Tuesday, 15th October 2019

(10.14 am)

SIR BRIAN LANGSTAFF: I am very sorry, particularly to Liz, our first witness of the week, that you have been kept waiting this morning and that the glitches weren't discovered earlier than they were, but we are now in a position, aren't we, to begin? May we have Liz, please?

ELIZABETH GAIL HOOPER (sworn)

Questioned by MS FRASER BUTLIN

MS FRASER BUTLIN: Liz, you have lost two husbands, both of whom received infected blood and contracted viruses from that blood and blood products.

A. Yes, that's right.

Q. You have described Jeremy as your first love.

A. Yes, he was.

Q. And Paul as your soulmate.

A. That's right.

Q. And you have a provided two pictures of them, which we'll have on the screen during your evidence.

A. Okay.

Q. You've said that Jeremy was loud, gregarious and larger than life.

A. Yes, he was. He was -- you always knew he was in a room. If you were in a party, you always knew that

Jeremy was there. He was always in the middle of everything, laughing and joking, proper charmer, he was, proper charmer, proper wide boy. Phil Mitchell. Think of Phil Mitchell. That's how he was, with his bald head and he used to wear his big leather jacket. He was a proper wide boy. He was from London and he always knew somebody who could do whatever you wanted, you know, whatever you needed.

Q. Jeremy had severe haemophilia B.

A. Yes.

Q. But he was not diagnosed until he was nine years old.

A. That's right, yes.

Q. He was treated in the Oxford Haemophilia Centre.

A. Yes.

Q. Under Dr Matthews and Dr Rizza.

A. Yes.

Q. In fact, his family moved house when he was 13 so that he would be closer to that centre.

A. That's right, yes.

Q. When Jeremy was given number Factor IX concentrate, was he or his parents ever warned about any risk of being exposed to any infection?

A. No.

Q. Jeremy joined your school when you were in your third year of secondary.

A. That's right.

Q. And you were warned that he was joining.

A. Yes, we were. The headmaster had all of the third year in and basically told us that we had got this boy coming who had got special problems with his blood and we weren't allowed to fight him, because he would bleed and he wouldn't clot. So we'd all got to be very careful of this new lad that was going to be joining us.

As it turned out, Jeremy was the one that started all the fights, Jeremy was the one that was always in the middle of any problems and he was the one that was always there instigating the trouble. He was a proper little terror.

Q. You stayed on in school after your O levels.

A. Yes.

Q. Whereas Jeremy didn't.

A. Yes. He left as soon as possible.

Q. And then you met again when you were 16.

A. Yes. Well, I was 15, just coming up to my 16th birthday, and we had an end-of-year party and Jeremy gatecrashed. I hadn't seen him for 12 months or more. I had seen him round the village, because he lived in the same village as us, as me, but I'd seen him round the village, but not really, you know, very much, and

then he walked into the party and it was just like something out of a love story. Our eyes met across the drunken teenagers and it was love at first sight. We were together from that moment on. We were -- we just didn't part. It was just incredible. He had gone from being this little fat, rotund kid with a pudding bowl haircut to this tall, lanky 16-year-old, and he'd got black jeans on and pointed boots on and he'd got a vintage German infantryman jacket on. Oh, he did look gorgeous. And he gave me his cigarettes at the end of the night and I kept them for weeks and week and weeks.

Q. You were together for five years and then you got married.

A. Yes.

Q. And had your son in 1993 --

A. That's right.

Q. -- who sits next to you.

A. Yes.

Q. Jeremy had worked his way up in a builder's merchants.

A. Yes, that's right.

Q. And ultimately became the sales and marketing director.

A. That's right, yes.

Q. You have described having a big house, nice cars, lots of friends.

A. Yes. We were the epitome of an executive family. Jeremy earned a good wage. We had a nice house. We went on foreign holidays to America and, you know, Egypt and all sorts of places. I had a new car. Jeremy drove a Mercedes. You know, we were living the dream.

Q. You have said Lewis's arrival was the icing on the cake.

A. It was the icing on the cake. It was unplanned. We weren't sort of -- well, I had been on the pill and had to come off the pill, and God decided that that was the time to strike. So after a couple of bottles of wine, the following day I said, "I am not going to have a baby, I don't want a baby", but it was too late; I was already pregnant with my beautiful son.

Q. Just tracking back a little bit, when there were reports on the television about blood being infected, what was Jeremy's attitude towards that?

A. Initially we neither of us really paid that much attention. Jeremy was very much a person that kept the haemophilia side of him and the Haemophilia Society and everything, kept it very much to one side. It didn't interfere with our family life. We didn't really discuss it, it was just something that we lived

with.

So when they started putting up the horrible gravestone tumbling adverts, initially it was -- we didn't really think much about it, but then I think it was playing -- started to play on Jeremy's mind, you know, obviously, he was a haemophiliac. So he questioned his consultant with regards to whether he could or would get HIV through this factor.

Q. From where you lived and your memory of the house, you think that was in about 1987?

A. Yes, yes. We were living in a house in Waterloo Close, because I remember that when Jeremy did ask Dr Matthews on just a routine -- he went up for his routine 12-monthly check and he just asked Dr Matthews, and I just remember him telling me in the living room of that particular house.

Q. What did Dr Matthews tell Jeremy about HIV?

A. He told him that he wasn't to worry, that because he had haemophilia B the Factor IX had to go through an extra heat treatment, which killed the -- as far as they were aware killed the HIV virus off, because they hadn't had any known cases of a haemophilia B contracting HIV.

Q. At that appointment in 1987, was Jeremy told anything about non-A, non-B hepatitis?

A. No.

Q. Was any form of hepatitis discussed that appointment?

A. No.

Q. Was Jeremy given any advice at all about any risks of transmission of viruses generally?

A. No.

Q. Lewis arrived in 1993.

A. Yes.

Q. In 1995 or 1996, Jeremy received a call from Dr Matthews asking him to go in for an appointment and to take you along.

A. That's right.

Q. What happened at that appointment?

A. He was quite mysterious about it because he wouldn't tell -- well, it was his secretary who actually phoned, and she wouldn't tell us what it was about. She probably didn't know, truth be told. So off we traipsed up to Oxford, after getting Lewis into -- mum would have looked after Lewis whilst we were up there.

We went into Dr Matthews's office and he sat us down and he explained that Jeremy had got hepatitis C, and that it would attack his liver and that he could have passed it on to me and, via me, to Lewis. Jeremy asked him, you know, how long he had had it. "Is this something new? Have I only just got it? What's

happened? How has this come about?" Dr Matthews said he had had it for about ten years and they had been monitoring how things were developing in the system, and they felt that his liver was showing signs of -- it wasn't working quite so well, which had prompted them to have to explain to him why. But he also said to Jeremy that one of the other reasons that they couldn't tell him or wouldn't tell him before is because they didn't know what to call it, and that they knew it as non-A, non-B for a number of years, and before they were able to -- they felt able to tell people that they'd got this non-A, non-B hepatitis, they had to have a proper name for it, to which, I mean, Jeremy just erupted. His language was foul and he said that he wanted to know how many hundreds of thousands of pounds it had taken the committee that decided to call it hepatitis C had got, because you didn't need to be Einstein to think, "We have got hepatitis A, we have got hepatitis B; oh, I know, let's call it hepatitis C".

So, yes, that's...

Q. Dr Matthews said Jeremy had had it for approximately ten years, which would put it back to about 1985 or 1986.

A. Yes.

Q. Before the discussion about HIV.

A. Yes.

Q. Jeremy also asked about the risk of passing the virus on and Dr Matthews said that was why you had been asked to come in as well.

A. Yes. He explained that there was a possibility that I could have got it through seminal fluid or, you know, if I used his toothbrush, all that sort of stuff. So it was easier for me, because if I had it, Lewis would have it. So it was easier for me to be tested, and if I didn't have it, then Lewis wouldn't have it.

