Wednesday, 12 June 2019

(10.30 am)

SIR BRIAN LANGSTAFF: Good morning. Our first witness is -- wishes to be known as Martin, does he?

MS RICHARDS: Sir, yes, Martin Beard.

SIR BRIAN LANGSTAFF: Martin.

MARTIN BEARD, affirmed

Questioned by MS RICHARDS

Q. Martin, you were diagnosed as baby with severe haemophilia A?

A. Yes, that's correct.

Q. That was in July 1969?

A. Yes.

Q. Your mother wanted you to lead as normal a life as possible but you did sustain a lot of bleeds and end up spending a lot of time in hospital?

A. I did, yes. Basically, I went through the normal rough and tumble of any youngster at that time, but obviously with being a severe haemophiliac I had a lot of bleeds and where I lived the nearest hospital -- well, the centre I was under was Birmingham Children's, which was a 30-mile journey from where I lived. So every time I had a bleed it was a trip in the ambulance to Birmingham Children's.

Q. And the available treatment at that time in your early childhood was cryoprecipitate, but you had an allergic reaction to it?

A. I did. I used to have anaphylactic shocks, anaphylactic reactions to cryo.

Q. In about 1974 you and your mother were told there was a new treatment that was going to be made available for you, Factor VIII concentrates?

A. Yes.

Q. If we look on screen, please, at a document.

Paul, it is 0012003. It should come up on the screen in front of you in a moment. We can see this is a letter dated 16 December 1974 from the Lister Institute for Preventive Medicine to the Birmingham Children's Hospital and it says in relation to you:

"We can let you have some bottles of globulin concentrate to control his bleeds now that he has become sensitised to cryoprecipitate."

There is a reference in the next paragraph:

"We have recently encountered some difficulty with positive RIA hepatitis B antigen tests. I suspect that some, possibly most, of these are false positives. The only concentrate we can send you is from a batch number HJ1025 which has given such a positive reaction which was 'diluted out'. Flewett knows of this problem and would probably retest this batch for you."

Do you have any observation to make about that letter?

A. Apart from the fact they clearly identified a potential problem with it but they were still prepared to distribute it, which -- it is still shocking, but given the time back then in '74 and the fact that this -- Britain was very -- struggling to be self-sufficient in factor, but it still shouldn't have happened.

Q. Now you received the Factor VIII concentrates initially at hospital rather than at home.

A. Yes.

Q. Then in 1975 you had a particularly dangerous bleed. You had a lot of blood from a head wound. Is that right?

A. Yes. It was an innocuous injury. Me and my middle brother were having a snowball fight and he threw one at me and it had got a little stone in the snowball, which cut me on the top of the crown of the head, a very tiny cut, and we were outside a social club at the time where my parents were inside and I went in and there was blood running down my face, and my mother jumped up and screamed. I can still see it to this day, but she took me home, cleaned me up, put a bandage on my head, and because it was such a small cut it, didn't really think it needed any treatment, but what happened was it kind of built up in the night the bandage came off and the following morning my brother described it as what he thought was like a murder scene. There was blood everywhere, and he went downstairs and said to my mum "I think Martin's dead", but because was a practical joker, my mother didn't believe him.

Luckily for me my eldest brother, he came down. He was the more sensible one at the time and he said, "It's true. I thinks' gone", and they rushed me in an ambulance to Birmingham Children's. I remember passing out in the ambulance, looking up through the frosted ceiling, and then I came round in a room in the hospital looking up at a nurse who was clearly cutting my hair away trying to find the wound, and then I passed out again and came round in a hospital bed, but they had to replace me with a few units of blood.

Q. Now it was in 1976, the following year, when the hospital started to train your mum on administering the Factor VIII products to you at home?

A. Yes. Her training basically involved, she had to try and inject the veins in an orange. That was how she was trained and it was quite bizarre as a 7 year old to watch my mum do this, but that was how she was trained and then -- but then we had to get permission from my local GP to be able to take Factor VIII home with me and initially my GP refused, so we changed GPs and the GP I went with was brilliant. He was a superb guy, who I was under for the next 40 years.

Q. And do you know why the first GP had refused?

A. He basically said that if he couldn't inject me, then there's no way my mum should be allowed to.

Q. Now, after you changed GPs and arrangements had been made for the home treatment, your mum would then store the Factor VIII in a fridge at home --

A. Yes.

Q. -- and would treat you at home?

A. Yes.

Q. And your mum kept meticulous handwritten records from 1977 onwards of every time you had a bleed that required her to administer --

A. Yes.

Q. -- Factor VIII to you?

A. Yes. She -- she never really trusted doctors and although the hospital had their own records, which were basically a sheet of paper written down with what the bleed was for and how many bottles of factor that you would have, my mum actually kept her own records and she wrote down the site of the bleed and when it was and roughly how many bottles you would have for that bleed.

Q. And it's clear from those records which you've shown to the Inquiry that you were having bleeds at least once a week, often twice a week?

A. Yes.

Q. Week in, week out for years?

A. Yes.

Q. And you required factor concentrates as the treatment for that?

A. Yes.

Q. You have also got an UK HCDO records which show that from 1977 onwards you received a range of different products: cryoglobulin, Factor VIII BPL, Cutter Factor VIII, prophylating Factor VIII?

A. Yes.

Q. As far as you are aware, was your mother ever given advice or information or warnings about any risks of infection associated with the use of those products?

A. No.

Q. As you grew into a teenager and continued to take those products, were you ever given any advice or warning or information?

A. No.

Q. Could we have up on screen, please, Paul, 0012004? If we could just have a close-up on the first part of it. Thank you. So this is a document from 1981. It shows a range of tests and you had some observations you wanted to make about this document?

A. Yes. I was watching another testimony and during the testimony this document flashed up and I thought to myself "I seen that before", and I went looking through my notes and I found this document and it is exactly the same document as another person was tested for in the same year. The only differences were the other person was about eight years younger than me and my test was done I think six months before his, and it just seems very strange that we were both tested in the same year for such a bizarre range of tests.

Q. And you've said in your at the same time you think that tests were undertaken without your --

A. Yes.

Q. -- you and your mother's knowledge and consent.

A. Yes.

Q. You would have been about 12 at this time?

A. Yes.

Q. As far as you're aware, was your knowledge -- was your consent, your mother's consent sought for these kind of tests?

A. No. No.

Q. Now in 1986 your care transferred from Birmingham Children's Hospital to the Staffordshire North Infirmary?

A. Yes. Basically, I was too old to be classed under the Children's Hospital anymore and I thought that I would transfer to the Queen Elizabeth, as most of the haemophiliacs under Birmingham Children's did, and we were like a community. I knew a lot of the haemophiliacs at Birmingham Children's, and that's what I assumed would happen, but then Frank Hill said to me one say -- he says "I'm going to transfer you to North Staffordshire Royal Infirmary, because I think it will be more convenient for you". It turns out it wasn't. It was a longer journey, and it was also apparent that he had a friend there.

So I got an appointment 1 September 1986 at North Staffordshire Royal Infirmary. Now, I wasn't driving at that point and my mother *[redacted]*, so she was only just learning to drive again. So we went in an ambulance car for this appointment and were in the waiting room, unlike any other. My name is called out and my mum is on my arm, because she is struggling to walk and she open the doctor's door and I am not even in his office. We are stood in the doorway, you know, and he doesn't even say, "Please take a seat. Hello, welcome to North Staffordshire. Hello, I am Dr Ibbotson". He doesn't say anything. All he says is, "Hello, I see you're HIV positive", and whether me being naive or the fact that I was a very healthy 17 year old, I just batted it away and I said, "Oh, well, that's life", because I didn't really understand the implications of it.

He looks as me and says, "That's your life for the next two years". I said, "What do you mean by that?" He says, "You've got about two years to live". That's when it hit me, and I can't really remember the rest of the conversation I had with that man that day. I just remember going home and having to break the news to my brothers, but I don't know what their reaction was, whether they went away and cried. I honestly don't know.

Q. And that's how you learned that you had been infected by HIV --

A. Yes.

Q. -- in consequence of the treatment you had received.

You have said in your witness statement you were in a state of shock and disbelief. One of the particular concerns you have looking back at your

recollection of that consultation is that this information was delivered to you in a way that others in the waiting room could hear.

A. Yes, yes. He didn't whisper it. He said it in a normal voice and the door was open and the normal public were sat in the waiting room behind me.

Q. Now that was, as you have said, 1 September 1986. We are going to look at a couple of documents now.

Could we have up on screen, please, Paul, 0012005. If we could again have that highlighted.

So we can see this is in relation to you. We see down the bottom it says:

"Date of specimen: 1983.

"Date of report." It is undated.

The test result is:

"HTLV-III antibody positive."

But we can establish some kind of time-frame for this by your age, which is given at the top as 14.

A. Yes.

Q. So in what year did you turn 14?

A. That would have been 1983. January 10, 1983, I would have been 14.

Q. This was a result showing you were HTLV-III positive. You think it is most likely a result from 1983 --

A. Yes.

Q. -- because of the age that's given there?

A. Yes.

Q. And you weren't told of that test result?

A. No.

Q. Were you told that you were being tested?

A. No.

Q. If we can have a second document up on the screen, please, 0012002.

We can see, Martin, this is a letter from the Leicester Royal Infirmary dated 11 October 1985. It is addressed to a Dr Perry, Senior Registrar in haematology at Birmingham Children's Hospital. So this is almost a year before you had the consultation you have described in which you learned you were HIV positive?

A. Yes.

Q. We will just look at this letter together:

"Dear Dr Perry.

"Reach: Martin Beard.

"Thank you for letter to Dr Hutchinson which he passed on to me. We did ask Martin and his mother to call in and see us, but apparently they got lost in the hospital and did not make it to the Haemophilia Centre. However, he did turn up this morning when I was holding a haemostasis clinic and I met him then."

The next paragraph refers, Martin, to you being in Leicester for a couple of months learning electronic assembly work at the skill centre and refers to home treatment and to a bleed into your knee and explains that the sister, that's the nurse, at the work centre insisted on you coming to see them?

A. Yes.

Q. There's then a reference to your health in the following paragraph.

Then if we can have the next paragraph, please, highlighted, the one after that, Paul, it says this:

"We note that he is HTLV-III antibody positive, but is not aware of this and that you do not wish this to be divulged to him. We shall make every effort to comply with your wishes."

