperately ill for a long time. In fact, I was ill with that hepatitis for a further two years and I didn't -- I wasn't able to return to work until 1985 and I was reliant on my sister keeping me living with her and looking after me, and she was a young Mum and struggling herself because she actually had also been infected the same year, earlier that year, after her first baby was born.

So there you had two of us infected from the same hospital by the same doctor and neither of us had any follow up.

Q. Now, I'm going to ask you to look at a letter. Can we have up on screen please 1056010.

You will see, Colette, this is a letter dated 22 February 1984 and it's from the Royal Free from Professor Kernoff, consultant haematologist, to your GP and it's about you and your sister; is that right?

A. Mm-hm.

Q. When did you first see this letter?

A. This morning.

Q. You've asked for your medical records over the years on a number of occasions --

A. Mm-hm.

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

A. Yes. I actually had to write not once but three times to the Chief Executive to complain because they would send out parts of my records. Interestingly, and most haemophiliacs will connect with this, general records are kept in a separate part of the hospital but the blood treatment records are kept in the haemophilia centres, so they are separated, so they have complete control over them. So when I requested my full records I was getting them in portions, bits here and bits there.

That letter -- that's the first time I've seen that is today. I've never seen that before but that makes it all the worse, that first sentence there, because as I read it it's quite obvious they were aware of the risks of using commercial products.

Q. Just for the sake of clarity, this is a letter supplied to the inquiry by the Royal Free and shown by the Inquiry to you.

A. Yes.

Q. If we just look at it, it refers to a phone conversation on 20 February of that year and then it says this:

"Because of the risk of hepatitis after transfusion of Factor VIII concentrate being very high in infrequently-treated patients, we try to minimise blood product exposure when treatment is needed to prevent or stop bleeding."

Just pausing there, Colette, were you ever told at the time, 1993-1984, that there was a very high risk of hepatitis for infrequently-treated patients such as yourself if Factor VIII products were used?

A. No, never, and this makes it all the more horrific because exactly a year later the Royal Free reinfected me with hepatitis C.

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

"DDAVP injection has proved to be very useful in this respect ..." and goes on to explain why and then in the last sentence of that paragraph:

"If DDAVP fails or a major elective procedure is to be undertaken, we would prefer cryoprecipitate to Factor VIII concentrate, because the former is prepared from the plasma of many less donors."

SIR BRIAN LANGSTAFF: The other thing which it notes is

that you have what it describes only mildly depressed Factor VIII levels.

A. Interesting because my Factor VIII levels started off in single figures as a child. At the point that they were talking about mildly depressed it might have been 23 per cent and it's gradually come up over the years. It still floats below 50 but, of course, also I had Factor XI that hadn't been diagnosed at that point which didn't help so it made things worse when I had a bleed. But, yes, they would often describe it as mildly depressed. Of course they still held the attitude in those days that I was just a carrier.

MS RICHARDS: Now, were you told anything at all at the time about the availability of DDAVP?

A. I don't honestly recall. I was mildly aware of the fact that the DDAVP was mentioned but there weren't any discussions --

Q. Was there any --

A. -- that I can recall.

Q. -- discussion with you about there being this hierarchy of treatment and for you or your sister ideal was DDAVP, if that failed or there was to be a major procedure, cryoprecipitate, and only if those two were unavailable, effectively, Factor VIII? Was that discussion ever held with you?

A. No, because if it had been have been then I would have been aware there was risks involved in this treatment and I wasn't aware of the risks at that stage, no.

Q. If we then just look at the next paragraph there's a reference to a number of the Professor's patients with mild Factor VIII deficiency being treated by GPs with DDAVP and that is suggested for the GP to consider as a practical proposition.

Then if we go over the page please, Paul, we'll see the second paragraph on that page, Colette, we'll see the professor saying:

"If you have problems in obtaining supplies of DDAVP, I should be willing to give you and your sister a limited supply to keep at home."

Then there's reference to record sheets being completed for the purpose of national data being collected, the view being expressed there that we're interested in assessing the blood product saving impact of DDAVP.

Do you recall whether at this time, 1984, you or your sister were given a supply of DDAVP at home?

A. No.

Q. No, you don't recall or, no, you weren't given?

A. No, we weren't given a supply, no.

Q. Were you given -- it seems unlikely if you weren't

given the DDAVP, but was anything told to you about record sheets or the collection of national data or assessment of the impact of DDAVP?

A. No.

Q. Then if we have the last paragraph, please, Paul, first sentence. It says this:

"If treatment with DDAVP is unsuccessful blood product therapy may be indicated and I think it is important again for you and your sister to appreciate this."

Were there discussions with you about the potential for future need for blood product therapy?