Q. And Jeremy was absolutely furious?

A. Yes. He was just -- he was beyond anger. I mean, he was just beyond anger. Jeremy was a big, big man. He was about 6 foot and he weighed 17/18 stone, a proper rugby player type, real big man, and you didn't want to stand in front of him when he got angry, and Dr Matthews was quite a petite man in comparison and I think he was a little bit scared, and I think he was a little bit glad when Jeremy just got up and said, "Come on, we're going home", and he just walked out rather than punch his lights out, I think.

Q. And Jeremy was particularly angry because the centre had known you were pregnant.

A. They had known I was pregnant, they had known I had

had a child, and yet they had not told us that he had got this disease that potentially he could have given to me and therefore to his son. He couldn't and wouldn't forgive them for that.

Q. And you were in shock and feeling terribly confused about what you had heard as well.

A. Yes. I mean, I was quite -- because I had always sort of been in Jeremy's shadow a little bit, and, you know, he was very much the man of the house and he -- I just was the little woman in the kitchen doing the stuff, I hate to say it. I am not like that now.

So, yes, I was very confused and didn't really understand what was going on, but we got home, talked about it on the way home, and, once Jeremy had calmed down, made an appointment for me to go back to the Haemophilia Centre to be tested. It was literally only two or three days after, and that came back negative.

Q. Jeremy waited to have treatment for the hepatitis C until Lewis was about 11.

A. Yes.

Q. When he did undergo treatment, what were the side effects that he had?

A. Oh, he had the interferon and Ribavirin treatment. They advised him that he was -- I think one of the

reasons that he did it was because they had advised him he was going to be trialing this new drug, that he was going to be helping his fellow haemophiliacs that had got hepatitis C and others that had hepatitis C. I think that's what drove him to kind of think "Yes, I am going to be heroic here and do something fab". So he agreed to go onto this trial, six months, and it was six months of absolute hell, hell.

He stopped communicating. He would only communicate in grunts and snarls. He shouted an awful lot. He spent a lot of time in his office playing on whatever computer game he'd got going at the time, and he would spend hours in there just keeping away from us.

He wouldn't speak to Lewis. Lewis could do nothing -- I mean, Lewis would be downstairs or in his bedroom, playing in his bedroom, and he would come out of his bedroom and scream, "For God's sake, shut up" at his son, and Lewis wasn't doing anything, you know, he wasn't being particularly noisy. But he got really, really aggressive. It was the closest that Jeremy and I got to having a divorce, because he wouldn't eat with us, he used to take his meals upstairs and eat on his own; he couldn't sleep, so he was awake all night, he was taking drugs to try to

make him sleep; he was taking -- he had a horrendous headache and the Oxford Haemophilia Centre told him to take paracetamol. You know, "Just take paracetamol, you can't take anything else, but just take paracetamol". And one day Jeremy was sat reading the leaflet out of one of the boxes of tablets he was taking, and it clearly said on the thing, "Do not take paracetamol with this drug". Yet he had been taking them for five or six weeks. It didn't get rid of the headache, but he was still -- Oxford had told him to take them.

Oh, it was a nightmare. It was a nightmare.

Q. You said after that Jeremy was never really himself again.

A. No, he did change. It did change him. He became very short-tempered. He didn't have a lot of patience. He was tired all the time. He just -- no, he was a shadow of his former self.

Q. And at the end of the treatment he was told he hadn't cleared the virus.

A. He hadn't.

Q. What was Jeremy's reaction to that?

A. He was -- I mean, he was angry that it hadn't worked, sad that he had been through all of this and it hadn't -- you know, he had still got this disease. He was apologetic to us, because he had put us through such an awful thing for no reason and, yes, he became very depressed, very withdrawn.

Q. Jeremy began to get stomach pains, but nothing was found on an endoscopy. Then, on 7th December 2008, you were at work and a colleague interrupted a meeting that you were in --

A. Yes.

Q. -- to say that Jeremy was trying to get hold of you.

A. Yes, that's right. I went -- I didn't have my phone. It was in my handbag. So I went back to my desk and picked my phone up, and there was a voicemail message on my phone to say "Liz, please come home, you have to come home". So I basically just picked up my bag and went.

When I got home, I went up -- I shouted to him and he didn't answer me. So I went upstairs and first of all went into his office, because I assumed that's where he would be. He wasn't there. So I went along the landing into our bedroom and Jeremy was lying on our bed in a semicomatose state. He was able to say he had been vomiting blood.

So I went into the bathroom -- I don't know why I went into the bathroom, it's just one of those stupid things, you know, go and have a look and see

what's in the bathroom, I don't know why. But I went into the bathroom and it was just -- oh, God, it was like the Texas Chainsaw Massacre. I have never seen anything like it. Blood everywhere.

I had phoned 999 obviously by that time and paramedics came and managed to get him out of bed and down the stairs, which proved quite difficult, because, as I say, he was a heavy man. They managed to get him down and into the ambulance and off to Warwick Hospital. I followed in the car. When I got there, they had managed to -- the bleeding had stemmed and it had stopped. They had got him in a little side ward and they said that they were going to do an endoscopy the following day. They couldn't do it in the afternoon, they had to do it the following day, because they needed to get the piece of equipment that they had used on a previous endoscopy that Jeremy had had at the hospital a couple of years previously, to which I thought, you know, why would you keep -- Jeremy thought it was highly hilarious that they had kept this piece of equipment, as he said, in the loft in a bag with "Jeremy Foyle" written on it.

So the following day he went for this endoscopy, but they didn't -- they got the camera down his throat but it didn't go down very far before the pharynges

ruptured entirely. Jeremy had an immediate cardiac arrest. They were able to start his heart again and they rushed him to surgery to try to repair the damage, but they weren't able to repair the damage. Jeremy bled to death.

Q. You meanwhile had contacted the family.

A. Yes.

Q. The family had driven down.

A. His one sister came all the way from Whitby. I phoned her to say that Jeremy had had a cardiac arrest and that he was in theatre, and she travelled down from Whitby to come to see him. She obviously didn't make it to see him, to talk to him, but she did make it down before he had finally passed, so she was able to see him.

There was only me -- they asked me if I wanted to see Jeremy, because there was nothing else they could do. His body was rejecting the Factor IX that they had given to him, and he had also had blood transfusions and his body was rejecting the blood as well. So, you know, there was nothing else they could do and it was only a matter of time before he passed. So they asked me and Lewis if we wanted to go in to see him in the theatre.

Lewis declined, and I am very glad he did, but

I went in to see him and his younger sister went in to see him. I wished I hadn't. It wasn't nice. It wasn't pleasant. There was this -- my big, strong, strapping man lying on a trolley in an operating theatre with blood basically coming from every orifice. He had blood in the corners of his eyes, it was coming out of his ears, down his nose, it was dribbling down his chin. So my last memory of Jeremy is, again, looking like something out of a horror film.

Q. You kissed him and told him you loved him.

A. I kissed him, told him I loved him. I told him that I couldn't stay, that I had got to go home to look after me and Lewis, and I walked out. I just went, got Lewis and we went home.

Q. And he died just before midnight.

A. Yes.

Q. You've said in your statement that before you could face up to the loss of Jeremy, you had to go into a survival mode.

A. Yes. My maternal instinct kicked in. On steroids, it was, because I knew that I was not going to be able to stay in the house that we were in. We were in this big detached house and I worked part-time for the NFU Mutual. My take-home wage a month didn't even cover the mortgage, let alone council tax and electricity and gas and all of that. So I knew I had to sell the house. So I rang our mortgage provider -- I mean, you have to bear in mind that Jeremy had done all of the mortgage himself. All I did was sign where he told me to sign. So I didn't know much about mortgages and all that sort of thing, but I rang them up and told them that Jeremy had passed away and they advised me that I had got a three-month mortgage holiday available. So I took that, but it meant that I had a three-month timeline. I had to sell the house and find somewhere else for Lewis and I to live within that three-month timeline.

So we did that. I did that. I got the house on the market. I organised a funeral. I packed up the house. I sorted out paperwork that was in the house. I sold Jeremy's car. I sold -- he had got a classic car. I got rid of that as well and all his fishing stuff, and even the fish out of the fishpond.