So that's a letter of October 1985, which may have been in any event a couple of years after you had been -- the test had been undertaken.

A. Yes.

Q. One doctor to another referring to your positive test result, to the fact that you are not aware of it, and that the doctor at the Birmingham Children's Hospital doesn't want you to be told.

A. Yes.

Q. Now, when did you first see this letter?

A. I saw that in 2006 when I got hold of my medical records.

Q. And what was your reaction to seeing that letter?

A. Stunned. Absolutely stunned. Total blatant disregard for me and disappointment, the fact that I had been under Birmingham all those years and while I was under Birmingham I was always very open to medical examinations, because I was blind in one eye and they liked examining me and I was always open to questions and things like this, but they never had the decency to tell me about this, and what also staggered me was the fact that they were prepared to put other people at risk, the people who I was working with.

Q. In terms of the work that's described there, the work that you were doing in Leicester, was that very physical work?

A. Some of it was. Some it I was doing sheet metal working, riveting working and then I moved on to the electronic assembly work which was less demanding, but when I was doing the sheet metal working and things like that, they were -- for a severe haemophiliac, it was very dangerous work and if I had have had a bad incident, people would have been at risk, and that is just staggering.

Q. And in this period, 1983 to 1986, before you

discovered your infection, did your mother continue to administer the Factor VIII to you at home or were you doing this by yourself by now?

A. I was doing that by myself. I started treating myself at the age of 11, I think. Basically, I was an in-patient at Birmingham one day and the haemophilia nurse came along and see said, "You're going to inject yourself today", and I said, "No, I am not". She says "You have got two choices. You either put the needle in yourself or you stick it in me", and I was that petrified at the thought of putting a needle in somebody I just grabbed it and did it. That was my initiation over, so from then on I treated myself.

Q. Dr Perry and Dr Mitchell, so the person to whom that letter was addressed and the author of that letter, have both been asked for their response. I know you have seen those responses, Martin. Dr Perry simply says:

"I cannot comment upon the screening for HTLV-III antibodies. I was during this period a trainee under the supervision of Dr Frank Hill, consultant haematologist, and whom I would advise is contacted to discuss this in detail."

Do you have any observations to make about

Dr Perry's response?

A. One way or another they know more than they're letting on. They were either ordered from higher up to keep it a secret or they made their decision on their own. I can't see any other way round it.

Q. And Dr Mitchell --

SIR BRIAN LANGSTAFF: Before you go on to Dr Mitchell, what you have dealt with thus far is his reaction to the screening.

Does he say anything about what is said in the letter about him not wanting to tell Mr Beard what he knew about his HIV status?

MS RICHARDS: Sir, no. I have read out verbatim the one paragraph of Dr Perry's statement which addresses the substance.

SIR BRIAN LANGSTAFF: So he simply doesn't engage with the criticism at all?

MS RICHARDS: The Inquiry team are going back to Dr Perry to ask for further responses.

SIR BRIAN LANGSTAFF: It might be useful when you do to confirm what date he knew there had been an actual positive test for HIV, because 1983 was before HTLV was identified. That wasn't until, as I understand it, May 1984.

MS RICHARDS: Yes, sir.

SIR BRIAN LANGSTAFF: So the test result you have shown us must be a retrospective test, but it is plain from the letter that they knew by the date of the letter.

MS RICHARDS: Yes, sir. It is not clear, as Martin knows, from that test result, because the report itself is not dated. Unusually, most of the reports in Martin's medical records are dated. That one is not.

Martin, you have also been shown Dr Mitchell's response. Dr Mitchell was the author of that letter saying they would do their best to comply with Dr Perry's wishes not to divulge your HIV status to you. What Dr Mitchell has said is:

"It is unbelievable that the doctors at Birmingham Children's Hospital Haemophilia Centre intended that Mr Beard should be kept in permanently in ignorance of his HTLV-III antibody result, a position which would be untenable."

Dr Mitchell goes on to say what was being asked was you should not be told the result by a doctor who you had never met before and would never see again.

Do you have any observations to make about that suggestion?

A. The doctor at Leicester was put in a difficult position. He was asked to keep something a secret. Morally and ethically maybe he had a duty to inform me or at least inform the nurse at the training centre, but to my knowledge even she was unaware. They obviously had their reasons for keeping it a secret from me. I will probably never know what they are, but the fact that they wanted it secret, full stop, is a blatant disregard for other people's health.

Q. There is one further document we will look at, Martin. It is 0012006. So we can see this is a result. It is stamped 1 May 1986. Again, it records a positive test result for the antibody to HTLV-III. That's May 1986.

Were you aware that tests were being undertaken in May 1986?

A. No.

Q. And this test result was not communicated to you either?

A. No.

Q. Because the first you learned was 1 September?

A. The first I learned was September that year.

Q. Now in early December 1987, the following year, you were admitted to North Staffs Royal Infirmary with a knee bleed.

A. Yes.

Q. What can you recall about the circumstances of your treatment there?

A. Well, whenever I had been admitted into Birmingham

with a knee bleed, the normal procedure was I would be put on bed rest. I would be given factor. The bleeding would be under control and then they would resume physio to get my joint mobile again.

When I was admitted into North Staffs, the first thing they did was put my leg in plaster and then they put me in a side ward and effectively left me. When they brought my Factor VIII in to me, the staff were in full medical gear, masks, gloves, gowns, the whole lot, but the Factor VIII wasn't even made up. I had to make it all up myself and inject myself. They have even brought my dinner in in full gear.

The isolation was just so Draconian it was ridiculous, and I was -- I was scared. I had been told by this hospital that I had only got two years to live and then all of a sudden I am being treated like this leper.

Unfortunately, back then I was a very quiet person and I didn't really speak up. Thankfully for me, behind the scenes my mother was having a word with the doctor and basically begging him to let me out for Christmas that year, and he said to her -- he says, "Yes, he can go home for Christmas as long as you bring him back", and kind of discharged me on 24 December, but I never went back there.

Q. And you have explained in your statement that was your first sign of any real stigma and isolation from medical practitioners --

A. Yes.

Q. -- in regard to your HIV status. Your mother was incensed and wrote to the Haemophilia Society about it.

A. Yes.

Q. And we can see the response at 0012009, and if we just have the second paragraph:

"I can only say that from our point of view, and the vast majority of haemophilia centres, the action taken by the hospital is absurd and ridiculous."

It goes on to talk about the irrational and over reactive way in which you were handled.

A. Yes.

Q. Now, you didn't return to the care to North Staffordshire Royal Infirmary for the reasons you have explained. You next came under the care of --

A. Derby Royal Infirmary --

Q. -- Derby Royal Infirmary.

A. -- in April 1988. I was effectively without a hospital for four months. In those four months I just basically went under the care of my local hospital, which doesn't deal with haemophiliacs, and

I can't remember which hospital I got my factor concentrate from for that four-month period. It might have been North Staffs. It might have been Derby. I can't honestly remember.

But in April 1988 I gave in and became a patient under Derby Royal Infirmary, which I had always been reluctant to do because it wasn't a proper comprehensive Haemophilia Centre and also growing up, I had seen my *[redacted]* and my cousin, who were all haemophiliacs, treated there and I had watched -- grown up watching them in calipers and with bad legs and things and I thought it was the care of the hospital had made them that way. It turns out, obviously, it's just a progression thing with haemophilia, but that's how I was feeling at the time.

Q. And your diagnosis and the fact that you had been led to understand you only had a couple of years to live led to you making a will at that time at the age of 17?

A. Yes, yes. It is still to date the only will I have ever made. I do mean to update it, but part of me thinks, well, if I do that, it is almost like an admission that I am getting on in life.

Q. In those early years after your diagnosis was finally communicated to you what was the impact on you of your condition, both physically and mentally?

A. Sorry, could you repeat that.

Q. In the early years after you were told in September 1986 of your diagnosis what was the impact physically and mentally?

A. Well, we started receiving some information. I can't remember who from. We got leaflets through the post of advice. I was advised to only eat tinned food. I was advised not to keep any pets and I had had dogs and cats my whole life.

I was toying with the idea of getting rid of my pets and I thought the psychological benefits of having pets far outweighs any potential risk in my book. Those pets had been with me throughout my childhood. Whenever I had had bleeds, whenever I was in pain, they always kept me -- they were always there as comfort. So they weren't going, but I found myself eating things that I wouldn't normally eat, you know, simply because of this advice, and I was told to only eat -- only drink bottled water and things like this, but Burton-on-Trent where I lived, we had some of the best water in the town because it was a brewing capital. I had been drinking tap water my whole life and I had never had any issues.

So it started affecting you mentally and how you

behave, and I was a very, very skinny person at that time, and people did actually say to me at times, "Have you got AIDS", and this kind of thing and I would say, "Why do you say that?" They would say, "Well, you're so thin". I'd say -- well, I was a very athletic person but, you know, when you live in a small town like that, it's difficult keeping those kind of things a secret.

You can go within yourself and hide away to try and keep these secrets or you can be open about it, which unfortunately can put you up to be shot at. I just tried to live my life day-by-day and just see where the future took me.

Q. In 1992 your haemophilia care transferred to the Oxford Haemophilia Centre, but for the time being your HIV care remained at Derby?

A. Yes. That basically happened because I was an in-patient at Derby with a bad knee, the same bad knee that I had had problems with for a number of years and they wanted to give me a knee replacement, but I was only 22 and I thought, "I am too young, surely", so we asked for a second opinion from Oxford, because one of my uncles who was a haemophiliac passed away in Oxford in '76 and they said to the family, "If any member of your family has a problem in the future,

you can always come to us for advice". So my mother wrote to Charles Rizza at Oxford explaining who she was and he said, "Well, we will see Martin. It is not a problem". So I went down there. I think it was about January 2, '92, something like that.

I met Paul Giagrande and Charles Rizza. They brought out my uncle's notes from 1976 with "deceased" written across them, which was quite freaky, but they said to me -- they said, "We keep all family's notes, because there may be some kind of genetic link further down the line", and he said straightaway, "Well, first of all, you are too young for a knee replacement". He said, "There is plenty each of other options. You could have a knee wash out. I see you are still under the care of Derby. We will ask Derby if they are prepared to pay for this. If they are not, we will go ahead and do it anyway". That's what they did and Derby did pay for it and I had the wash-out in June, I think, '92 and I became a haemophilia patient under Oxford, but I was still going back to Derby every quarter for blood tests for the HIV.