A. I mean, it seems quite incredible to me that, you know, this advice and, you know, suggestion of treatment, et cetera, and, you know, Dr Taylor would be established with the local hospital and Dr Taylor, Dr Taylor not only did he not impart to me when he was busy injecting the commercial product into me, not only did he not impart to me the risks of what he was doing, but he also failed to tell my sister in the earlier part of that year and, in fact, he refused to see her in clinic.

She twice tried to get an appointment to see him and she was rebuffed. She then approached him when he -- because she was nursing in the other hospital

that was linked to the one I was working in. She actually approached him on the ward twice and said, "I need to speak with you", and he rebuffed her again and actually told her off for being unprofessional in approaching him, you known, whilst on the ward and that, you know, "See me in my clinic", and she said, "I've tried twice and I can't get an appointment with you".

So the communication level was utterly disgraceful and, you know, when I think about the way she was treated the obstetrician when my sister was rushed back into hospital after a massive haemorrhage actually stood at the end of her bed and said, "people like you shouldn't be allowed to have children".

So you can see the level of contempt that we're talking about, so all this -- this letter would suggest that there's great communication going on and advice. No, that's not the case.

Q. So you have said none of this was imparted to you by Dr Taylor?

A. No.

Q. It's a letter between the Royal Free, *[redacted]*, and your GP. Was any of this information shared with you by your GP or by the Royal Free Hospital?

A. No, no.

Q. That's 1984. In 1985, you were given treatment again for a third time with Factor VIII products.

A. Yes.

Q. Where was that treatment given?

A. The Royal Free.

Q. You were given treatment with Factor VIII made as you understand it by Alpha Pharmaceuticals?

A. *(The witness nodded)*

Q. Were you given any options to have either cryoprecipitate or DDAVP instead?

A. No.

Q. Were any of the matters set out in that letter discussed with you by the Royal Free at the time you were given this Factor VIII treatment in 1985?

A. No, no. And really it's quite appalling because they reinfected me with non-A non-B, or hepatitis C as it's now known. Not only did they infect me but they didn't follow me up. They would have known using commercial factor on me was high risk. They've laid it out the year before, what's the safer option, so they know, so they knew what they were doing when they took that bottle all of the shelf.

I would suggest that they were using up old stock as a lot of haemophiliacs had happen to them, and that's what they did, they took that off the shelf knowing it was high risk and they used it on me, and that particular batch is registered in the American courts, because I went to America, you know, and it was acknowledged in the American courts as a defective batch.

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

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

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

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

A. Yes.

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

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

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

A. Yes.

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

A. Yes.

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

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

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

A. No.

Q. -- was there any discussion at all?

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

have hepatitis.

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

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

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

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

"I agree that this lady has chronic non-A non-B hepatitis. This has presumably been transmitted from Factor VIII concentrates."

Were you told in 1985 that you had chronic non-A non-B?

A. No, and, actually, the first time I saw that letter was when I accessed under Freedom of Information my GP's files and records, and when I pulled that letter out I couldn't believe my eyes because they'd been communicating about a condition that I had not been informed of.

Q. In terms of you first seeing this letter, that was a number of years later?

A. Yes, quite a number of years later.

Q. But in 1985 you were not told that the view was that you had chronic non-A non-B hepatitis?

A. No.

Q. And moving forward to the meeting in spring of 1987 that you and the Royal Free --

SIR BRIAN LANGSTAFF: Just before you move forward, can we have a look at the rest of that paragraph. Is it saying that there is potential infectivity to any child, baby in the womb, and that has simply not been mentioned to Colette?

MS RICHARDS: Colette, if we look at this, and you can assist us with your understanding of the letter, it

says -- it sets out the doctor's view that:

"The non-A non-B hepatitis is only mild, suspect the prognosis is good, no contraindication to pregnancy. At the present time we do not know whether the virus will be transmitted to the neonate. The amount of non-A non-B virus in the blood is much lower than with the hepatitis B virus. For this reason the level of infectivity to the infant should be lower [it doesn't say non-existent]. I have not mentioned this aspect of the problem to her."

A. Mmm. There you are.

Q. Was there is ever any discussion of any of these concerns or issues with you?

A. No.

MS RICHARDS: Thank you, sir.

That's 1985, and then moving forward to 1987 when you were having this counselling session with your then future husband, Keith, and Dr Goldman, was the information that had been set out in this letter two years previously by the Royal Free shared with you at that stage in 1987?

A. No, not at all.

Q. As you have said you had a particular concern, you and Keith, about the fact that this wasn't disclosed because you were going to Oman for the reasons you

have explained?