Lewis and I moved into a small, two-bedroomed semidetached house, and I had a small mortgage which I was able to afford to pay on my part-time wages, and because it was a much smaller house, so the council tax was less and the running costs were less. So it was tight, but we still managed.

Q. In terms of financial assistance, the consultant that signed Jeremy's death certificate told you about the Skipton Fund.

A. Yes.

Q. And you received a stage 2 payment.

A. Yes. I had never heard of the Skipton Fund until he mentioned it. We went in to get the documents, to get the death certificate, and he was just sat writing it out and then he just mentioned it. He said, "I think you'll find that you are eligible for a payment from I think it is the Skipton Fund, they call it, but I think you will find you are eligible for a payment because of how he's died", because otherwise I wouldn't have known.

Q. But only recently have you discovered you were also entitled to a bereavement payment.

A. Yes. I didn't get that. I have only just had that 11 years too late. But, yes, I just had that.

Q. The move of house was a huge emotional wrench for both you and Lewis.

A. Yes.

Q. You got Lewis through his GCSEs.

A. Yes.

Q. Then you said it was like you hit a brick wall.

A. Yes. Once we were settled and Lewis had, as I say,

gone through his GCSEs -- and he did tremendously well. He still managed to get 13 GCSEs. They weren't to the projected levels, but he still managed to get through them after everything he had been through and helping me and reading mortgage stuff and things like that. We were sat having our tea one night. It was spaghetti Bolognese. I had a forkful halfway to my mouth and Lewis just said to me, "I think I am going to stop at such-and-such's on Saturday night", and that was it. It was just like somebody thumped me in the stomach and I just couldn't breathe and I started to cry and, boy, did I cry, and I did not stop and I could not stop. Lewis actually phoned Jeremy's other sister, Julia, and Julia came round because he didn't know what to do because I was just sat there wailing, weeping and wailing. I had a catastrophic mental breakdown.

Q. You have described it as: "I couldn't speak to anybody. I didn't want people

To talk to me. I just wanted to sit in a corner with a duvet over my head. It was a very, very dark time for me. It hurt even to make decisions, even whether or not I wanted Marmite on my toast. He had been my life. He was my everything."

A. Exactly. It was just the realisation he wasn't going

to come back. I suppose in the back of my mind there was always this, you know, "This is all just a bad dream and I am going to wake up. None of it is going to be real, you know, he is going to come in with a cup of tea and we are just going to carry on as we have always done". I just suddenly realised that that's not going to happen, and it was just -- I couldn't -- my brain was just -- it was just like I had got fog in my head and I couldn't see through the fog. I couldn't make my mouth work to say the words. People would speak to me and I would just look at them as if they were talking to me in a foreign language. I didn't understand. I didn't want to understand. I didn't want to understand and I didn't want to make decisions. I just wanted to sit and hoped it all went away, and if that meant that I didn't eat and Lewis didn't eat and the house went to rack and ruin, at that point in time, I didn't care.

Q. And throughout that time Lewis provided you with huge support.

A. Lewis was the hero of the hour. Lewis and my parents, but Lewis primarily. He would go and do the shopping, he would make something to eat, he would bring me cups of tea, he would coax me to drink them. You know, he would berate me, he would cajole me -- anything to try to break this wall that I'd built up in front of me and I just didn't want anybody, not even Lewis, to get past it and get to me, because I was too vulnerable, fragile.

Q. During that time were you or Lewis ever offered any counselling or psychological support?

A. No, nothing. The only time I -- Lewis had -- our local GP did offer some counselling to Lewis as a child, but I think he was so wrapped up in his life, the fact that he'd lost his dad and the fact that he'd got me sitting there like a big lump of marshmallow in the corner that was no use to neither man nor beast, he was having to do so much, so he declined that. But, no, we didn't.

The only time that certainly the Oxford Haemophilia Centre got in touch with me, I had a letter from Dr Giangrande to say, yes, Jeremy was eligible for the Skipton Fund and briefly at the end to pass his condolences. But that was all. There was never anything offered from them. They didn't advise me to go anywhere, to try anything, nothing. We were just cast adrift. That was it.

Q. In 2009 Lewis set up a profile for you on Facebook.

A. Yes.

Q. You ended up connecting with Paul.

A. I did. It was just a comment, friend of a friend sort of thing, and the comment -- we started to talk via Facebook, via Messenger, and then from Messenger on to texting and then from texting to phoning one another up and -- yes, then I met him first of all in April, and that was the first time I met him. We just -- it was absolutely uncanny. It really was uncanny. I picked him up from Stratford train station, because he had -- first time I ever met him and he was coming away with us to our friends' in Cambridgeshire to celebrate Jeremy's birthday, actually. I always thought, what a brave bloke to actually come and first meet this woman that he's been talking to, although we'd been talking for a few months and we'd got on like a house on fire, you know, the first time you clap eyes on her in the flesh was to go away and stay with some people you hadn't met. We just literally -- I got out of the car and walked up to him and we started to chat, and then we didn't stop chatting up until he died, really. We just carried on. It was as if we were carrying on a conversation that we had had decades before. We both felt very much like we had met one another in a previous life, if you will, because it was just really, really special, really

uncanny.

Q. Paul told you he was a haemophiliac.

A. Yes, he did.

Q. What was your reaction to that?

A. "Is that all?" He said, "I am sorry, I have got to tell you something. I'm not very well", and I said, "What is the matter with you?" He said, "I am a haemophiliac" and I went, "Oh, is that all? I have been married to one for 23 years. Haemophilia? I laugh in the face of haemophilia." So, you know, that was that. He didn't tell me he was HIV or hepatitis C until we met, I hasten to add. He didn't tell me that over the phone. But it didn't matter. I mean, I was smitten. He could have had leprosy and I wouldn't have cared.

Q. Paul had severe haemophilia A and was treated at the Haemophilia Centre under Dr Hill and then Dr Wilde.

A. That's right.

Q. He was treated with Factor VIII concentrate.

A. That's right.

Q. As far as you are aware and as far as he ever said, was he ever warned of any risks involved in receiving Factor VIII products?

A. No, he was never told.

Q. As you say, when you met, Paul told you he had HIV and

hepatitis C.

A. Yes.

Q. And he had been infected for 25 years.

A. Yes.

Q. At the time you met, Paul was also emerging from what you have described as a dark period of isolation after an attack that was entirely unrelated to anything involved in this Inquiry, just a random attack.

A. Just a random attack on the streets of Walsall. He was badly beaten up by a group of young men and it ended up with him having a burst -- his spleen burst. They didn't think he would survive. He had to be resuscitated a number of times on the way to the hospital. He had to have his spleen removed. He had come home from that. He had been mugged a couple of times as well, just random, where they had knocked him over and stole his wallet sort of muggings. So basically he just sat in his house. He had stopped all of the combination treatment for his HIV and he -- I think he was just sitting there waiting to die. I think he just wanted to die. He didn't want to go out. By his own admission he was quite reclusive. He would go out to -- he would go to Flan O'Brien's on a Friday night to have a pint and that was about the limit. He would have a driving lesson with his friend

Lynne, but that was about it. He didn't mix. He didn't go out.

Q. But when you met, he helped you come out of a horrible place you'd been in.

A. Yes. We helped one another.

Q. And you ordered him back onto his combination therapy.

A. Yes, we saved one another. I am not particularly religious and Paul wasn't particularly religious, but we always said God brought us together because we both needed saving for different reasons and, you know, we did save one another quite literally. We saved one another.

Q. You said that by the time you moved in together you had settled into a routine of a happy middle-aged couple.

A. Yes.

Q. But that Paul's illness had a much greater impact on your lives together.

A. Yes. Paul was -- Jeremy had -- if you looked at him, he was a big, hefty chap, but he didn't look particularly ill. His mobility wasn't particularly good. He struggled to walk very far. But he just looked, you know, like a healthy bloke. Nobody would know there was anything the matter with him.