Q. A couple of years after that in 1994 at Derby it was suggested to you that you should start on AZT treatment?

A. Yes. It was early '94. It might have been about

March, something like that. I went to the HIV clinic as it was then. As I say, it was really just a case of routine bloods, and the two doctors, Mitchell and Maine, handed me a bottle of pills and I said "What is this". They said, "Well, it is AZT". I said, "Why are you giving me this?" They said, "We think you will benefit from them", and I thought, "I feel fine. I feel healthy". It just didn't feel right.

Anyway, I took the pills home with me and I mentioned them to my mother, because I had already got this link to Oxford, I thought, "Well, I'm going to ask for some advice", so I phoned the Haemophilia Centre at Oxford and they put me in touch with the HIV clinic there and Chris Conlon. He said, "Well, I notice that you are already come down here for your haemophilia. If you like, you can come down here and we will give you a review", so I did and he said, "Well, first of all, we don't give our patients anything unless they need it". He says, "And I notice here that you have been exposed to hepatitis C. Have you been vaccinated against hep A and B?"

This was the first I ever knew about any of the hepatitises. I said, "I haven't got a clue what you are talking about", and he said, "Right, we will ask Derby if they have vaccinated you against A and B".

He asked Derby and Derby said they wouldn't do it because it was too expensive, and he says, "I can see you have been exposed to hep C", which fortunately I spontaneously cleared it, and he gave me the opportunity to become a fully fledged Oxford patient, which I took.

Q. You didn't take AZT?

A. I didn't take AZT, no.

Q. You had a cousin --

A. Yes.

Q. -- who had also been infected in the same way as you, who had embarked upon AZT at that time --

A. Yes.

Q. -- and who died some months later?

A. Yes. He started taking AZT. I think it was the same day that I had been to the clinic and I refused it. He was offered it and he took it and he was dead in July that year.

Q. One of the observations you have made in your statement is at your cousin's funeral you recall family members looking at you and your sense is they were thinking, "How long has Martin got?"

A. I remember going to see him in the hospital about two hours before he passed away and I was there with his brother. We walked out and he said to me, "Is that

normal?" And I said, "I have got to be honest", he was the first person I had seen die from it. I have seen people die in front of me. I have had a couple of friends die of heart attacks right in front of my eyes, one 29, one 55, die just like that, but I have never seen anybody suffering like that and that scared me.

Then at his funeral I thought, "My God, is that what's going to happen to me", and I felt all these eyes looking at me, you know. They probably weren't, but that's how paranoid I was.

Q. Now, by 1997 you were starting to be physically unwell in consequence of the HIV infection?

A. Yes.

Q. You put it in this way in your statement:

> "HIV was starting to get a grip on me."

A. Yes. I had been in a relationship and I always knew that the person I was with would want her own children one day, because she was adopted. Children -- having children has never been a massive issue for me and, even before HIV came along, it was a moral dilemma whether I wanted to carry on the haemophilia gene or not. So I took the decision for us to end, for us to split, at the end of 1996 so that she could go off and

have children and thankfully she did and she is happy, but I went downhill to the point where I effectively wanted to die.

I was as low as you could get, and then in January '97 I started getting all kinds of internal infections, and whether it was self preservation kicked in I don't know, but I drove myself down to Oxford and I checked myself into the John Warin Infectious Diseases Clinic at Oxford, and Chris Conlon came to see me and he started treating me for the various infections, and he said to me, "Your CD4 count is down to 70 at the moment and I think it is time we started thinking about putting you on some kind of a drug regime", which for me taking pills is something I have always been against, but needs must. He put me on a double therapy of didanosine and AZT.

When he said to me he was putting me on to AZT I had a rye smile on my face, because I thought the difference is I trust this guy. I didn't trust the ones at Derby.

Q. And you were on that combination of drugs for two years --

A. Yes.

Q. -- until early 1999, during which you regained some of the weight --

A. Yes.

Q. -- that you had lost and your CD count did go up?

A. Yes.

Q. Then since that time you have gone through a range of different drugs?

A. Yes.

Q. In 1998 the medication that you started Crixivan had a lot of side effects.

A. Yes, indinavir.

Q. What were they?

A. The main side effect of indinavir, or Crixivan as it is known, is a condition called lipodystrophy. Basically, what it does is it takes the fat off your arms and legs and backside and it moves it and your body and it puts it in places where you don't really want it, round your stomach, round your internal organs and in my case on the back of my neck. You end up with what is known as a buffalo hump.

I have also had ingrowing toenails and I also -- one of the biggest problems with indinavir was you were supposed to drink plenty of fluid and during the summer of '98 I went travelling in America and, basically, I didn't drink enough while I was out there and I came back and I started with kidney crystals, so I had to be flushed out for them as well.

Q. And that was a very painful condition whilst it lasted?

A. It was, yes.

Q. You then changed to Viracept?

A. Yes. I think I went on to probably nelfinavir before that.

Q. You went through a trial. You describe it as --

A. Yes, in 2001.

Q. -- ESPRIT trial.

A. It was a trial called the ESPRIT trial, interleukin. This basically came about in 1982 when I was in having my ingrown toenail sorted. A professor came to see me at the Churchill Hospital in Oxford. He said, "We are doing this trial called the interleukin trial for people with a CD4 count of 300 or more". At the time mine was 450.

I said, "Okay. What does it involve". He said, "It involves two subcutaneous injections a day for five days and it is to basically stimulate your immune system. We don't know what your base CD4 count is because we don't know what it was at the point of transmission, but if we can get it up as high as possible, the better".

He says, "There is quite a few side effects with this interleukin". I thought, "Well, I am prepared to

try it. I am already infected. I have got nothing to lose", so I took this interleukin home and after three days I was practically bed bound. I had put on 9 pounds in weight. I was aching, feverish, all kind of symptoms, diarrhoea.

Then on the final day I tried to have a bowl of soup and I was just projectile vomiting everywhere and I lost all 9 pounds in one go. The doctor phoned me up to see how I was doing at the end of the week and I told him about the side effects. He said, "Right. Give yourself a week to recover. Then come down and we will take some bloods".

I went down and he took some bloods and my CD4 count had gone up to about 1,300 and I felt like superman at that time. Bugs were just bouncing off me, but over the next six months my CD4 count dropped and I think they estimated my base level was probably around 700.

Q. After the conclusion of that trial you went on to Viracept and then in 2014 to Truvada?

A. Yes.

Q. Then in 2017 you switched into your current regime --

A. Triumeq.

Q. -- which is three pills in one. That has not had any particularly bad side effects?

A. No, I was at the hospital yesterday and they were asking me how I was doing with that. Triumeq, I don't seem to have any issues with that. One of the main reasons they put me on to Triumeq because of all the other protease inhibitors before that had caused this lipodystrophy and basically they were hoping -- they said it is irreversible, but they can probably stop it getting worse and it does seem to have worked because quite a few people look at me and said, "You look like you have lost weight", which I don't think I have, but if they think so, then fine.

Q. You have told us already about the experience you had being treated late '87 at the North Staffs Royal Infirmary. What impact, if any, has your HIV status had on your dental care?

A. I did have one bad episode with a local dentist some years ago. I had got bad toothache and I went to see him and he took x-rays and said, "Yes, there is no problem with your teeth". I went home and it got that bad that I contacted Oxford and they put me in touch with their haemophilia dentist.

I went down there and they examined me. He said, "How has this been missed. You've got four wisdom teeth coming through". I was admitted into the John Radcliffe where under general they had to break

my jaw and get the wisdom teeth out. I do believe that dentist was just scared. He didn't want to treat me. Thankfully, he's the only dentist I have witnessed that from, but I have heard that it is quite a lot more commonplace.

Q. Martin, can I ask you about how your infection -- the treatment you have received for it over the years have impacted on your family and your private life.

A. My brothers thankfully they have got no health problems. I am probably built to withstand these kind of things. I can deal with them. I wouldn't wish it on anybody, but I've seen the look of anguish on their faces at times.

I remember one incident. I was being taken to hospital some years ago and I remember seeing out the back doors of the ambulance my eldest brother running down the street after the ambulance. They don't talk about it to me. I think they can't even use the word HIV, you know. My eldest brother refers to it as the lurgy. Whether they talk to their friends I don't know, but they do struggle.

I learned from a very young age to use a bit of reverse psychology on people, because I was born blind in one eye and I had a very bad squint in my left eye, so I used to get the Micky taken out of me from a very young age. I used to turn this around and take the Micky out of myself and give these people no room for manoeuvre.

I have always been able to deal with it. I have got a bit of a wicked sense of humour in that fact, but the years between '87 and 2000 really were dark years for me and I started playing pool. This was -- it was almost -- it was an emotional crutch as well, but it also helped me build myself confidence because I was good. I was good at it, but that didn't always go that smoothly. I had problems with prejudice from people in that area, but I also gathered a lot of good friends.

Q. We have got a newspaper article you shared with the Inquiry. 0012008. "AIDS scare youth ban".

Can you tell us what happen?

A. Yes. I had been playing pool for that pub in South Derbyshire for a number of months. This wasn't a local pub. This wasn't a five minute walk round the corner. This was a 7-mile trip. I wasn't driving at the time so I had to get a lift there. I had been playing there for a number of months and I went there one Thursday night to play my match and I walked in the door and the pool team and the *[redacted]* were all stood in a circle by the bar and as soon as I opened

the door he just looked at me and pointed at the door and said, "You, get out", and I just felt numb, empty, worthless.

This wasn't a spur of the moment thing. This was done to humiliate me, because these people had my phone number. As I say, it wasn't a five minute walk round the corner. These people could have -- one of them could have phoned me up and warned me, but they didn't. They wanted to publicly humiliate me, but the crazy thing is about human beings is that bunch of people were there to put me down, but I got home. I can't remember whether I was in tears or not. I certainly felt low. I know that, but within half an hour of me being back at home, there was another public house, which was 100, 200 yards down the road from that one, phoned me up. They had heard about what happened and they asked me to go and play pool for them. Somebody is there to kick you down and somebody is there to pick you up.