A. I went to live in Oman. What happened was that we went out to Oman. I was there for three months and then my husband was asked to go and establish a publishing house in the United Arab Emirates so I had to come back home and then a residency application had to be put in before I then went back out to the UAE.

Q. You had expressly requested a medical letter to whom it might concern.

A. Yes.

Q. The purpose of which was if you became ill whilst away, you would show the letter to any doctor who was treating you; is that right?

A. Mmm.

Q. We should just look at that letter, Colette. It is 1056005. We see it is 18 September 1987:

"To whom it may concern."

It's a letter signed by Dr Eleanor Goldman and we should just look at the second paragraph of the letter, please, Paul, if we could just highlight that second paragraph.

You will see there, Colette, it refers to the events of 1976. It refers to treatment with Factor VIII, it says there in 1983, followed by an

acute attack of hepatitis B and then it says:

"Liver function tests remained mildly abnormal afterwards, you remained had been negative since February 1984 when she came under the care of the Royal Free Hospital."

Then it says this:

"She had a further attack of hepatitis, probably non-A non-B, in 1985."

Do you recall whether -- this letter was given to you at the time, I think, to take with you; is that right?

A. Yes, it was a protective letter and really it was just to say she's had hepatitis B, recovered from it, and I didn't actually pick up on that particular bit because I didn't know what she was talking about. I should have questioned it but I didn't know what she was talking about. But the idea it was probably non-A non-B, well, blimey, they should have known because they knew they had given me an infected batch off their shelf and I think the reason they didn't explore that with me is because they would have to explain why they did that to me having the year previously set out what was the safest treatment.

Q. So this was expressed as being you had had in the past this further attack of hepatitis in 1985, described as probably non-A non-B.

Did you pick up at all on the significance, if any, of the reference to non-A non-B?

A. No.

Q. Did you understand this to be communicating to you that, in fact, they thought you had chronic non-A non-B?

A. No, no. If I had, then surely they would have been following me up and surely they would have referred me to a hepatologist but that didn't happen.

Q. We've actually got a letter from your first husband for the purposes of the Inquiry. It is 1056009. It's the last three paragraphs on that page. Keith says, he confirms that:

"At no time was it ever mentioned to us during our counselling sessions that Colette was infected with the hepatitis C virus."

Pausing there, it was then known as non-A non-B but, again, for the avoidance of doubt, as I understand your evidence, it wasn't mentioned as non-A non-B either?

A. No.

Q. Then reference to, in the bottom of the page:

"Had I/we been informed I would never have put Colette's life and freedom at risk by moving to the

United Arab Emirates", and over the page he explains why that would have been particularly problematic.

Top of the next page please, Paul. Because having such a condition would have been exceptionally difficult to treat in the UAE and having it as an expatriate resident could have led to serious legal consequences.

A. Yes, exactly.

Q. In 1991 by which time you had met your current husband Steven, who sits beside you, and you were intending to get married in the course of 1991?

A. Yes.

Q. Is it right that at some point in the first half of 1991 you and Steven had a counselling session at the Royal Free?

A. Correct.

Q. Was that again for similar purposes?

A. Absolutely, yes.

Q. With Dr Goldman again?

A. Yes.

Q. Was anything said to you in the course of that counselling session attended by you, Steven and Dr Goldman about chronic non-A non-B or chronic hepatitis C?

A. Never mentioned.

Q. Non-A non-B mentioned at all?

A. Never mentioned.

Q. Hepatitis C mentioned at all?

A. Never mentioned.

Q. When did you discover that you had been diagnosed with hepatitis C?

A. Months after I got married to Steve. They called us into the clinic. We had had the session and they saw me two weeks before we got married in clinic at the Royal Free, and there was not one single mention of hepatitis C.

They obviously -- as routine when you go to the centre they inevitably always take blood samples from you while you're in there and clearly they would have done that and probably -- well, doing what they normally do with them, you know, testing them, looking at your clotting levels. That's what I assumed that they were doing, was looking at my clotting levels, but it's evident that several months after that happened, several months after we were married, they called us back into the clinic to deliver the news that I'd got hepatitis C.

Q. Steven has also given a statement to the Inquiry and in that he said:

"At no point during this counselling session was

there any reference or mention of Colette's hepatitis status. Shockingly, it was several months after our marriage but in the same year, 1991, that we were informed by the Haemophilia Centre that Colette was positive for hepatitis C."

So having been told finally in late 1991 that you had hepatitis C, what information was provided to you about that condition?

A. It was tremendously played down. I was told not to worry about it at all. It was just like having bad flu really, and I remember thinking, well, this doesn't feel too, you know, good if it's flu because you know, the classic symptoms are, you know, bone ache, muscle ache, fatigue, all of that.