Paul was a different kettle of fish. He was

actually physically better than Jeremy in that he could walk a lot further. We used to walk miles. As Paul would say, we would go bimbling. We would go bimbling around the shops and things like that, and he loved to just bimble about. He was a keen photographer, so he was always -- I would lose him. I would walk along and I'd turn around and he would be miles back taking a photograph of a gargoyle on the top of a church and things like that.

So he was an awful lot more able to physically got out, but he looked a lot iller. He was only about 5 foot 8. He was a very slight man. He was only sort of 10.5 or 11 stone. You know, you could see that there was something -- he didn't look as healthy as Jeremy had looked.

Q. Paul had liver cirrhosis --

A. Yes.

Q. -- kidney disease, arthritis and obviously ongoing immune issues. Then towards the end of 2015 he went into the Haemophilia Centre and had high blood pressure.

A. Yes. He went in -- it was just again a routine trip to the QE. One of the nurses took his blood pressure and she just sort of said as a passing comment, "Oh, your blood pressure is high today" and wrote it down

in the notes, as they always did. I mean, I was there with him. That was it. Carried on doing what they did. Took bloods and, you know, just the normal routine check in the centre. She didn't say anything to us about how high his blood pressure was. Maybe we should have asked. I don't know. We didn't think. We naively assumed that if it was high enough to cause her concern, she would either have gone and got one of the doctors to look at him or at least would have said to him, but she didn't say anything to him about going to see the doctor. So he didn't. We just went home and that was that.

Then a couple of months later, Paul said that he'd got -- he woke up one day and he'd got a headache and he couldn't get rid of the headache. He kept on and on about, "This bloody headache is driving me mad". So in the end I said to him, "Maybe it's a migraine", because it sort of dragged for a little bit, not developing but making him generally feeling poorly. I had some Migrelief tablets, so he took a Migrelief tablet and went to bed. That was that.

The following day he got up. The headache still hadn't gone. It was no worse, it was no better. But he had got squiggly lines in his sight. Again, we just assumed that it was his first ever migraine. He

had never suffered from them before, but, you know, because of the squiggly lines, we just seemed to think that was more likely the case. But as the days went on and the lights didn't disappear and things just got worse and worse, in the end I said to him, "You had better go and see the doctor". He went to see the doctor and his blood pressure was astronomical.

He immediately went onto blood pressure tablets and things, but they sent him -- referred him to see an ophthalmologist because of the eyesight issues, and it turns out that -- they did a brain scan and it turned out that Paul had had a stroke from high blood pressure. He had developed hypertensive retinopathy because of the stroke.

Q. Over the next few months his eyesight deteriorated to the point where he was registered blind.

A. He was registered -- yes.

Q. For Paul, that was terrifying.

A. Absolutely took the floor -- the ground from underneath him. He had always liked -- we lived in a small rural village and he liked to, you know, bimble, bimble down the village to the shop and to our local pub to have a pint of Guinness of a lunchtime and pop home, you know, just live the life that he had earned and we all want, you know. He used to go out.

He was very popular in the village. A lot of people knew him. So -- and that was suddenly taken away from him, because he could not do it on his own. Although he had support from Warwickshire Vision Support and they came out and helped him with the use of the white stick and encouraged him to try to go out on his own, because, as I say, it was only a small village, so, you know -- but the most he ever really got was he would go up to the doctor's, which was literally just the other side of a big Georgian house, but that was about it. If he went for a walk round the village, I had to be with him. He wouldn't go out on his own.

Q. His health also became more precarious.

A. His health started to deteriorate. Really from that moment, his health started to decline. He started to lose weight. He was a very picky eater. He would just have things like Cup-a-Soups and stuff. He didn't want to eat anything. You know, he started -- he got a big bloated tummy like somebody, you know, that was starving. His arms -- he was just wasting away in front of me. He was so, so depressed.

Then we started to -- I started to recognise that he was having some mood swings and his whole character was starting to change. He actually had a seizure. My dog woke me up actually, because by

that time I was sleeping in the other room to Paul because he wasn't sleeping at night. I was caring for Paul and I was also caring for my mum, you know, who is elderly. I needed to sleep. So my dog woke me up and I went in. Paul was just on the floor fitting. So I called the ambulance out and he ended up in hospital, in ICU, for 24 hours until they stabilised him. He got round and he came out of it. He came home.

But I had actually spoken to the doctor whilst he was in hospital, and the doctor said to me that he felt that Paul -- he was very poorly. His words were that, "He could last five minutes, he could last five weeks, he could last five months, but you've got to prepare yourself that he isn't going to last forever". So I sort of had that warning, so I had the time to, you know, get myself, you know, aware of the fact that he was going to die.

Q. Did they ever say what was actually wrong with Paul, what the issue was?

A. No, not until he died, no. It was just a case of he had got HIV, he had got hepatitis C, and I think it was just a case of they just saw those and that was it, that was what was going to kill him. And they were right at the end but, you know ...

Q. Then one morning he said he didn't want breakfast.

A. Yes. I got up one morning. He had come home from hospital obviously. I went in and I said -- because obviously he had to take his meds after food. He couldn't take them on an empty stomach. So I went in to say, "What do you want for breakfast so you can have your meds?" and he said, "Actually, do you know, I don't really want to have anything to eat, I feel a bit bloated and don't want anything". So I said to him, "Right, I will go and walk the dogs and sort out my horses and then I will come back and we will get you something to eat then because you have got to have something because you have got to take your meds", nag, nag, nag.

When I went -- I went off, came back about an hour later and went upstairs. Paul had been sick and had had diarrhoea. So I went in to him and said, "Oh, crikey. Come on, let's get you up and cleaned". So we had an old commode that my mum didn't use anymore, so I had said to mum, "Can I have it, just in case?", because Paul was blind by this time obviously. "Can I have it so I can put it by the bed so if he is struggling, he can at least get up and use the commode so he doesn't have to walk to the bathroom". So I got him up, stripped him down, got him on the commode,

stripped the bed, started to clean him and he basically started to slouch in his chair, and I thought, "This isn't -- I think I had better phone for an ambulance". Because, I mean, he was talking to me, you know, he was saying to me, "Oh, I am sorry about this, dearest", because he used to calm me "dearest", or "posh bird" was his other one. "I am sorry about this, dearest. I'm sorry that you're having to do this. This isn't right that you are having to do this. No wife should have to be doing this to her husband". So he was talking to me, but he was just -- this slouching, and I was thinking, "No, this is not quite right".

So I phoned the ambulance. We were very lucky, because the first responder actually lived in the village that we lived in. So -- and he had been to Paul before when he had had a seizure. So he was there within five minutes. He knew that I had got dogs and he knew that the door was open, so he literally walked straight in and straight up the stairs. I think he knew straightaway and he was already sending messages and whatever to the ambulance that was on its way. He took Paul's vital signs and they were obviously weak. He advised me at that point that the ambulance was on its way and would be imminent, but that he was going to get the Air Ambulance as well, so just to warn me that the Air Ambulance was going to come.

At this point I was sitting next to Paul, crouching on the floor, and I had got Paul's head on my chest and my arms around him, and he is still naked. He was still naked and I still hadn't had a chance to fully clean him up below. So there he was, sitting on a commode in the nude with faeces all up his back. I whispered to him as all these paramedics started to come in, "Don't you be dying on me, Hoopy. I am not ready yet, so don't you be dying on me", and he said, "Don't be silly, don't be daft, you silly woman, I am not going anywhere".

We heard the helicopter. The paramedics said to me, "Can you go and guide them in". They were coming in to land in the playing field at the school behind the cottage where we live. So I gave Paul a kiss on the head and I said, "Don't be too cheeky to them", because one of them was a woman paramedic and he was a bit of a flirt, and off I went and came back with the Air Ambulance crew. They had a doctor on board.