Q. You have travelled to the States on and off. What's your experience been of trying to get visas to travel there?

A. Well, my eldest brother went to America in the early '90s and when he came back, he had a picture of himself sat on the edge of the Grand Canyon and I used

to look at it and think, "I want to go there". I had asked my 16 year old cousin at the time, I said, "Do you fancy going to America?" He was big into going to airshows and things. We talked about going to San Diego and various places, so 1998 I thought, "Let's go".

I asked at Oxford about going and I said, "How easy is it to go there?" They said, "Well, if you want our advice, we suggest you are open about it and contact the American Embassy and tell them everything", so I filled in an application form for a visa and I put that I had got a communicable disease and they refused me point blank.

I was deflated but I thought, okay, let's persevere with this", you know, because I have been open. I have been honest and I kept asking, asking and asking. Eventually they gave me a two month visa, so me and my cousin, we went. We had a week in San Diego and a week in Florida. I drove from San Diego to the Grand Canyon, had my picture taken, great time. No issues at all over there.

I came back and then a friend of mine asked me to be best man at his wedding. I thought, yes, brilliant. Where is it? Florida. I had to apply for another visa and, again, they refused me and I said,

"You have already given me one. What are your grounds for refusing me?" Eventually they gave me another visa so I went over there for the wedding. I came back and then I went again in 2001, did a five-week trip. That's when I had the -- came back and had the kidney problems, because I wasn't drinking enough.

Then I went again in 2002, 2003 and the final time I went was 2004, but in 2003 I landed at Boston Logan Airport and I was at immigration. I handed my passport over and my visa was in the passport. The guy in the booth he says, "Why, have you got this visa", and I said, "Well, I have got a communicable disease", and I went "and", and before I could say anything else, he says, "Right. Come with me". He closed his booth up and put me in a holding cell for an hour. So I just sat there and I thought, "Okay. Well, you know, there is no point in getting angry. It's not going to get you anywhere. Just let things settle down".

Eventually, this guy comes and gets me out. He says, "Can we have a chat?" I said, "Yes". He says, "Why have you been pulled in?" I says, "Good question". I said, "Well, I am HIV positive and I have put that on the document", and he says -- well, he was all apologetic. He said, "Look, all I can do is apologise. I can't guarantee this won't happen again but you have got my sincere apologies. I will sign you in for six months. Go off and have a good holiday".

Q. Martin, in terms of your employment you did a Youth Training Scheme?

A. Yes.

Q. 1987/1988. What happened there?

A. Well, after I had finished at the training centre in Leicester, when I came back to Burton, I started on a Youth Training Scheme. I think it was Friday, December 6, 1985. This was basically a two-year course doing electronics.

During that period we were trained in all various aspects of electronics. I remember -- obviously it was during this two-year period that I was told of my diagnosis, and I think this happened probably some time in '87. I was talking to a lad who I was working with and I mentioned that I was HIV positive and one of the bosses overheard me and he pulled me to one side and he says, "I think it would be a good idea if we informed everybody".

I don't know why, but -- so he took everybody into a conference room. There was a couple of hundred people in there and he just stood up and he basically

told everybody.

Q. Sorry.

A. He basically stood up in front of everybody and told them about my HIV status and I am thinking -- afterwards I was thinking, "This guy probably knows less about it than I do", you know, and there he is telling everybody. I mean, thankfully, I didn't receive any prejudice from the other colleagues, you know, whether they didn't have any full understanding of it, I don't know.

Q. You then went to work at a local electronics company.

A. Mm-hm.

Q. You had an experience there again with one of the members of the management.

A. Yes. I finished the Youth Training Scheme in January '88. It was a month or two after that I started on a three-month placement at a company called *[redacted]* doing electronics. Basically, everybody sat at a desk and you have got to assemble circuit boards. The work crew were predominantly women. There was one man next to me, a gay man next to me, and there was another man in the stores and the rest were all women.

The days went by and there never seemed to be any issues. We all got on with our work, you know, and that was it.

Then after about two months the bosses called me in and they said, "The work force isn't happy and they have basically said 'either he goes or we go'", and I was forced out.

Q. You have since that time spent a significant portion of your time doing public speaking --

A. Yes.

Q. -- at various places across the country. What can you tell us about that?

A. That started in 1997 after I came out of the John Warin Ward, started on the regime of pills and I was on the road to recovery, as I call it. Some time that year there was a clinical nurse specialist who phoned me up. She had got my details I think from Derby Royal Infirmary. I think she was doing a dissertation or something and she asked me if she could come and have a chat. So she came over and we talked about my experiences and things. She said to me, "Would you be interested or would you talk to some medical students?"

She worked for Staffordshire Health Authority. I said, "Yeah, okay", so she arranged these meetings three or four times a year at various places around the country and I would go. I would tell them my experiences and then I would do a Q&A session at the

end. This was all voluntary.

Then there was other people got to hear of it, word of mouth, and I also did talks at a prison to the prisoners and the prison staff, and then a few of the doctors at Oxford heard about it, so I got invited to do talks at Oxford University and the John Radcliffe Hospital and Cardiff University. Basically, my attitude has been it has happened to me. It shouldn't have done, but if people can learn from me, then fine, and I did that for the next 22 years.

Q. You are now involved or you were at the time you prepared your statement for the Inquiry with a review of quality standards --

A. Yes.

Q. -- in hospitals.

A. Yes. I got invited to join the West Midlands quality review group last year and this, basically, involves going round haemophilia centres seeing where they can be improved and seeing what things they need to be pulled up on.

The first one I did was at Derby Royal Infirmary, which was an eye opener, because it is good to see how well the place is run. The staff there are superb I have to say, but they are under a lot of pressure.

Q. Martin, you have made applications to the MacFarlane Trust over the years?

A. Yes.

Q. You have said you didn't find the form filling problematic but having to trace your medical record and provide the required documentation to the MacFarlane Trust is where you had some difficulties?

A. Yes. I mean, when I got my medical records from Birmingham, considering they had 17 years' worth of my notes, they were the most helpful out of everybody. They sent me 17 years' worth of notes and they never charged me a penny for them or anything. It was easy, but other places I have struggled to get hold of records.

Q. Although you have, as you have said, a number of records, you haven't been able to locate in those records a copy of whatever letter it was that Birmingham Children's Hospital sent to Leicester --

A. Yes.

Q. -- which elicited that October 1985 letter?Yes.That we looked at earlier.

A. Well, when I got hold of those records in 2006, when they call came in the post -- through the post, big boxes, curiosity, I started looking through them, and I found that letter from' 85 where it was being

withheld from me and I thought, "Well, I am going to make a copy of that", and I made a copy of a few others and then I put them all in the box. I thought, "I don't want to read anymore".

I sent them away to the solicitors in Preston. This was all to do with the US litigation. One of the forms I actually ticked that I would like a copy of these notes back. I think I got them -- got the copies back a couple of years later or something like that, lo and behold the original of that 1985 letter is missing and those notes have been through three different solicitors.

Q. We have the copy because you had made a copy of it?

A. Yes.

Q. But you don't have very much else from the 1980s --

A. No.

Q. -- in terms of records?

A. No.

Q. Martin, those are the questions I have for you.

Is there anything else that you would like to add?

A. There's many -- there's many sad things about this entire scandal. It's not just the loss of life and the destruction of communities that this has caused and the pain on people. People are accountable.

I am not going to sit here and bash doctors, because I don't believe that all doctors go into the profession to hurt people. They make mistakes along the way. They are human beings. They lose track sometimes of what they are there for, but this goes higher up than that. There are MPs that are accountable and they should be made to answer and I believe now is the time for justice.

Q. Thank you, Martin?

A. Thank you.

MS RICHARDS: Sir?

SIR BRIAN LANGSTAFF: There's just one thing that I want to ask you about. When after 1997 for the next 20-odd years you went around talking to medical students, the doctors of tomorrow, you gave them your presentation and then you say there were question and answer sessions.

I just wonder if there was any general theme that you picked up of interest from the questions that these future doctors were asking you.

A. One of the main questions was do I believe that attitudes have changed and on the whole they have.

There is still stigma out there, especially in the small communities. I have met haemophiliacs over the years that live in small communities that are too

afraid or too scared to speak out about what's happened to them because of the possible repercussions.

The town I live in is not a massive town, but it is bigger than most, and I have always tried to encourage people to ask me questions and be open and, you know, I don't want people walking away from me thinking, "I wished I had asked him that. I wish I had asked him this". You know, take the opportunity.

One thing that does sadden me, and I had this conversation with my HIV consultant yesterday. I said to him, "How long have you been in the medical profession?" He said to me, "Oh, I long time". I said, "No, how long". He said, "Since 1993". I said, "So really you are still a newcomer. You weren't around when all this kicked off". He says, "No". I says, "I tell you what saddens me. When I get doctors that have only been in the game 10, 20 years, apologising to me and a lot of them do and they are red faced and they apologise, and it saddens me that they feel they have to apologise for the mistakes that their predecessors have made".

MS RICHARDS: Thank you.

A. Thank you.

SIR BRIAN LANGSTAFF: Martin, thank you very much indeed for that. Thank you for being here and sharing your experiences with us.

A. No problem. Thank you.

SIR BRIAN LANGSTAFF: We will take a break now until 12.05. At 12.05 who do we have?

MS RICHARDS: We will be hearing from David Gort.

SIR BRIAN LANGSTAFF: Thank you. 12.05.

(11.35 am)

(A short break)

(12.08 pm)

SIR BRIAN LANGSTAFF: Now our next witness wishes to be known as Dave, does he?

MS RICHARDS: That's right, sir.

DAVE ANTHONY GORT, sworn

Questioned by MS RICHARDS

Q. Dave, you have haemophilia A classified as severe.

A. Yes. That's right.

Q. And that was diagnosed when you were a baby?

A. That's right.

Q. You would receive during your early childhood cryoprecipitate administered by the GP?

A. Yes.

Q. You also then started to receive Factor VIII, but that was reserved for very severe bleeds in your case. Why

was that?

A. Because I developed antibodies to the treatment Factor VIII, so I developed inhibitors, so I would always have to be admitted into hospital. So the first treatment would work to some degree before my immune system would recognise that the clotting factor was not its own and suddenly put up the barriers to that treatment, so it was always administered in the hospital.