Of course, when you put all that together it then starts to make sense and when you connect it back over the episodes and then when I think back even to '76, you know, when I didn't feel right even though I had supposedly recovered from that dreadful episode, it made sense, you know, that terrible fatigue. There's nothing quite like it.

Yeah, it was quite devastating really, wasn't it, to find that out and also that, you know, laterally, the knowledge of what was in my records and what was known but it hadn't been imparted to me, to us, or the risks. It was just like, you know, "It's okay, it's just a bad flu. You'll be right", not the devastating consequences of what it was doing to my liver and, obviously, you know, retrospectively looking back, how long my body had been under attack from hepatitis virus literally from the age of 17.

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

A. 1999.

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

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

I was fortunate to be blessed with a massive head of hair and thank God I had some to lose it was quite horrific because it came out in great big clumps. So, you know, if had a bath it was floating in the bath, if I was in bed I would wake up, it was on the pillow, it was lying on the carpet, it was just everywhere and most women will relate to this. You know, your hair is very much your sense of being feminine, you know, and making you feel nice about yourself. When your hair drops out like that it's horrible, really horrible.

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

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

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

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

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

You have referred to the hair loss:

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

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

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

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

A. No.

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

A. Yes.

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

A. Yes.

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

A. Yes.

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

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

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

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

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

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

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

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

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

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

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

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

A. No.

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

A. Yes, yes, I do.

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

A. Hm mm.

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

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

A. Yes.

Q. What happened?

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

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

Clearly that's not been recorded because there's no record in my notes but that conversation was had because I remember discussing it with my sister and saying, "I'm really terrified that here we go again, this is something else", that, you know, and I said, "Knowing my luck, I probably have been exposed to it".

Q. In 2004, November 2004 -- if we have up on screen please, Paul, 1056006 -- you received this letter from the Queen Elizabeth Hospital Birmingham where you had moved and your care had been transferred there by this time.

A. Yes.

Q. It says this:

"Dear Colette, following your recent out-patient clinic appointment I wrote to Christine Lee with regard to the variant CJD exposure situation and have had a reply today from her. As per the instruction of the patient reply sheet that you returned to them, I am writing to let you know that you did receive UK sourced Factor VIII concentrate between 1980-2001 and that in 1993 you received a quantity of Factor 8Y from a batch that had been contributed to by a donor who subsequently went on to develop variant CJD."

Then there's a reference to the possibility of arranging a date to discuss it further.

A. Yes.

Q. What was the impact on you of receiving that communication?

A. I was horrified, absolutely horrified and bloody angry because I asked them, "Tell me, have I been exposed", and I was told no. I actually asked Jonathan Wilde to contact Christine Lee because my gut was telling me differently and when that answer came back, I was furious because if you look at the time gap between 1993 and when I was actually informed, you know, it's nearly -- it's ten years' gap.

But worse still I actually had, to get to the nitty-gritty of exactly what had happened, I had to write myself and I have a set of communications between me and the CJD surveillance team in Edinburgh, to actually get the batch number and find out about the person who donated the blood, how long they were ill with the disease and, you know, from the point that they donated the blood to the point they were diagnosed and then subsequently died. So that information wasn't freely given to me. I had to go seeking that information.

Q. Do you recall whether there were any further discussions between you and whether it's Dr Wilde or anybody else about those issues?

A. No, and in fact further to that I was still suffering from quite severe nose bleeds and had to be treated. I had to have my nose cauterised for the umpteenth

time and, of course, it occurred to me, well, what guidelines are being given to different departments in the hospital if they are faced with a patient like me who's discovered that they've been exposed to new variant CJD? What happens to the equipment? How is it autoclaved? Is it thrown away? If I need an endoscopy, will that equipment be reused or, you know, for the purposes of trying to avoid infecting others will it be thrown away?

I was talking to the doctor as he was, you know, trying to stop my nose from bleeding and he said, "We haven't got any such guidelines", and I said, "Well, why not, because by then you should have had them". He said, "They haven't been handed out to us". He said, "I've got no idea what the protocol is here".

So, again, I'm having to push for answers and ask the questions.

Q. You set out very clearly in your written statement and you have set it out again in your oral evidence, your understanding and belief that neither your parents originally nor you were put in a position to give informed consent to the use of blood products because you weren't given the requisite information.

A. Mmm.

Q. You also say in your statement that you have found in

your medical records evidence that at the Royal Free you were tested without your knowledge or consent for hepatitis G, and if we just have on screen 1056008, that's a test result there recorded that -- you found this in your records subsequently?

A. I found it in my records, no date attached -- well, yes, 1995, but no reference to who ordered the test, why they ordered it and certainly no discussion with me as to why they were testing for hepatitis G. There is nothing in my records to identify who was behind that and why.