I sat downstairs, because by this time I must have had -- I think I had got four paramedics, the first responder, the pilot from the helicopter and the

two medics all in my bedroom, so there was hardly any room. So I sat downstairs and I could hear them talking. Then I heard all this banging and crashing, and then it all went fairly quiet. Then the doctor that was with the Air Ambulance came down and she sat next to me and she held my hand and she said he'd had a cardiac arrest, that they had brought him round, but she didn't think he was going to survive. She said they were going to get him to the hospital, but they couldn't take him in the Air Ambulance, because they had already brought him round with a defibrillator and she was pretty much certain that they would have to do it again on the way to the hospital, and they can't do it on the helicopter, obviously, for obvious reasons.

I wasn't allowed to travel with Paul. I had to go in separately. They wouldn't let me on the ambulance. But when they brought Paul down, he was alive, but he didn't -- he looked horrendous. He was ashen. He had got no colour.

Q. He had two more cardiac arrests on the way to hospital.

A. Yes, yes.

Q. There was not much more they could do for him.

A. They put him on life support. When I got to the hospital, they said that he was on life support, but

he wasn't going to survive and he was going to die, basically, and could I have their permission to turn the life support off. I said yes, they could, but I needed to let his brother and his sister know, who he hadn't -- he was estranged from his sister. I met his sister for the first time at Paul's funeral. They hadn't spoken for very many years. His brother he was a little bit more, you know, closer to his brother but, you know, they weren't a particularly close family as such. So they waited until Vic and Maureen came from Birmingham. Once they had been in and said their goodbyes, then they turned off the life support.

Q. You have said in your statement that for the second time in less than a decade the Contaminated Blood Scandal had left you bereaved.

A. Yes.

Q. Paul hadn't worked since his HIV diagnosis --

A. No.

Q. -- because he had been made redundant after his employers found out about his diagnosis, and you had been Paul's carer, so hadn't worked for six years by the time of his death.

A. That's right.

Q. You have said in your statement that EIBSS have been nothing short of rubbish. Why is that?

A. Well, Paul died in the December and I phoned up EIBSS to tell them that Paul had passed away, and their immediate reaction was they were going to stop payments. That was it. Paul had had monthly payments from them as well as a couple of benefits from the government, a Disability Living Allowance, an ESA, that sort of thing. So everything stopped. We went from having, you know, three grand a month coming in to nothing. It just -- that was that. It just stopped dead. It was actually one of the other widows of the Tainted Blood group that told me about -- "You are eligible for a top-up payment". They didn't tell me. It was one of the widows who said, "You do know you can have this top-up payment".

So the rigmarole began. Bearing in mind there was no money coming in. We had a mortgage, we had council tax to pay, we had electrics and everything to pay and I had nothing. All I had was £179 widow pension a month from Jeremy, one of Jeremy's pensions, a frozen pension he had had years before. That was my monthly income. I didn't have anything. I went to the EIBSS and, "Yes, we will send you the forms". I had to wait for the forms. Then it was, "Yes, you fill this form in". Then they want this piece of evidence, then they want that piece of evidence.

"When you have done that piece of evidence you need to get this piece of evidence to back that piece of evidence up". That's how it feels. It is just constant, you know, "We want this, we want that, we want three bags full". Then you send it to them and they write back to you and say, "Right, we have had all of that but we now need this as well". It was just a constant round of jumping through endless, endless hoops, endless red tape, and it took from Paul dying in the December, I had my first top-up payment from them in the April. So I'd gone for those months with nothing, and the only way that I was able to survive again, up steps Lewis, paying for food, and my elderly mother, who is a pensioner, giving me money to put petrol in my car, to put food on my table, otherwise I would have had nothing.

Then the real bitch about it, and excuse my language, but the absolute bitch about it is that I had my first payment in April and then I had a letter from them in June to say I'd got to do my 12-monthly reapply, because every year you have to reapply. So I rang them up and said, "Why am I reapplying for something that I have only just had?" "Oh, well, because that's what we have to do, so you've got to reapply". I said, "So what are you

saying?" "We will send you a form".

So they send me the form. It was the same form that I had filled in a few months prior wanting all the same evidence. So I rang them up and said, "You've got all this, I have supplied all of this", and they wanted it all again. So I had to send the whole lot again. Even though they had got it on their files and they'd only had it for a few months, I had to send it all again. So it just -- so the rigmarole went on.

Q. Because of your financial difficulties, you then lost your home again.

A. Yes. I was unable to -- the top-up payment was not enough to cover mortgage, outgoings, house outgoings, food. So I am afraid my mortgage had to be put aside in order for me to simply survive to get through each day, and it was a day, because I was paid monthly, but there was never -- it didn't last. As soon as I paid out what I could on the bills that I had, I just didn't -- there was too much month at the end of each money. I think we have all said it. But literally the money would come in and a week later it was all gone. So I then had to wait three weeks with nothing again.

Q. Eventually you managed to sell your home.

A. It took 12 months to sell it or thereabouts.

Q. You have downsized to a leasehold property.

A. I downsized to a leasehold. I was able to pay off the mortgage and the mortgage arrears, and with the money that I was left I bought a little maisonette, my mansionette as I call it.

Q. What has been the emotional impact of losing Paul and all of that turbulence around finances?

A. It's just been a nightmare. Last year was probably the worst of my life. I mean, losing Jeremy, it was awful and it ended so abruptly, and having to go through losing my house. But the actual transition, although it was heartbreaking, heart rendering and I was on autopilot, but I managed to get through it, and it felt like it was much more simple. The house sold for a start. You know, I put the house on the market one day and the following day, pretty much, it was sold. So it all seemed to sort of all drop into place. Fate helped me with Jeremy. Fate did not help me with Paul, and I was left destitute, because thankfully the mortgage suppliers were amazing and they didn't start any kind of repossession order on me for the cottage until it was -- my luck changed, because I finally managed to sell the cottage and about three or four days after accepting the offer on

the cottage and getting things -- getting solicitors sorted and all of that, I had the letter from the mortgage supplier to say they were actually starting repossession to get the cottage away from me and I was able to ring them up and say, "It's sold". I mean, they had been -- I can't knock them. They had tried everything they could. They even put me in touch with somebody they use to try to sell a house on their behalf. So last year was just -- it was the year from hell. It was awful.

Q. You finished your statement very happily. If I may, I will just read a paragraph from it.

A. Yes.

Q. "I have known and lost two of the best human beings ever to have walked this earth. For me, it is about answers. I want to know why. I am honoured to have known both of them, I really am. I have been a privileged, privileged woman. I had my first love and I had my soulmate. They will always be with me and I will love both of them equally. My heart overflows with love for the pair of them. They are amazing men and they need their stories told, both of them."

Those are the questions I have for you. I am just going to turn to Mr Snowden, who as you know represents you, and see if there is anything else he wants me to raise.

Before we finish, I think there is something else you wanted to finish with?

A. Yes. I wanted to be a little bit different from everybody else, so please forgive me. I have written a poem.

I'd like to thank my son, Lewis, and my mum for their love and financial support, and to the Tainted Blood family for holding me up on the worst of days.

But mostly I'd like to thank my husbands, for heros they are both,

Never got the chance to tell their stories under oath.

Two good men in every sense of the word,

Taken away so cruelly before they could be heard. I would like to thank you for your love and for making me your wife,

And to tell you both, my beautiful men, you really were my life.

My first love and my soulmate, I couldn't ask for more,

Maybe one last conversation, before you closed the door.

So now I am sitting here in the capital of our

land,

And I am hoping that Sir Brian will take things into hand,

And the justice that so much deserved can finally be found,

Before any more casualties fall on this battleground. Thank you.

SIR BRIAN LANGSTAFF: It is a great wonder to me that since you have every right to be bitter, some may think, you have shown no trace of that and you have described yourself instead as privileged. You've given us a remarkable account, full of detail, some of which is truly horrible, but you have given it in an undaunted way. I can only say I am in some wonder and I thank you very much.

A. Thank you.

(Witness withdrew)

SIR BRIAN LANGSTAFF: We will start again at 11.55.