Q. The care that you received at the time was Royal Manchester Children's Hospital in Pendlebury.

A. That's right.

Q. For reasons you have explained when you received Factor VIII, you received it there.

A. Yes.

Q. You think it was around 1983 there that you first received Factor VIII?

A. Yes. My mum kept a diary and there is a note of me having a knee bleed in 1983 where I was administered Factor VIII. That's the kind of earliest record we could find.

Q. You would have been about 6 years old at the time. Is that right?

A. Yes.

Q. Now, as far as you are aware, were your parents given

any information or warnings or advice about any risks to you of infection from receiving the factor products?

A. No, they weren't.

Q. They weren't?

A. No.

Q. There is one letter that I am going to ask to be put up on screen. It should come up on the screen in front of you, Dave. It is 1244003. We can see it's a letter of 24 August 1985 addressed to your parents form the Royal Manchester Children's Hospital and it says this:

"We have been sending blood samples away from the children with haemophilia and similar disease to see if they are at risk of AIDS. None of our patients has developed AIDS or has shown any signs of doing so, but all of us, both parents and staff, are anxious about the problem. The results are now coming through. The blood tests on your child", then we have inserted, "[David] show he is negative for HTLV-III (ie the AIDS virus). This is good news. We hope to be able to repeat the test every year or so to see if there is any change."

Do you know whether your parents were aware before receiving this that you were being tested for

HIV?

A. No. As far as I am aware they were not told I was being tested for HIV.

Q. Now, that was 1985 and you were given or your parents were given the news you were negative in terms of HIV. Your care then transferred in 1992 to the Royal Hallamshire Hospital?

A. Yes, that's right.

Q. You received a letter in June 1992 asking that you come in for an appointment?

A. Yes, to register with the Haemophilia Centre there in Sheffield.

Q. I think you said in your statement that the letter specifically referred to coming in for testing for HIV or hepatitis C, but you have now found the letter and, in fact, it simply invites you in for an appointment?

A. That's right.

Q. But when you attended that appointment, were tests undertaken in relation to hepatitis?

A. Yes. When I registered at the Haemophilia Centre in Sheffield, they just said all new patients, they are routinely tested for hepatitis C and HIV.

Q. What can you recall about being told of the results of those tests?

A. I seem to remember it was a couple of weeks later and the tests came back and I was called in, I think with my parents present, to say that they'd found that I was hep C positive, and that was the first I'd ever been told of that.

There'd never been any mention at Royal Manchester Children's Hospital. In fact, I think there is a letter somewhere in my records from Royal Manchester Children's Hospital denying that. My parents actually wrote to them to ask, because I think it was referred to as non-A non-B or something --

Q. That's right.

A. -- before they called it hepatitis C. My parents had obviously heard something, I think in the press, had written to Dr Evans at the Royal Manchester Children's Hospital and there was a flat denial that, you know, I had received that, so ...

Q. So you were told in around the middle of 1992 at the Royal Hallamshire that you had contracted hepatitis C.

Were you given information about the condition?

A. The sort of key message to me I think was that not to pass it on to anyone else. I think that was one of the main things is kind of to be careful of sexual contact, that I wasn't to pass it on. From memory they gave me a booklet about sort of healthy eating and foods to avoid. I have tried to find that but

I've unfortunately not been able to locate it.

Q. You have said in your statement you were told that you shouldn't be too worried, but you were also told that there'd be regular scans to check for liver lesions and liver cancer?

A. That's right. So they did say, you know, not to be too concerned, that the treatments that were available at the time they thought were ineffective for hepatitis C and the side effects were worse than kind of the outcomes I suppose, that they would monitor it through quarterly blood tests and I had I think it was yearly ultrasounds.

Q. You said if your statement also you think you were provided with the information that the doctors had at the time.

A. Yes.

Q. The one message that you say wasn't spelt out to you was advice about not drinking alcohol.

A. Yes. I don't think that was communicated strongly enough really considering my age and the fact, you know, I would be drinking fairly soon, that I don't think they spelt out the possible consequences really of that strongly enough.

Q. Now, you don't know precisely when you were infected with hepatitis C, but you have seen something in

a more recent letter, which we will look at. It is 1244004. If we just look at the first part of that letter under the heading "Diagnosis", we have got some numbered paragraphs and (2) says:

"Chronic hepatitis C genotype 4 -- infected before 1985 ..."

That's the first time you have been given any kind of date range?

A. Yes. That's the first time I have ever seen that in writing, that I was infected with hepatitis C.

Q. Can I just ask you about what information you received about the risk of vCJD?

Now, you have said in your statement that you learned about that, first of all, from communications from the Haemophilia Society. We will just look briefly that.

It is 1244005, please, Paul.

We can see that you received this communication from the Haemophilia Society dated September 2004, which talks about:

"You should have received notification from your Haemophilia Centre about steps that some people will need to take to prevent any possible transmission of vCJD to other patients."

A. Yes.

Q. Then that I think triggered you contacting your Haemophilia Centre and having a conversation with the doctors there?

A. Yes. During a review clinic, you know, I was obviously concerned about the possibility of developing vCJD -- contracting vCJD, and sort of gave me some reassurance about that but then I had subsequent letters that said I had not received implicated batches, but then I think the Department of Health changed their mind and decided that for public health purposes all haemophiliacs were considered to be at risk for public health.

Q. We can just look at a couple more documents. In the same -- with the same reference number, please, Paul, but the seventh page.

We can see here in late 2004 this is a letter from Sheffield Teaching Hospitals to you and it refers to:

"The recent information we have sent you regarding the vCJD and our subsequent conversation.

"I am writing to confirm that we have checked our records and these show that you have received UK NHS clotting factor concentrate at Manchester Children's Hospital but not at the Royal Hallamshire. In view of this you are at risk for public health purposes."

Then if we go to the second paragraph of the letter, please, Paul:

"As discussed, I can also confirm that you have not received any of the implicated batches of clotting factor that have been prepared from plasma of donors who subsequently developed variant CJD."

Then you produced a letter you received some five years later.

That's at 1244002, please, Paul. Next page.

This is a letter, February 2009, and it is:

"... writing it all our patients who have received clotting factors made from UK plasma during 1980 to 2001 to tell them about a person with haemophilia who has been found to have evidence of the infection that causes vCJD in his spleen at post mortem. All haemophilia centres are contacting their patients throughout the UK to give them this information."

What you have said in your statement is that although you have been told that you hadn't received implicated batches in 2004, you still worry about the possible implications --

A. Yes.

Q. -- of these risks?

A. Absolutely.

Q. Do you have a clear understanding from the communications you have received about the extent of any risk to you?

A. Not really, no. I think it's mixed and that is sort of evidenced to me through the treatment I have had since then. So in 2014 I was diagnosed with cirrhosis of the liver and I was sent for tests, endoscopy to check for oesophageal varices. Because of the severe nature of my bleeding disorder I had to take an injection of my clotting factor before and the clotting factor only has a half life of two hours. It is a recombinant product but only lasts for two hours in the system. I think it is radiographers. They spent an hour and a half of that time deciding what they would do with the scopes afterwards because on my records it said that I was at risk of vCJD. So I got quite panicky in that last half an hour. I knew clotting factor was running out but they were going to push this scope down my throat and possibly cause, you know, bleeding during that procedure.

Q. What physical impact has the hepatitis C had on you in those first few years?

A. I don't think I realised it at the time, because I suppose I didn't know what life was like without

hepatitis C so I had nothing really to compare to, but I just felt extremely tired. I just thought everybody felt like that. I can remember driving home from a job and almost falling asleep at the wheel and thinking "This is dangerous. Maybe I am working too hard". I was thinking, "No, everybody works the same hours I do", so I was inexplicably tired. Sometimes I would be okay but I would hit a wall of tiredness and I just couldn't explain that.

Q. You said you tried to remain positive, but when you were having the blood tests or scans, you would worry about the results and their consequences.

A. Yes, absolutely. I think my coping strategy was -- I hate to say it -- but was to stick my head in the sand and hope that everything would be okay and, you know, that was just my way of coping really.

Q. In 2011 you embarked upon a course of treatment for the hepatitis C, Interferon and ribavirin?

A. Yes.

Q. What was that like?

A. Horrendous, absolutely the worse thing in my life I think. I wonder to some degree whether that brought on some of the cirrhosis -- it is hard to say -- or just if hepatitis C progressed anyway.

I was working full-time then for the Civil

Service at the time and I had no social life at all. It was just work. Work were very good with me. I had to go to hospital every Friday in Sheffield because the treatment was so severe it was knocking my platelet count and I would have to have a blood test every week to check my level and then they would adjust the dose of the Interferon and ribavirin, but my sort of viral load was decreasing so, you know, the advice was to carry on.

I did this for a year, but the treatment made me -- I had dry skin, very itchy. I couldn't sleep. I'd get very hot. I was incredibly moody. The hospital did say that that was a known sort of side effect of the treatment and they offered me anti-depressants, which at first I declined, but after I think only a week I said, "Okay, yes, I will have the antidepressants please". So throughout the course of treatment I was on antidepressants as well because I would just have complete mood swings. I would be low and depressed or high as a kite, and kind of -- but just so fatigued all the way. That was probably worse than the hepatitis C itself really.

I was very irritable with people around me. I would get very angry and I think that has caused me some sort of brain fug. I lose my thread, I lose my track. I was very sharp and I feel that mentally that has affected me.

Q. You have also described in your statement that during the course of the treatment you suffered from memory loss.

A. Yes.

Q. You found it difficult to concentrate and you would read stuff at work and not be able to take any of it in.

A. I think I just read a sentence and I have no idea what it says in that sentence and have to start again. You know, I work in communications. So, you know, I would be proof reading document and, you know, it was so frustrating that I couldn't keep my concentration.

Q. You ended up accepting voluntary redundancy because of it?

A. Yes.

Q. What was the outcome of that treatment? Did it clear the virus?

A. So by month 12 I had cleared hepatitis C and there was no detectable virus and then in month 13 it came back, because obviously I had sort of gone six weeks without treatment and so the virus just came back.

Q. How did that make you feel, that news?

A. I was completely gutted really because of all that I had been through, you know, and I would have done anything to sort of get rid of the virus. I really would. To have been through what I have been through, it just seemed, you know, futile really.