Q. As far as you are concerned you were not asked to give that consent and did not give it?

A. No.

Q. Was the result, negative, one that was ever communicated to you as far as you know?

A. No.

Q. In terms of issues about obtaining medical records you have described the position in relation to the Royal Free, you've described the position in relation to the hospital in Kent and Dr Taylor?

A. Mm-hm.

Q. You also set out in your witness statement that you had some difficulties obtaining your Scottish health records from the Glasgow Royal Infirmary; is that right?

A. Yes, huge problems. Again, I had to write to the head of the trusts and complain that the records were incomplete. Where were the blood batch records? I explained exact dates of when I was admitted, how long I was in hospital for, all the address details and my maiden name, hospital number, the exact dates during which I believed I was treated and where were those records?

They couldn't -- no, they don't exist. I said that's -- "No, they will exist, I want them". Effectively, what I had to do in the end and, again, it was force, through my campaigning, I've done a lot of stuff with the media and at that time I was working with Sarah Smith who was working for, I think, Channel 4 then and I had to threaten them with turning up at the hospital gates with the cameras rolling and I said, "Make no mistake, I will not miss and hit the wall". I said, "You produce those records or I'm going to embarrass this hospital so find them".

Low and behold they miraculously turned up. Found on a microfiche somewhere outside of the hospital and had been moved, but they existed where I had been told, "Oh, they are 26 years old. You'll never -- they don't exist". Well, they did, yes.

Q. Now, I would like to ask you some questions, Colette, about the impact upon you and your family of your infection with hepatitis C and consequent treatment for that. In terms of your family circumstances, you said you have got your husband, Steve, and you have a daughter now in her 20s, and in your witness statement you said:

"The impact of my chronic ill health has had a very negative and damaging effect on our family life."

Could you elaborate upon that.

A. Yes, for the majority of my daughter's younger years I couldn't be the Mum that I needed to be for her. I couldn't join in on family events because I was too ill, invariably struggling to get out of bed every day with fatigue and trying to cover it up from my daughter as well because I didn't think it was fair for a little person to have the worry of mummy not being well and potentially mummy getting sick and maybe mummy dying. Trying to be a wife to my husband who had, you know, a blossoming career and he's trying to keep hearth and home together.

He's terrified, you know, to leave me, can't support me in the way he'd like to, but it stole time from him too and he felt like a lone parent for a long

time. I'm sure that Steve will maybe make a comment about that but it must have been horrible for him living with that fear, me living with the fear and, of course, you know, the other thing that I didn't mention was that, you know, I was suffering from depression as well.

Q. I wanted to ask you about the effect on your mental well-being.

A. Yes.

Q. You have talked about in your statement, about everything having had a huge effect on your mental well-being. It's caused you anger, it's caused you in the past to contemplate suicide.

A. Yes.

Q. And you say in your statement that you almost carried out that desperate act a few years ago but you realised you would leave behind unresolved grief and anger which would have been hellish for your family.

A. Yes, that's true. I had reached probably the lowest I think I've ever been in my life. It's common when you've got a chronic condition like this, they want to put you on a variety of different tablets and I do believe that the antidepressants that they put me on at the time probably actually made my mental state worse and on this particular evening I just --

I couldn't hack it anymore.

I was in my night clothes and I ran from the house barefoot down a dark lane, because we live in rural countryside. I ran down that lane, tears streaming down my face -- I still think about it now. I ran down there thinking how I need the courage to just put myself in there. There was a series of quite deep ponds that people go and fish and I ran through that gate and headed for that pond and I was covered in mud, it was wet, slippy, scratched by the bushes as I was running past and getting nearer and nearer and I got to the edge of the pond and I put my foot in the water and thought, "Just get on with it, Colette. Just do it now and then the pain will be over".

Whether it was a guardian angel or something there's another little voice sitting here saying, "Excuse me, what are you going to leave behind? A little girl who doesn't fully understand, you know, what's happened to Mum and a husband who has been fantastic, supportive", he's been with me on this journey and, believe me, from when I started campaigning in '94 this man has walked across Westminster bridge with banners, he's had T-shirts on him, "hep c bloody murder", you name it. He's been to debates with me, he's been to Westminster, the

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

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

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

A. Yes.

Q. How was that?

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

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

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

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

A. Yes --

STEVE: They said it needed to be six months.

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

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

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

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

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

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

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

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

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

A. That was 2014.

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

A. Yes.

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

A. Yes.

Q. Pain?

A. Yes.

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

A. Yes.

Q. You have fibromyalgia?

A. Yes.

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

A. Yes.

Q. In terms of dental care, you have been able to access that -- is that right -- but through a specialist clinic at the Queen Elizabeth Hospital in Birmingham?