MS FRASER BUTLIN: Thank you, sir.

SIR BRIAN LANGSTAFF: 11.55.

(11.22 am)

(Short break)

SIR BRIAN LANGSTAFF: How would our next witness wish to be known?

MS FRASER BUTLIN: She is called Theresa.

SIR BRIAN LANGSTAFF: Theresa, please.

THERESA ANN SMITH (affirmed)

Questioned by MS FRASER BUTLIN

MS FRASER BUTLIN: Theresa, you are here to tell us about your infection with hepatitis C.

A. Yes.

Q. In December 1983, you required an emergency appendectomy.

A. Yes.

Q. And you understand that you were given a plasma transfusion at that time.

A. Yes.

Q. About a year later you noticed you were becoming jaundiced whenever you got a cold or were poorly.

A. Uh-huh.

Q. And then at some point that jaundice became severe and you were admitted to hospital.

A. Yes.

Q. Can you tell us about that?

A. The doctors weren't sure what was causing it, because you shouldn't randomly become jaundiced. So they took me in to do some tests to find out what they thought was causing it. They did a liver biopsy and a couple of days later came back to tell me -- I believe it was then -- I had got non-A, non-B hepatitis.

Q. During that biopsy a blood vessel was also nicked --

A. Yes.

Q. -- and so you needed further blood.

A. I did.

Q. You don't actually remember very much of that time at all.

A. No. It's a blurry week that week. I was quite poorly, yes.

Q. When you were told you had non-A, non-B hepatitis, what did you understand about the condition at that time?

A. Nothing. I just knew it wasn't A or it wasn't B, but they didn't really explain what the difference was, if there was a difference, what it meant.

Q. Were you told anything about managing the condition?

A. Not at all.

Q. Were you told anything about any precautions you should take?

A. Not at all, no.

Q. Did they monitor you at all?

A. No. Not to my recollection, no.

Q. In 1989 you gave birth to your son, Tom.

A. Yes.

Q. Who is sitting with you today.

A. Uh-huh.

Q. It was a difficult delivery --
A. Uh-huh.
Q. -- and your son was in distress.
A. Yes.
Q. When you asked about the chances of your son being infected with hepatitis, what were you told?
A. I didn't actually think of that until I started treatment myself over at Derriford, but I was told it is quite rare for children of mothers with hepatitis C to be transmitted in the womb. However, it transpires that he was infected in the womb, we believe. So, yes, that's what they told me. He was infected with the same strain.
Q. Your son was born with a rare illness called sacral agenesis. Can you tell us what that means for Tom?
A. It basically means the bottom part, the sacral area of his spine, did not form properly. So all these nerves -- because they showed me a CT scan once and it is all bundled up like a ball of wool. So all of the nerves that should be kept in a line by his vertebrae are just protected by a bit of cartilage.

So there are lots of different effects. It affects mobility. I think he had his first operation at nine months old to release the tendons at the back of his legs, because he had no heels, and he was born with his feet inverted and inwards and crossed over his chest, which is why I believe it was quite a difficult delivery, because they thought he was breached, but he wasn't; he was just in that position. It meant he has had quite a few operations over his life. They had to build him some feet, effectively, over at Bristol Children's Hospital when he was 7. He had two within a year. They broke all the bones in his feet, because he was walking on the top of his feet. They thought he would never walk, to be truthful.

When he was first born, the doctor had to go and look it up in a book, because he had not seen it before, he didn't know what was happening. He came back, explained that it was this condition called sacral agenesis, and he explained to me that he would probably never walk, that he would crawl all his life, that he could get renal failure, that he could have hydrocephalous.
Q. Which is fluid on the brain?
A. Yes, which is common apparently in people with sacral agenesis. I don't know why, but so I am told. As it turns out, the doctor was incorrect. He took it upon himself to stand up and walk one day. But I was given the impression -- it is a severe disability, but I was given the impression it would be extremely debilitating and he would never be able to walk and it might affect the length of his lifespan.

Q. At that point, the doctors also said they wanted to do some tests.
A. Yes.
Q. What were those tests for?
A. They didn't know what caused it, because it is a very rare condition. It usually only occurs if the mother has diabetes, and then only in 1 in 200,000 children, I believe, so they couldn't work out why Tom was born with it because I don't have diabetes and never have had. So they did a few blood tests, and they also said they wanted to check me for HIV because I had had blood transfusions, which was very unpleasant because at the time you used to wait quite a long time to hear back. So I was under the impression, as many women who give birth to children with any congenital problems, that you might have caused it.

So I was wondering for six weeks if my baby was going to die, because I had heard what happened to babies born to mothers with HIV. They died routinely. They were always on the news at that time. I had to wait six weeks. Then I made a phone call to the clinic. She didn't want to tell me because you are not allowed to tell people over the phone, but I couldn't go in, so she said, "I am just going to say it's not as bad as what you think it is". I said "That's okay", because clearly that's not "You have got it".

They did want me to go back and have it done again six months later, but I didn't because I didn't think it was that in the first place and I didn't want to put myself back through that, to be honest. As they already knew I had got non-A, non-B, I don't know why it didn't occur to them either. It was a bit stressful, to say the least. It was a traumatic time.
Q. But at that stage nobody said anything to you about non-A, non-B hepatitis?
A. Absolutely not, no. Never came up.
Q. The tests were for HIV. They were negative.
A. Uh-huh.
Q. And that was the end of the investigations?
A. Yes. They had no idea. I saw a geneticist when Tom was about six months old and he couldn't explain it either. Nobody could.
Q. Then in about 2002 you realised that non-A, non-B hepatitis was, in fact, hepatitis C.
A. Yes.
Q. What was it that triggered that realisation?

A. I had a conversation with somebody who said that what I was describing with the repeated episodes of jaundice and the fact that I had what was termed non-A, non-B many years ago, he said, "That's classic hepatitis C. Did you know?" I didn't know. So I got in touch with the Lighthouse Trust and they confirmed that, that hepatitis C is non-A, non-B. I still didn't know at that point. That's what sort of prompted me to go and have some tests to see if I actually had got that and what I could do about it.

Q. And until that point you had no interactions with anybody about your hepatitis C?

A. No, for 20-odd years, I suspect. It is about 20 years. Nobody had said a word about it.

Q. You then sought out treatment.

A. Uh-huh.

Q. And you went to see and asked to be referred to Dr Cramp.

A. Yes.

Q. When you first saw him, you said he was excellent.

A. He was really good, yes.

Q. Can you tell us why he was particularly good?

A. Well, I do actually know that he's sort of like a leader in his field, but at the time he was very -- he knew his subject. He explained to me what it meant. He explained to me there were treatments available. He offered me the chance to be involved in a trial that was running at the time, which was the Ribavirin and interferon trial. So he put me on that. And he also offered to check Tom. When I mentioned Tom, he also offered to check Tom with a view to getting treatment for Tom once he was of a legal age to do so, because he was too young at the time. So he had to wait until he was 18 to have it done.

He also mentioned the Skipton Fund. I believe it was Dr Cramp who brought that up, because I had never heard of that before either. So he was the one that signed the forms and got it all sent in.

Q. You said he explained everything to you in a very calm manner.

A. He was.

Q. And set everything out for you for the first time.

A. Yes.

Q. You went ahead with the trial --

A. I did, yes.

Q. -- for about six months, and you cleared the virus.

A. Yes.

Q. But you've described the side effects as "vile".

A. Yes, they were.

Q. Can you tell us anything about that?

A. After the first few weeks I was constantly nauseous. They had to give me medication because I just wanted to vomit all the time. At the time my dad was in Derriford Hospital, because he was in renal failure. So I was having to go there every day anyway, so ...

I have never really suffered from depressive illnesses, but that treatment gave me such a depression. I just woke up one morning and it was like I was just crushed. I couldn't work out why. For a day or two it didn't sink in, but I just couldn't stop crying. I just felt like everybody I knew had died overnight. It was just awful. Apparently it was one of the side effects from the treatment.