Q. You have mentioned that in 2014 you discovered that you had developed cirrhosis of the liver and an enlarged spleen?

A. Yes.

Q. And you were becoming prone to infections and so you had a fibroscan. What did that show?

A. So the hospital obviously sort of said to me that they would monitor with regular blood tests and they had said -- they had always said to me from 1992 that my liver function test was normal, within a range for somebody who had hepatitis C.

Obviously, because of the bleeding disorder of haemophilia I couldn't have a liver biopsy, because it would cause bleeding and obviously, you know, risk of dying. So a new test became available called fibroscan, which sort of flicks the body in the side and measures the elasticity of the liver and the scan came back with a really high score of 21.4 showing that I had got cirrhosis. The consultant at the Hallamshire said to me that, you know, he was really surprised that. It didn't correlate really with my blood results and it did show that I had got cirrhosis of the liver.

They then referred me to a hepatologist in the infectious diseases team. I was very worried about the prospect of developing cancer of the liver. I discussed that with the hepatologist and he just didn't seem to have any empathy with haemophilia and he just said "Well, if you get a bit of cancer, we will just cut it out", so I said to the Haemophilia Centre, "I'll cut him out and I won't be seeing him again. Thank you", so ...

Q. You were desperate to rid yourself of the hepatitis C by this stage.

A. Yes.

Q. And there was a particular drug, Harvoni, that you wanted to take.

A. That's right.

Q. But you couldn't get that drug. Why was that?

A. Because the strain of hepatitis C I had contracted was genotype 4, which is an Egyptian strain of the virus. It seemed that the drug companies were not really investing in that because not many people contracted that strain of the virus. My partner, Lee, he had -- I didn't realise this at the time, but he had -- sorry ...

Q. It is all right, Dave. Would you like me to read that bit of the your statement for you?

A. Please.

Q. So your partner Lee, now your husband, became very concerned and he was obsessively trying to find some kind of trial that you could get on because you and he both feared that because of the fibroscan result you would develop cancer?

A. Yes.

Q. And he would stay up at night researching hepatitis C, researching possible trials and possible treatments for you?

A. That's right. He had been going into work and breaking down and he didn't tell me any of that. He was just desperate to find something, as you would be for the person that you love.

Q. You went to see a doctor in London at Bart's, Professor Graham Foster in February 2015 to discuss the possibility of a course of treatment of Harvoni. What happened?

A. So at that time he said that NHS England sort of were discussing, you know, the availability of Harvoni and whether they would fund the treatment and to come back and see him in a couple of months' time. We went back in the April and he said, "I am really sorry to say this. I thought NHS England would have got their act together by now". He basically suggested that if we had the means to pay for it, to do it. He more or less said that.

I had been given an ex gratia payment of £50,000 after the diagnosis of cirrhosis of the liver and we used £45,000 of that to fund a 12-week course of Harvoni. After that 12-week course, touch wood, I have been clear of the virus ever since.

At the time NICE were saying that for somebody with genotype 4 rather than taking 12 weeks to clear the virus. It would take 24 weeks. Therefore it would cost nearly £100,000, so it wasn't therefore clinically effective for me.

What I found really perverse was that they were funding treatment for people whose liver had already -- was already decompensated, but they had just kind of written me off really in the process.

Q. Just taking you back to the discussions you had with Professor Foster, he told you your liver was currently holding up, but without treatment there was a possibility it might degenerate to a stage where you would need a liver transplant.

A. Yes.

Q. You wanted to make it clear you are not critical of

Professor Foster at all?

A. No, not at all.

Q. Your criticism is reserved for the lack of funding?

A. Yes.

Q. Which meant you used the money which the Skipton Fund had given you because of you being infected?

A. You know, I would have -- like I said before, I would have done anything to clear myself of the virus. I had always kept very private about having contracted hepatitis C, but I really felt that point I was fighting for my life.

Q. So you spent the £45,000 from the Skipton Fund on the 12 weeks of treatment?

A. Yes.

Q. Were there any side effects during the course of that treatment?

A. To begin with it made me a little bit drowsy, so I just learned to take it just before bedtime. I kind of got a better night's sleep but compared to interferon and ribavirin it was a walk in the park.

Q. And the treatment was successful in clearing the virus?

A. Yes.

Q. You have had a fibroscan the following year. What did that show?

A. That showed a score of 11.4 I think it was that, you know, my liver had become much more elastic again and kind of showed signs of improvement.

Q. You put it this way in your statement, your liver was still cirrhotic but there had been a dramatic improvement.

A. Yes.

Q. Since then you have continued to have regular liver function tests?

A. Yes, yes, and I still have -- Professor Foster, when he kind of discharged me from his care said to have quarterly ultrasound scans just to check for any lesions or cancer of the liver.

Q. Now, one of the observations you have made in your witness statement is that you think it should be a matter of priority for the NHS that treatment is funded for those who were infected through the NHS?

A. Absolutely, yes.

Q. Can I just ask you about a couple of trials you have been involved with?

First of all, if we go back to document 1244004, please, Paul.

We looked at this letter earlier. If we go to the second page, in the penultimate paragraph it says:

"There are a number of trials being undertaken

in individuals with severe haemophilia and inhibitors", and you might well be eligible for one of those.

Was that a trial you participated in?

A. Yes. So I took part in the trial of Emicizumab. It is a recombinant product, that rather than it being an intravenous injection, it is an injection into my stomach once a week that gives me a low level of background clotting factor.

Q. That's a treatment you participated in a trial that relates to your haemophilia.

A. Yes.

Q. Then you participated in another trial. You said in your statement you have been told you were exposed to HIV but didn't contract it. Is that right?

A. That I think is the implication of the trial, yes, that -- for people with inhibitors who had been -- it seems had been exposed to HIV but not gone on to contract it.

Q. If we just have up on the screen 1244006, we have got a collection of documents that relate to this trial.

If we just go to page 4, please, Paul, it should be a letter of 20 November 2009. Thank you.

So this is an invitation you received, Dave, from Sheffield Teaching Hospitals enclosing information about a research study which might be of interest to you. It is headed:

"Genetic basis of resistance to HIV in haemophilia A."

Do you know how it was you were identified as a possible candidate for this?

A. No, I don't know how I have been identified other than, you know, somebody somewhere thought that I had been exposed to HIV through contaminated blood products.

Q. If we go back to the first couple of pages of this set of documents, please, Paul, we can see that in relation to this trial you were asked to confirm your understanding about the information you were given. You were given a detailed patient information leaflet that you have given to us.

A. Yes.

Q. The ramifications and implications of the trial were explained to you.

A. Yes.

Q. And recorded in writing.

A. Yes.

Q. Can I ask you then, Dave, about the stigma generally that you have felt or experienced in relation to the hepatitis C infection. You have described what

happened with the treatment in 2014.

Have you kept your infection private generally or have you shared the information with others?

A. I did, so obviously when we learned that I have been infected with hepatitis C in 1992, I kept it completely private even sort of from best friends and so on. I just really felt the stigma. You know, I had seen how people with HIV were treated and, I mean, even during my sort of working career -- I worked for the Disability Rights Commission and I worked for the Equality and Human Rights Commission and it still didn't feel at work that I could tell people.

It was more the people I worked with I thought might treat me differently if they knew that. For example, when I was undergoing the treatment, you know, I didn't make it clear what exactly I was going for. They just knew it was related to my haemophilia and I left it at that.

Q. And you said in your statement that you had horrible experiences when treated by medical professionals. You would have nurses always putting on gloves and being particularly cautious around you. Then there was an incident where a doctor stuck himself with a needle. What happened?

A. I think it was a female doctor. It was a junior doctor. I was in hospital with an active bleed and I think she had been taking some blood from me or giving me clotting factor, one or the other. She didn't have gloves on, I don't think. She stuck herself with the needle, the butterfly needle, as she was taking it out, and I didn't really think any more of it, went to sleep and I was woken during the night, actually taken out of bed, taken to a side room and asked about what sexual partners I had had, was there a possibility I had HIV.

They knew I had hepatitis C and how I had contracted that, but had I -- you know, they asked about sexual partners and so on. It was just humiliating, yes.

Q. And you have also described how whenever you have had blood tests you see a label on your file that says "Category C risk".

A. Yes.

Q. In terms of friends and family who you have shared this with, your husband, your close family, what has the impact been on them?

A. I mean, I felt guilty for keeping the secret from them for so long and I only went public about it when for me it became life-threatening, so when I got the

diagnosis of cirrhosis I felt, "I have nothing to lose really. I need to be open and honest about it". I feel guilty about it because I know a lot of people have campaigned on the issue.

In terms of impact on others, you know, my parents -- having haemophilia is difficult enough, but thinking I had then got an infection on top of that I think there's a burden of guilt for my parents.

You know, I have already spoken about my partner and kind of it's only come out after the fact that he was -- he was getting no sleep really. He was staying up, researching every clinical trial and so on and, you know, he has a really professional job. It must have impacted on him, and for him going into his work place and kind of breaking down, I feel guilty about that as well. There is a lot of guilt really for me.

I just think it's really difficult all round, but people have been very sort of understanding really and friends and family because I have got fantastic friends and family.

Q. Have you ever been offered any counselling or psychological support?

A. No.

Q. Do you think it would have been helpful?

A. Yes, I think it would. I mean, the whole thing has been so traumatic, yes, I think it would help.

Q. Have there been impacts in terms of your ability to obtain insurance?

A. Yes. So trying to get travel insurance or life insurance is, you know -- well, it's sort of impossible to get life insurance. Travel insurance is just prohibitively expensive, you know. I thought once I had cleared the virus, that would make a difference, but the series of questions that underwriters seem to ask, you know, first of all, you say you have got haemophilia. Then I think it asks about any joint replacements. There is a path and it asks about, you know, have you ever kind of contracted hepatitis C. So, of course, you must answer honestly and yes, I have. Have you cleared the virus? Yes. Have you had oesophageal varices? No. And some insurers just decline you completely, you know. You only get so far and that's it. It's declined, so ...

Q. In terms of other financial impacts, you took voluntary redundancy during that first course of treatment for the reasons you have described. Did your infection or the treatment and the symptoms you experienced impact upon the development of your career?