A. Yes, it's done in the hospital. They have a clinic for haemophiliacs and they invite you in either six-monthly, if you need it, or annually for general care, dental care. So that luckily hasn't been an issue.

But when I was living in Kent, I had -- yes, I had to actively seek a dentist who was willing to treat someone with chronic hepatitis and, obviously, I didn't know about the CJD exposure until I moved to the Midlands. But I'm sure that a lot of haemophiliacs have experience, and I've heard them say they have experienced this problem, yes, getting dental care.

Q. You have talked about in your statement how the conditions, the infections that you've had or have, have led in terms of treatment to you having to be operated on last to being regarded as a dirty case to there being a lack of knowledge on the part of the NHS staff who treat you often about the history of how these infections have come about. But you also said this. You're asked or you have been asked on several occasions by NHS staff if your infections were due to lifestyle choices, such as drug abuse or alcoholism; is that right?

A. Correct, yes. That was said to me. I actually had to transfer my haematological care from Birmingham. I'm quite angry about this. But I presented on two occasions with an active bleed and was refused treatment and I was deeply, deeply unhappy about that but I think, possibly because I'd had an exchange with Dr Wilde and he knew that I was an active campaigner and quite vocal on my criticisms of Government, the NHS, the doctors that treated their haemophiliac patients in such a way of putting them at high risk, and I felt compromised.

So I was forced to go to St Thomas', which is quite a distance to travel. But on this particular occasion, I had to go and have a pre-operative check-up before having a procedure done. This lady was a trained sister and I recall sitting down and the first thing out of her mouth was, "So your chronic hepatitis C: is this down to your lifestyle choice of alcohol or drugs?" I was horrified.

It's been said to me when I am -- I mean, I have regular six-monthly scans. Now, most of the staff have obviously got to know me thankfully now but in the early days, you know, you could see straight away what was going through their mind "why's she got cirrhosis of the liver?" You're constantly having to

explain, you know, and you're almost on the defence all the time and anticipating every time you go into hospital and you're faced with medical staff what they're going to surmise of how you came to be in this predicament.

But I'm a great believer in education and I've spent my entire life since my knowledge of hepatitis came about trying to make sure that the stigma that people have suffered (and actually it still does exist) that they wouldn't have an excuse if I told them and explained to them how it came about. Education's a great thing because it empowers people and you're far more likely to not just educate them but create in them an understanding and an empathy that maybe wouldn't be there because they wouldn't know about what's happened to people like me with a bleeding disorder who don't expect throughout their lifetime to be infected with multiple viruses over decades. It's just something people don't expect to hear. I mean, it's like a horror story really when you unfold it as to how things evolved over the last three decades and how I came to be in this predicament.

Q. One of the other things you've said in your statement is having had to, as you've explained, take early

retirement in 1998 and been unable to return to the workplace, you often find yourself having to explain and justify the fact that you're unable to work and have to reveal very private information to friends or people you might meet in social circumstances and elsewhere?

A. Yes, that's right, and there have been many occasions where my husband's job involves quite a lot of corporate, sort of, entertainment and as his wife, you know, I go along to support him and, you know, help him with customers and so on, and invariably the conversation will naturally come round to, "So what do you do?" I have to say, "Well, I don't work" and they say, "Oh, very nice". And I'll say, "No, you don't understand. It's not out of choice. I don't work because I can't work" and they look in amazement.

Well, I suppose part of the problem is this facade because you learn over time if you paint your face and put a smile on your face, then to all intents and purposes I look normal and I guess we all want to look normal, don't we? We all want to be accepted by others and don't want to feel we're different. It's embarrassing at times to say, "No, I don't. I had to retire when I was, you know, 38 years of age and I wouldn't work again" and then have to go into the detail. Then I feel guilty because on occasion Steve would say, "Could you just not talk about it" and then you -- What am I going to say then? Why don't I work? Because I'm a lazy so and so? No, I'm not going to say that. Yes, you do have to justify it.

I told a funny story earlier. My daughter -- you know, kids at school, you know how they talk, "What does your mummy do? What does your daddy do?" and so on and Rebecca didn't find out really what the issues were with me until her early teens. But invariably, you know, kids come and have a sleepover and whatever and would say, "What does your Mummy do for a living? What does she work at?" and she would say, "Mum just does dishes at home". Just does dishes at home.

But Mummy meantime is out there campaigning, trying to raise the profile of this damnable disaster, and she's coming home and saying, "Well, what's that camera doing in the garden, Mum?" or "Why are you going to the local radio station? Is that you in the paper. Eventually, it started to unfold but, yes, it's been pretty tough having to reveal those private aspects of my life and tell the story of, you know, what has happened to me physically and what the ultimate prognosis is going to be. And believe me,

I mean, having nursed people who have died from liver cancer, it is quite a horrible way to die.