So I went along to the GP's and they treated it with anti-depressants, but I also couldn't go -- I used to take regular exercise. I couldn't do that, because you couldn't breathe, because your sort of blood cell count was affected by it. It just -- it wasn't very nice. It was very unpleasant. It was worth it, but ...

Q. When you first realised that you were depressed, you went to see a GP.

A. I did, yes.

Q. And they insisted you had to wait two weeks.

A. Yes, because that would be the normal -- that's their normal sort of course of action if you have a psychological depression. However, I knew it wasn't a psychological depression, because it just -- I have never had it before and it was just -- I went to bed okay and when I woke up the next morning I wasn't okay. So I left that with that GP and then the next day I went back and saw a different GP in the same practice and explained to him that I know what this is, and he was kind enough to listen and provided me with anti-depressants.

I am not sure how well they worked. I don't know. I can't remember, truthfully, because it's quite a little while ago. Maybe just the fact that somebody listened might have helped a little bit, but it had gone by the time I stopped taking the treatment, so...

Q. Were you offered any counselling or psychological support during the time?

A. No, no, no.

Q. You say in your statement the effect of the hepatitis C on Tom has been tremendous, and you believe there's a link between the hepatitis C virus and his sacral agenesis.

A. I do.

Q. Can you explain that for us?

A. Okay. So because I have none of the normal risk factors that might indicate your child could be born with it if it does happen, even though it is so rare, I have wondered for so long what could have caused this. I started looking into it, and it appears that hepatitis C is what's known as a flavivirus, the same as some other big viruses like Zika, for example, which affects bone formation in the womb. Tom's physical problems are caused by a lack of bone formation in his spine. I am aware that they have done a little bit of testing, but not on humans yet, to find out if there's any link, but I do know that hepatitis C does do that in other mammals, such as cats. If you inject a pregnant cat with hepatitis C, its kittens will be born with deformed spines.

So I feel, because I haven't got the risk factors in place, and because there seems to be evidence that suggests it could be that, that it's more than likely that's what caused it.

Q. You said earlier in your evidence that Tom surprised everyone by getting up and walking.

A. He did.

Q. But he's needed a number of operations to rebuild his feet.

A. Uh-huh.

Q. And calipers as well.

A. Yes.

Q. He suffers constant pain in his feet.

A. All the time. All your life, haven't you?

Q. And hasn't been able to work.

A. As he's got older, it's got worse, you see. It is progressive, because he is walking on plastic, effectively. It is rubbing away the fat underneath his feet, which is what you need to protect your bones when you walk. Tom basically has got no fat left underneath his feet now, so the illness is progressing, and it's so painful now that he can't work.

Q. He surprised everyone by going to university and then trying to find work.

A. Yes.

Q. But just couldn't sustain it because of the pain.

A. I think it was -- the last time was about a year ago. He started a new job, and after his shift, which was 12 hours, 10 until 12, Tom doesn't complain about the pain in his feet, but he rang me because he was in agony and he couldn't make it to the bus stop, which was not very far from where he was working, and he actually lacerated his feet just by being on them all

day. He couldn't walk for days. It is just not practical, because he's putting himself through too much pain to go out and work. Although there's a downside to that in that you need to go out and work, not just for the money, but he's a young man. You don't want to be stuck at home all day. And he is a clever man, I have to say. It feels like it's a waste and it's been caused by that condition.

Q. As you said, Tom was also diagnosed as hepatitis C positive and, once he was 18, he also underwent treatment.

A. Yes.

Q. With similar side effects.

A. I don't know. I think he sailed through it slightly, but that could have been an age thing a little bit. I don't think it was quite so bad. They cleared it. It started to clear quite quickly again, didn't it, as well? So, yes.

Q. He cleared the virus.

A. Yes. We cleared it quite early on, after a few weeks, but they kept us on the whole six months obviously, just to see if it had gone.

Q. Since then, what has been the effect on you in terms of your physical health since you have cleared the virus?

A. It's difficult to quantify. I don't have ill health per se. I have a suspicion that it may be having an effect on my blood vessels because I get really cold hands, and when I say cold, they are so cold that I can't hold the steering wheel of the car because it hurts. I can't grasp things. It is not so bad this time of year, even though they are cold today, but in the winter it is... it went away for a little while while I was on treatment and then came back again, so I'm not sure. I'm investigating whether there's a link in that. That concerns me slightly, because you can't see the blood vessels inside your body. I can see the ones in my hands, but all the blood vessels in the smaller parts can be affected. So I need to find out, just in case it is that, because it's a risk to your life. It's life-threatening. So I need to find out. Apart from that, I can't honestly say that I think it affects my health.

Q. But it has had a huge emotional impact on you, and particularly the fact of Tom's illness.

A. Yes. It is difficult to believe that it would have happened had I not had hepatitis C in the first place. So, yes, I think it's a guilt thing. Nobody has a baby expecting to give them something that's going to have a significant effect on their life, and

I honestly believe that this did. I know it's not my fault I had it, but I still transmitted it. So, yes.

Q. You said in your statement you have tremendous guilt over your son's illness following his birth and ongoing, as you thought you must be somehow to blame for it.

A. Yes. Yes. When he was born I thought, "It has got to be me. How did that happen? What did I do?" I felt that way for quite a long time at the beginning, And really, to a certain extent, it is true; I may have passed on something that's had a considerable effect on the way his life has developed. So, yes, it does make you feel guilty. It does.

Q. And you have ongoing fears of things in the future. You described it as continuing to live knowing you are a living experiment in this illness.

A. I think we are. I think all of us who have been infected by it are, because they don't know -- even if they clear it, so we are living hepatitis C negative, this is a new thing. People used to get liver disease and they would pass, but with this we are getting liver disease and we are being treated and cured, but nobody knows what's going to happen in the future. For all we know, there could be a ten-year period where all of a sudden that treatment stops working

or... nobody knows.

All the time there are new concerns coming out, because people are living longer. There's a special category mechanism, is it called, that's just been introduced, because the amount of people that have developed illnesses which are related to retrovirus, as hepatitis C, it's a new thing. They didn't know about it. People would have died before. Many people probably have died before, but the treatment is keeping us alive and the effects are sort of stacking up now.

Q. You thought about bringing a legal case in relation to your infection and your son, but when you went to a solicitor, they assumed that you were an IV drug user.

A. Yes, they did. They did. I mean, the first time I came across hepatitis C myself was when I was working in care homes. I came across a few patients who had it and they were described as drug users because of the hepatitis C. So I think that was a general sort of stigma that went along with it at that time. Bringing it out into the open in the form of an Inquiry and people coming forward has changed that, many people are aware now, but it happened -- when Tom went to have treatment at Derriford, he had

a spider bite which had tracked, because it was infected, and the nurse assumed that was from intravenous drug use. So there was a lot of ignorance out there around it.

Q. And now if you tell anyone that you have hepatitis C, you are very quick to say that you contracted it through infected blood.

A. I always say that. I do always say that just to be on the safe side. But I think people are much more knowledgeable about it now, but I do tell people. I always tell people, because I work in the health profession, but yes.

I am a little bit concerned that I was working with it for years and years and years without any knowledge of what was going on inside my own body and the risk of transmitting it to other people, because I will have worked with thousands of people over the years, and it does occur to me occasionally that -- it is difficult to know if you have infected anybody if somebody doesn't tell you to take precautions, because they didn't. So hopefully not, but ...

Q. You are now a qualified nurse.

A. Uh-huh.

Q. Quite recently.

A. Uh-huh.

Q. But you still find it difficult at work that you were hepatitis C positive?

A. It's something I have to bring up in the course of every job, because it's my responsibility, and also because I would anyway, because I'd hate to think I did infect somebody by accident. I can't now, I am hepatitis C negative, but all the same. As I say, I am never sure that we are hearing the whole truth, because at the beginning we didn't hear the whole truth. We clearly didn't, because they weren't explaining what non-A, non-B was, for example, whereas in other countries they knew what that was.