A. Yes. I think I would have gone on to progress my

career within probably the Civil Service and, you know, somebody who was one of my trainees is now an assistant director of communications and policy at a local authority. Hopefully I would have achieved that level, but I was just kind of so tired and, you know, just -- at one point I was really sort of sharp and I had to be. I worked in public relations. I was dealing with journalists. I had to be ready for questions and kind of -- yes, I'd just kind of lose my thread.

The concentration aspect, like I say, of just proof reading and reading the same paragraph over and over until I have actually taken it in, I am sure is an impact of either hepatitis C or the interferon treatment.

Q. You have told us obviously how, again, in terms of financial impact, you spent the money from the Skipton Fund on funding the treatment that you couldn't get funded by the NHS. In terms of applications to the Caxton Fund you have said in your statement that that had implications in terms of life decisions you were making, because they would take into account partner's income?

A. Yes. So we sort of delayed moving in together and I think because my partner has a decent career and so

on, I think it is unfair that he is kind of expected to pick up the bill. When we looked at total household income, you know, why should he have to foot, you know, that bill really.

Q. So Dave, those are the questions I have for you. Is there anything you'd like to add?

A. Just going back to the point about treatment, I think if ever there was a cure for HIV, just as with hepatitis C, I do think that those of us who contracted contaminated blood through contaminated blood products should be put to the front of the queue and I wouldn't want anybody to go through what I have gone through in terms of, you know, having to fight to get the treatment. I just think that's disgusting, so ...

MS RICHARDS: Dave, I am just going to ask Mr Snowden, who represents you, if there are any other further questions he would like to add. No, there aren't. Thank you.

SIR BRIAN LANGSTAFF: I have no further questions. Just let me thank you very much for coming and coming at such short notice to give the evidence which you have to us. So thank you, Dave.

A. Thank you.

SIR BRIAN LANGSTAFF: Well, we will take a break now until

2 o'clock. So 2 o'clock for our third and I think final witness of the day.

MS RICHARDS: Yes, sir.

(12.43 pm)

(Luncheon adjournment)

(2.01 pm)

SIR BRIAN LANGSTAFF: Our witness wishes to be known as ...?

MS FRASER BUTLIN: Darren.

SIR BRIAN LANGSTAFF: Darren.

DARREN RAWSON, affirmed

Questioned by MS FRASER BUTLIN

Q. Darren, you were infected with hepatitis C in 1988 when you were 5. Can you tell us what happened.

A. Yes. I had a ...

Q. Tonsillectomy?

A. ... tonsillectomy, and they left a tag on the adenoid and then obviously they took me home, my parents, and I haemorrhaged on the moving day, 1988.

Q. So your family were just about to move house?

A. That's right.

Q. You had had the tonsillectomy. Got home. Two days later you say you started to froth at the mouth.

A. Froth at the mouth, yes.

Q. What happened next?

A. I was rushed to the hospital and then obviously I was given a blood transfusion. I was rushed on to the -- into theatre and that's when they gave me the blood.
Q. So you were taken back to hospital for a further operation to sort it out and during that operation you were given a transfusion?
A. That's right, yes.
Q. You think it was about two pints of blood?
A. About two pints.
Q. Before the operation was your mum, as far as you are aware, was your mum told about any risks associated with having a transfusion?
A. No, she weren't, no.
Q. In 2004 you started to have severe nosebleeds. Can you describe what happened?
A. Yes. I was walking home from the town centre and my nose just burst. I lost quite a bit of blood. This was going on for about a week or so and I just went for a check up at my GP and, at this point, I had found out then that I had hepatitis C.
Q. So you had one huge nosebleed and then a few days later another huge nosebleed and it went on for about a week.
A. Yes.
Q. You went to your GP and he did a series of blood

tests?
A. That's right, yes.
Q. When you were told by your GP that you had hepatitis C, can you remember anything else you were told? What did the GP tell you about hepatitis C?
A. Nothing. He was just going to refer me to a specialist and that was the last I heard from him really.
Q. Were you told anything at that point about the risks of transmitting hepatitis C?
A. No.
Q. You were referred to a specialist and seen about six months later. What can you tell us about that first appointment?
A. Well, they just said basically that I got the hepatitis C. They'd do a bit of monitoring and that was really it really. That's the last I heard until probably about a year later.
Q. At that first appointment you said in your statement that the doctor asked you a series of questions that made you really quite angry. Can you tell us about those.
A. Say that again, sorry.
Q. At that first appointment in your statement you have said the doctor asked you a series of questions that

made you really quite angry. Can you tell us about those.
A. Yes. Basically, he asked me how I could have got this. He asked if I was using drugs. Obviously I wasn't. I never touched drugs in my life other than prescribed and that's how it come to light and I got a bit angry at that.
Q. The doctor asked if you were a drug user and you responded by showing her your arms and saying, "No, absolutely not"?
A. That's right.
Q. You were asked whether you had a sexual partner. There was a series of questions about tattoos as well?
A. That's right, yes.
Q. At that stage did you understand that you might have been infected through a transfusion?
A. I didn't have a clue. It was later on that I found out in the local newspaper by a local chap and, obviously, my mum said, basically, "Well, you had a transfusion in '88", and this is where it all come to light.
Q. Because we have looked at your -- at the medical notes of that first appointment and there is a note that says "blood transfusion" with a star next to it but, as far as you were concerned, that wasn't discussed

with you?
A. That wasn't discussed, no.
Q. At that appointment what were you told about hepatitis C? Were you told anything?
A. Not a thing, no.
Q. Again, we have looked at the note of the appointment and it does refer to telling you about how hepatitis C is transmitted, but you are clear you weren't told that?
A. That's right, yes.
Q. Why are you so clear about that in your mind?
A. Just -- because I just know it weren't true, what they said.
Q. You said that you had to go away and look it up.
A. Yes, I had to go away and look it up myself to find out how you could catch it and stuff and what impact it would have.
Q. Can you tell us what the effect on you was of that appointment, on your mental health?
A. Yes. I just -- I tried ending my life.
Q. That was a little bit later on in the time, wasn't it? That was 2011, but the very first time when you had that appointment I think you said your head just blew?
A. Yes. My head just blew. I felt dirty. I was getting in the bath every hour or so and I felt disgusted in

myself.

Q. Because at that stage you didn't understand how you'd come to be infected?

A. That's right, yes.

Q. And you've described that as the time when your depression started to set in.

A. When it started setting in, yes.

Q. You had a couple of further appointments with specialists at the hospital, but then you didn't attend appointments until about 2011.

Can you recall what was happening for you in terms of your mental health during that time?

A. I just couldn't face up to knowing it and I just wanted to get it all clear out of my mind that I never had hepatitis and I just didn't feel right going to the hospital and finding if there was anything else the matter with me and that's it.

Q. If we can have document 1963008, please, this is a letter from the specialist actually in 2011, but if we look at the very first few sentences of the letter, we can see that it says:

"This gentleman came to the clinic today together with his mother and his girlfriend. He was first tested positive for hepatitis C back in 2005. However due to his anxiety and other problems he

didn't turn up for any further follow ups and has now been re-referred as he now feels more able to face his diagnosis."

Is that what was going on?

A. Yes.

Q. Periodically from 2005 through to 2011 you were drinking very heavily?

A. I weren't drinking heavily. It were just not as much as --

Q. More than recommended?

A. More than recommended, yes. I just had to try to get it out of my mind and that, you know.

Q. If we can keep the letter up, Paul, we can see on the letter there is reference in the middle of that first paragraph to you drinking 310 units of alcohol a week. In fact, you think that's a typographical error and it was about 31 units of alcohol a week.

A. Yes.

Q. By 2011 you had cut it down to 12 units a week?

A. Yes.

Q. You have said -- you referred to it just a moment ago -- in 2009/2010 your mum read an article in the paper?

A. That's right.

Q. What did she tell you about that or from that article?

A. Obviously, they knew about the hepatitis C and it started to spring to the mind that this is where the hepatitis could have come from. So we sat down, had a chat and started looking into it a little bit more and that's obviously where it's all come out that it was from the blood transfusion.

Q. How did that realisation make you feel?

A. I was angry. I was really angry about it, because obviously what they had put into me.

Q. You referred earlier to an attempted suicide?

A. Mm-hm.

Q. In 2011. That you have said was really the lowest time for you?

A. Yes.

Q. Can you tell us a little bit about that time in your life?

A. Yes. Everything just got on top of me and I just thought it was time for me to go. I got a bottle, a small bottle of vodka, drunk it and tried hanging myself.

Q. You were rescued by a neighbour who heard a thud.

A. Yes, that's right, yeah, because I was living in a flat at the time and she heard the thud. Luckily my door was open and she come in and she rung the police and ambulance.

Q. And you were admitted --

A. And I was admitted to the hospital.

Q. To the hospital. But you have also said that that moment was something of a wake-up call for you and you realised that you needed to deal with the hepatitis C.

A. That's right, yes.

Q. And that's why we saw that letter a moment ago from 2011 where you had been re-referred --

A. Yes.

Q. -- for treatment.

So in 2011 you then underwent some tests to see what state your liver was in and 2012 you were offered some treatment?

A. That's right, yes.

Q. You didn't have the treatment at that stage?

A. No, because --

Q. Can you tell us why not?

A. I had a child on the way, so I delayed the treatment and that's the reason why I delayed it, because obviously there was too much going on. I didn't want to be poorly, you know, when the baby come out. I didn't want to be poorly.

Q. 2013, your second child --

A. Second child.

Q. -- was arriving. So again you didn't feel able to undergo treatment then?

A. That's right.

Q. Then there was a further short delay while you waited for Harvoni treatment to become available --

A. Yes.

Q. -- instead of having to have the interferon.

A. That's right, yes.

Q. So you had Harvoni treatment in 2016 and you cleared the virus?

A. Cleared the virus, yes.

Q. Can you tell us a little bit about what the side effects were when you underwent the Harvoni treatment.

A. There was no real side effects to it, to be honest. It is more after where my health has sort of like deteriorated a bit.

Q. Can you tell us about that. What are the ongoing difficulties that you're facing?

A. I have had pneumonia. Just my mental health has got a little bit worse, not as much, but it's creeping back up. I feel more tired. My memory seems to be going quite a bit to what it was before.