I have regular nightmares. I don't sleep. Maybe if I get an hour or two's decent sleep a night that might be it. The rest of it's just surface sleeping. My body's in constant flight and fright. I suffer night sweats all the time. I'm sure a lot of the haemophiliacs will tap into that one. So yes, it's pretty horrible to have that.

There's no getting away from this. You wake up with it in the morning, you go to bed with it at night, and it's sitting there with you all the time, yeah.

Q. In 2010 as part of your campaigning, you met with the then Health Minister about the availability or lack of availability of counselling and psychological support. Have counselling or psychological support ever been made available to you or to your family?

A. We had a short spell of counselling at the Royal Free but it was more related to the early years when I was finding it very difficult with Rebecca. Some people have expressed this already that it affects your brain, you're foggy-brained, you get angry, you get fidgety and very, very difficult and if you've got a young child, you know, who's having a difficult day

and you're physically and mentally not up to it, you know, it's very, very hard to deal with.

Q. In 2010, when you met the Health Minister, you were told that the Government would be willing to offer counselling or psychological support to be made available to victims but you've said that the funding was such a small amount of money, it wouldn't have been adequate to meet the needs of the community --

A. Yes.

Q. -- and it was going to have to be through the trusts and funds?

A. Yes. I raised it with Ann Milton and actually more directly with Rowena Jeecock, who was the head of the Blood Policy Team, and asked her -- this is quite late in the day 2010 but, you know, knowing that so many haemophiliacs, you know, would be suffering with depression and PTSD -- and I asked how much money, you know, had been set aside at all because they had announced that they would provide money for counselling. The sum that was told to me was 300,000 had been set aside for an entire community of patients.

I said, "Well, that's not going to stretch anywhere near enough". I said, "If someone was to apply for it", I said "how do they get it?" "Well,

they have to go through the Hep C Trust". So I said, "Okay".

And I said, "How many sessions would that actually allow them to have if they were able to secure that?" A maximum of six, I was told.

Well, I'm sorry but, you know, my experience in what's happened to me I know six sessions wouldn't help me one jot; so I don't know what they were thinking about. 300,000 is a drop in the ocean of what really is actually needed.

Q. In terms of the funds themselves, what's your experience, your direct experience, been of the application process and the information which the Skipton has required applicants such as yourself to provide?

A. An appalling process as people have described it and I've described it this way myself. You're made to feel like a beggar with a bowl. The method and way in which they ask people to apply, the level of intrusive information that they ask of people is a disgrace. They've also set out about a divisive process which has set many, you know, people against each other because one's getting a certain amount of money, the other one's getting another lot and it's clearly grossly unfair, demeaning and derisory the sums of money we're talking about here and the means testing issue is utterly appalling.

I said at the outset that if -- and I know a lot of these trusts just weren't meeting the needs of victims, just aren't, and even when they decided -- and I wasn't consulted and, you know, I still remain angry about this, some of the longest-standing campaigners were left out of a lot of meetings that took place when, you know, we were looking at a change in the financial reviews on these trust funds, and I said at the beginning, you know, and I've said it for several years that it's absolutely shocking that the state is responsible for the multiple infections of a very vulnerable patient group -- and, I'm sorry, I'm just speaking as someone with haemophilia.

It seems to me an absolute disgrace that the state can infect people in this way, spend three decades covering it up, and insult us with these pathetic sums of money which in no way could possibly meet or represent the losses that people have suffered and they are not enough even now for people to get by on. They're the most basic levels.

I actually said something in the Department of Health and it raised a few smirks round the room but I asked directly in a meeting with Ann Milton and the

Head of Blood Policy, "Who came up with the sum of money that we're talking about?" That was back in, I think 2011, I asked that question. "Who come up with these sums of money?" And they couldn't answer me.

I said, "Well, would you be satisfied in receiving that if you'd had done to you what I've had done to me? Would you be accepting that" I said, "because whoever thought these up should be shot". There was a smirk and a giggle around the room but I actually meant it because it is deeply insulting, really insulting, and cruel that people have been in some cases pushed into financial penury. Some have not been able to afford to buy their own homes.

My worry -- I mean, my husband here, you know, he won't get a penny from the current trust fund or the previous ones if I die because he would be means tested; so he wouldn't get anything. I think that's wrong and the only way you're going to properly help people is to give them proper compensation. We don't want begging bowl funds.

Q. Colette, you've said in your statement, in summary in your statement, this:

"My life has not been what it is or what it could or should have been because of what has been

done to me by the people who were supposed to be caring for me."

That's the end of the questions I wanted to ask you and you know, I think, that a number of the themes you raise in your statement issues about the trust and schemes and so on are matters that the Inquiry will indeed be investigating in due course. But is there anything else before I ask Mr Stein if there are any further questions that you would like to say at this stage?

A. Yes, I just set some thoughts out. If you'll bear with me, I'll read them.

I'd just like to say that I do welcome this Inquiry as a final opportunity to seek the real truth behind the contaminated blood disaster and I hope the final outcome will really deliver truth and justice where there has been none; that there will be recognition of the extreme pain, suffering and an acknowledgement of people's financial losses, which have hugely impacted on my life and that of my family and many others; the damage that's been done to my family life and the relationship with my child, which has taken many years to repair and we're still trying to get there; and it's my hope, Sir Brian, that you'll re-look at Lord Peter Archer's recommendations that he

made in his independent report, which I was a witness to, because I think they remain arguably a most comprehensive set of recommendations and it would be nice to see them implemented, as they should have been at that time in 2009 when the report went out.

I think most of us feel -- you know, we want -- every infection that we've been exposed to should be taken into consideration in those recommendations if we're talking about compensation proper. You know hepatitis B hasn't been considered here and certainly there's no word of compensation for being exposed to CJD. We're just talking at the moment about hep c and HIV.

I want to see accountability for lies that have been told by Government officials and that even when those lies have been exposed, nothing's been done about them. Those decisions have blocked justice for haemophiliacs for quite some time and for people who have been infected in other ways. I hope it does become clear in summarising of this Inquiry that, you know, as more people give evidence that this was not a medical accident, it was largely avoidable.

And I want assurances too that, you know, certainly from Government that long-standing campaigners won't be blocked and left out of meetings, as we have been, because that's had a very serious impact. It's certainly not a democratic process if you exclude people, you know, that should be there and part of discussions because, obviously, it's affected the way that the new payment schemes and financial trusts were folded. I'm referring particularly to the Macfarlane Trust was set up under a legal framework and people signed to that and it was meant to be for life and widows were not meant to be means tested but that is happening and it's happening in the new scheme.

I want financial security for my husband if I die because, you know, this new announcement with EIBSS and victims are furious about means testing but, you know, as I said, under the current rules that Steve won't get a penny for the loss of my life and there's too many anomalies across the devolved governments which are shocking because if I'd remained living in Scotland for example, I would have been entitled to that scheme plus my husband would have got 75 per cent of that pay-out if I lost my life. That's not the case here.

Finally, I'd say that as a victim of the worst treatment disaster in the history of the NHS I want to say to every successive Government, past and present,

and to the current Parliamentarians that you had, and still have the responsibility to ensure justice for every person who has been afflicted and bereaved by a life-threatening treatment supplied by the state. I think we're talking about, as far as I'm aware, over 2,500 haemophiliacs have lost their lives and those of us who are left still battling every day with the physical and mental damage of being infected with multiple viruses and having to fight for scraps of *ex gratia* payments.

You know, I want my pain and suffering recognised and it's so stressful because that delay in getting justice is compounded by the anger and the disgust that I feel for those who have been complicit in covering up this blood scandal.

I would say too finally that it's deeply, deeply upsetting to me that I have *[redacted]* in Dublin both of whom were paid out over 20 years ago by a government who, without any admission of liability, did accept that they had to recognise the pain and the hardship that were inflicted upon victims. So I would say one thing: why is my life worth so much less here in the United Kingdom than *[redacted]* in Eire? That's not right.

Q. Thank you, Colette. I am just going to turn my back and ask Mr Stein if there are further questions.

Nothing.

SIR BRIAN LANGSTAFF: I have nothing of my own to ask. Just let me thank you for what you have said to us this afternoon and for being here to give your evidence and to tell us what you have.

A. Thank you.

SIR BRIAN LANGSTAFF: Thank you very much.

I omitted to but I should have thanked Steven as well.

We now take a break for the next week until the Tuesday after next when we reassemble in Belfast.

MS RICHARDS: Sir, that's right. We resume our hearings in Belfast on 21 May.

SIR BRIAN LANGSTAFF: We will not be back here in Fleetbank House until 4 June. If anyone wishes to follow the Belfast hearings, it will be for the four days beginning the 21st, after which there's another short break. Then they can do so following the live streaming if they are not there in person. They are, of course, very welcome to be there in person but I suspect that most of you will be following online and by getting the transcripts in due course. Thank you very much.

MS RICHARDS: Thank you, sir.

(4.07 pm)

(The hearings adjourned until 21 May 2019)

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