Q. You have described in your statement of having extreme tiredness, deep fatigue. Your sleep pattern is totally unpredictable and you are tired most of the

time. You had pains in your joints, itchiness and you feel like your immune system is weakened, because you constantly get coughs and colds --

A. Coughs and colds.

Q. -- and pneumonia.

A. Yes.

Q. You have also said you suffer from brain fog?

A. Brain fog, yes.

Q. In terms of your mental health, what that has been like since you had the treatment?

A. It's been on and off. I can have my good days, I can have my bad days. It is unpredicted. Going back a couple of weeks ago, I just went on a downer. I wanted to drive my car off a cliff.

Q. And you found it very difficult as well to interact with the health service, with any doctors?

A. Yes.

Q. Can you tell us why that is.

A. Because they just don't seem to give me the support that I need. My doctors took me off all my medication because obviously he said he don't want to affect my liver, didn't want to give it any more damage, so now I'm just seeing a mental health nurse.

Q. So you've been taken off your anti-depressants because of concerns about the liver but for you you said to me

earlier that that was causing -- obviously causing difficulties with your depression?

A. That's right, yes.

Q. You have also said in your statement you were angry at the system, that the public health system you had been brought up to respect, had let you down?

A. Yes.

Q. You said in your statement:

"I have trusted that the system, including the medical professionals, would take care of me for years. My mum did too. That trust has gone and I have been left feeling totally vulnerable as a person and completely let down. I feel particularly vulnerable, because I now have to seek help from the system that has hurt me so badly. I simply can't trust it now."

A. That's right.

Q. You struggled to receive counselling and psychological therapy during this time. Can you tell us what provision has been given to you.

A. Obviously, I have had my tablets, depression tablets, I have seen a hypnotist, hypnotherapist.

Q. You did that privately.

A. Privately, yes, yes.

Q. But in terms of NHS provision what counselling and

psychological support have you been given?

A. They just referred me to a Let's Talk service, which I had a few sessions with them, and it just weren't right for me really.

Q. You had just three sessions.

A. Three sessions, yes.

Q. With a counsellor.

A. I just didn't seem to be getting anywhere.

Q. Now you are being seen by a mental health nurse, but that's relatively recent.

A. That's right, Yes.

Q. So until very recently all you had had was three sessions of counselling.

A. Yes.

Q. In terms of the on going monitoring of your liver, have you had a fibroscan since you cleared the virus?

A. No.

Q. You have said you feel you should be monitored more regularly?

A. More regularly, yes.

Q. What do you feel should be done?

A. I think they should just keep -- you know, just keep a regular check on me. It seems to be every year that I'm having these checks and I think it should be more like every six months. I think a year is far too much. You don't know what's going to happen in that year. Could get worse, you know.

Q. Each year since you have cleared your virus you have just gone to your GP for some blood tests, not for a fibroscan?

A. Not for a fibroscan, no.

Q. That's something you have had to initiate, you have had to sort out?

A. I have had to sort out, yes.

Q. What you feel is you should be monitored by the hospital every six months?

A. That's right, yes.

Q. Until about 2016 you didn't tell anyone about your infection. Why was that?

A. I just felt dirty. My wife knew. My parents, but like my friends and stuff, they didn't know.

Q. You were worried about what would happen on social media as well, I think.

A. Yes, that's right, yes.

Q. Can you tell us what you were worried about.

A. Just about all the backlash and, you know, probably losing friends, but since I have come out with it, it's been fine, especially meeting people in like the groups, you guys that are here today. It's been -- you know, it's helped me a lot actually but, yes,

I just didn't want to -- just kept it secret.

Q. You said in your statement you were worried about being trolled on Facebook?

A. Yes.

Q. Or being bullied or harassed about it?

A. That's right.

Q. You are now married with children. What was the impact of your infection on them, on your children?

A. They are fine. *[Redacted]*. *[Redacted]*.

Q. In terms of your relationship with your partner and your children.

A. Yes, they are all fine. *[Redacted]*.

Q. You have said that it was hard for you to be a partner and father that you wanted to be. Can you tell us a little bit about that.

A. Yes, because obviously it is like I can't really do much with my children, because I just get too tired. My motivation, I have got just no motivation. I want to do more with my children, but it just doesn't happen.

Q. You said that your mum and grandparents have worried about you a lot and that's caused difficulties in your relationship with them as well?

A. Yes.

Q. In 2015 you wrote to the hospital trust raising

concerns about the original transfusion?

A. That's right.

Q. Could we have document 1963006, please. This is the response you received, and if we can look at paragraphs 3 and 4, there was a -- the Chief Executive was asked to convey to you the following information from your treating consultant:

"Transmission of viruses via blood transfusion was a worldwide problem until the mid 1980s when it was known as non-A non-B hepatitis. Hepatitis C was not identified until 1989. In England and Wales blood began to be heat treated to destroy any viruses during 1985 and slightly later than this in Scotland.

"According to our records you were given blood in 1988 and this was done in the belief that the blood from the Transfusion Service was safe and heat treated. We have formally requested if the blood transfusion service could trace the blood given to you but they do not keep records this far back. As our investigations stand we acknowledge that it may have been the blood transfusion that caused your hepatitis C infection and if this is the case we sincerely apologise. However, we are unable to confirm this."

Q. How did you feel when you received this letter?

A. I was angry, especially, like with, the Blood

Transfusion Service. How come they can't trace it? There's got to be something there and it -- yeah, I was just angry.

Q. Because you have the blood numbers.

A. I've got the blood numbers, yes. So why can't it be traced. This is what I need to know. It's ridiculous.

Q. Because you are clear that there's no other risk factors. There's no other way in your mind that you could have contracted the hepatitis C.

A. That's right.

Q. But you would like more definitive confirmation that it was the transfusion?

A. Yes.

Q. You have received some financial assistance from the Skipton Fund and from Caxton and, more recently, you applied for special category mechanism payments because of your mental health condition. That was refused. Can you tell us why?

A. They didn't have enough evidence.

Q. Of what?

A. On the forms that my specialist put in.

Q. So your specialist had filled in the forms for you and put in information about your mental health condition?

A. That's right, yes.

Q. But the form was rejected because -- and you appealed. So it was there was not enough evidence that on the balance of probabilities your mental health condition was caused by the hepatitis C?

A. Yes.

Q. And that's why they rejected it?

A. And that's why they rejected it.

Q. When that was rejected, you had a phone conversation with them?

A. That's right.

Q. What did they say to you?

A. They told me to apply for the stage 2 application.

Q. So they had rejected the special category mechanism.

A. Yes.

Q. But on the phone they said you should be applying for stage 2?

A. Yes.

Q. They sent you the application form.

A. Sent me the application form. Sent it off to my specialist. She filled it out and it took about a month to get it back from the specialist. Sent it off to -- and they rejected it.

Q. Do you know why they rejected it?

A. They didn't say.

Q. And you have now applied again for the special

category payment?

A. Yes.

Q. Again, on the basis of your mental health condition?

A. That is with my specialist at the minute.

Q. You are just waiting to send it off again?

A. Yes.

Q. How have you found the process of dealing with EIBSS through this?

A. A nightmare.

Q. Can you tell us a bit more about why?

A. Yes. They just seem to be wanting too much, because it is always -- every time you apply for things off them, it is always "go see your GP" or "go see your specialist".

Now when you go see them, it could take months to get a letter off them or any form of anything. It is just like a waiting game. It is just ...

Q. You said to me earlier that you had found it very difficult to understand what was required of you as well?

A. That's right, yes. Because every time -- obviously, when you fill these forms out, it always says "Is this caused by your hepatitis?", you know, and then obviously when you send it into your specialist, they are going, "Oh, well, we don't know". It's -- so it's

just like a fighting battle with them and I don't think it's right.

Q. Because you are clear that your mental health difficulties started with the diagnosis of hepatitis C but the clinicians can't say for sure what caused your depression?

A. That's right, yes.

Q. Those are all the questions I have for you. Is there anything you want to add?

A. No. I think that's it.

Q. I am just going to talk to Ms Gibbs, who, as you know, represents you, to see if she has any points she wants me to raise.

Just two points that Ms Gibbs would like me to raise with you. Can you tell us how the infection has impacted on your education and work?

A. Yes. Obviously I haven't worked for a long time. The first job was being a Red Coat at Butlins and I was only there six months.

Q. What made you stop work there?

A. I just couldn't cope. I was too -- I was too distressed, but I was just more tired than anything, because obviously it was long hours, but this was before I found out like I had the hepatitis C. This was 2002. Obviously, I didn't know nothing about

that, that I had the hepatitis C then, so that's ...

Q. Because of that lack of regular income you have struggled to have any form of credit scoring and mortgages and things?

A. That's right, yes.

Q. Secondly, even though you have now cleared the virus, what fears do you still have for your family and your children?

A. I think it's -- it is like if I have a bleed or anything, I still think I've got it to be honest and it is just -- I don't like to be too close near them when things like that happen. That's my biggest fear, you know, still having to -- yes. That's my biggest fear.

Q. You are still fearful that you will infect them?

A. Yes.

Q. Because you're worried that although it's cleared --

A. It's cleared.

Q. -- it hasn't gone away?

A. Yes.

Q. I think you said earlier to Ms Gibbs that you were scared of even kissing and cuddling your children?

A. That's right, yes.

MS FRASER BUTLIN: Sir, do you have any further questions?

SIR BRIAN LANGSTAFF: Yes, I do. You said in your evidence that you'd lost trust in the system, including medical professionals.

What in particular do you think they did that caused you to lose trust?

A. Obviously, they never told me that about the blood transfusion. It is just that it's been going on and they've sort of like lied about it sort of type thing and that's -- when they put that blood into me, never told me, that's my trust just ... it's -- I just -- I don't know.

SIR BRIAN LANGSTAFF: Thank you very much. Well, thank you, Darren, for telling us your story. It can't have been easy for you, so thank you very much for coming and doing that.

A. Not a problem. Thank you.

SIR BRIAN LANGSTAFF: Now, Ms Fraser Butlin, that's the last witness, I think, for today.

MS FRASER BUTLIN: It is, sir.

SIR BRIAN LANGSTAFF: Who do we have tomorrow?

MS FRASER BUTLIN: Tomorrow we'll be hearing from Lesley McEvoy, Leroy Scarlett, and Sean and Eleanor Nevin.

MS RICHARDS: Tomorrow we start at 10.30. 10.30 tomorrow.

(2.31 pm)

(Adjourned until 10.30 am the following day)

INDEX