Yes, I feel possibly things have been hidden from us for a long time and they might be continuing to be hidden from us, because it was a mercenary act to buy infected blood and nobody has taken any responsibility for it, and there's lots of stories out there where people have suffered.

Q. And your fear is that that's continuing, which impacts your interactions with people at work and interactions with medical professionals.

A. Yes, it does, yes.

Q. You and Tom received money from the Skipton Fund.

A. We did.

Q. But then only very recently have you made a connection with EIBSS. How did you come to know about the EIBSS and why was there the gap?

A. The gap could have partially been because I've moved, although I found out about the EIBSS payments through a documentary that was on the TV prior to the start of the Inquiry hearings and it mentioned payments, and it also mentioned within the course of that documentary that people with hepatitis C, they had made efforts to contact them. They had not made efforts to contact them unless I am an individual case that they didn't contact, because they would have contacted me, is the way I see it. So I found out about the EIBSS payments through that programme essentially.

Q. So there were two issues that programme raised for you. One was why you had not been traced much earlier~--

A. Yes.

Q. -- about having hepatitis C, having been previously diagnosed with non-A, non-B.

A. Definitely.

Q. You were concerned by that gap, that nobody had been in touch.

A. Particularly because it was made as an explicit statement that there had been great efforts made to track people down so that they could inform them what

was happening and explain about any finance they may be due or... I wouldn't go so far as to say it's a deliberate lie, but it's a misstatement, because they never bothered contacting me.

Q. Secondly, in that programme you realised that Skipton had become EIBSS --

A. Yes.

Q. -- or replaced by EIBSS, and you realised you weren't in contact with EIBSS and were missing out on financial assistance.

A. I rang them that afternoon just to check and they said, "Yes, you should have been paid from last year". So I did that and I let Tom know as well. So we did.

Q. But as far as you are aware, there was no effort to trace you from your Skipton application to when EIBSS came into play?

A. No, I don't think so.

Q. You have said in your statement your real concern is Tom.

A. Yes.

Q. Especially once you have gone and the future effect on his own health.

A. It concerns me. If you have an illness, they can give you a prognosis of how it's going to develop and what's going to happen in the future. If it's a rare

illness, it is harder. They can often give you an idea.

With Tom, I don't know that they can actually give me an idea, because they don't know what caused it in the first place. Therefore the prognosis that would normally accompany sacral agenesis that has been contracted through the mechanism of a diabetic mother, they don't apply. I don't know what will happen. I don't know how this will progress. That does concern me.

Q. It also concerns you in terms of financial provision for Tom.

A. Yes.

Q. Very practically what will happen.

A. Yes, yes, it does. It does. I mean, because we have talked about -- the pain is so bad, you've talked about having amputations on your legs, and he will definitely get arthritis in his feet, both feet. He had a lot of surgery on his feet. So there's a lot of pain in the future. I'd like to think that there's something in place to make sure that if he needs anything, then it's properly looked after, because you didn't do anything to deserve it. So, yes.

Q. Those are the questions I have for you. Is there anything else you would like to say?

A. No, not really, no. It's difficult, because it feels like I haven't been that affected, truthfully. There's some heartbreaking stories out there and it's had massive impact on people's lives, but at the same time when somebody said, "Would you like to give a statement?" I just think, well, we all need to really, don't we, because we need to get to the bottom of this and we need to prevent it happening again. That's it, really.

SIR BRIAN LANGSTAFF: Well, I don't think you can possibly say that it hasn't affected you. It obviously has affected you and Tom. But you have given us a very lively account of living with uncertainty and looking for answers to the questions that you have, because they still -- I wouldn't say worry, but concern you.

A. Yes.

SIR BRIAN LANGSTAFF: And I would just like to thank you very much for that.

Can I thank you both as well, Tom too, because you have come here today to describe the conditions from which Tom suffers and which you have mothered, and that's not easy. It's very brave, in my view. Thank you.

A. Thank you.

(Witness withdrew)

SIR BRIAN LANGSTAFF: Well, we will take a break until 1.30.

MS FRASER BUTLIN: And after the break, sir, there will be no live stream for the next witness, but we will have a live stream for the fourth witness of the day.

SIR BRIAN LANGSTAFF: So if anyone is out there and taking a stream, they might expect that the next witness will be, what, about an hour and a quarter, we think?

MS FRASER BUTLIN: I think so, sir, yes.

SIR BRIAN LANGSTAFF: About an hour and a quarter. So it may very well be some time around 3 o'clock that we will resume streaming.

MS FRASER BUTLIN: That's correct.

SIR BRIAN LANGSTAFF: But for now I will see you again at 1.30.

(12.31 pm)

(Luncheon adjournment)

SIR BRIAN LANGSTAFF: As you were told at the end of this morning's hearing, the next witness is anonymous and there will be no live streaming. He will be known to you and me as Mr AM. For those who are wondering whether that's an M or an N, it is Alpha Mike in phonetic.

The order in his case is this: the name and address of witness W0125 -- that's Mr AM to you and me

-- the name of any member of the witness's family and any other identifying information, such as the witness's image or a description of his appearance, cannot be disclosed or published in any form unless express permission is given by me or by the Solicitor to the Inquiry acting on my behalf. Witness 0125 must be referred to only as "Mr AM".

This order remains in force for the duration of the Inquiry and at all times thereafter unless otherwise ordered, and I may vary or revoke the order by making a further order during the course of the Inquiry.

Now that that order is in place, Mr AM, please.

Mr AM (sworn)

Questioned by MS RICHARDS

MS RICHARDS: You have severe haemophilia A.

A. Yes.

Q. As do your two brothers.

A. Yes, they do.

Q. And your condition was diagnosed when you were a baby.

A. That's right, yes.

Q. Most of your treatment during your childhood was at Great Ormond Street Hospital.

A. Yes.

Q. If we have up on screen, please, Henry, 0125002,

please. It should come up on the screen in front of you. If we can have page 9, we can see there in the bottom half of the page -- and this is from your UKHCDO database records -- the treatments that you received in the course of the 1980s. So we have cryoprecipitate 1981 and 1982, then Factor VIII (BPL) and Oxford Factor VIII in 1982, cryoprecipitate in 1983, Oxford Factor VIII in 1983 and BPL Factor VIII in 1983.

A. Yes.

Q. So far as 1984 and 1985 are concerned -- and the significance of that we will come back to -- you are recorded as having received cryoprecipitate in 1984 at Great Ormond Street, Factor VIII BPL in 1984 at Great Ormond Street and Oxford Factor VIII in 1985.

A. Yes.

Q. It was in 1984 that you went on to home treatment.

A. Yes, around then, yes.

Q. Now, on 30th September 1985, you tested positive for HIV.

A. Yes.

Q. You were only four years old at the time. If we keep this document up on screen, Henry, but go, please, to page 10, we can see in the top right-hand corner "Date last negative: 15th December 1984". Then if we go to

the next page, page 11, please, you will see in the top left-hand corner, "Date first positive: 30th September 1985".

I understand from your statement that your parents were not aware that you were being tested for HIV.

A. No, I don't believe they were.

Q. They have become aware of another Great Ormond Street patient being diagnosed with HIV at the same time.

A. Yes.

Q. One inference you have suggested in your statement is there may have been some form of systematic testing of patients going on.

A. Yes.

Q. Now, you believe the treatment which affected you was in all probability the BPL Factor VIII you received in 1984.

A. Yes. You can see the window of opportunity for me to be infected can be narrowed from the earlier negative test. So between then and the positive test, there was, I think, only one treatment during then. So the likelihood is that that is when I was infected.

Q. One particular reason why in all likelihood it is the November 1984 treatment, not a 1985 treatment, is that one of your brothers was also given Factor from the

1985 batch but was not infected with HIV.

A. That's right, yes.

Q. The late 1984 batch, which was given to you for a bleed in your left elbow, is the one treatment within the relevant window which was not shared by any of your siblings.

A. That's right, yes. Back then, it is important to know we were very careful about batches, and until even recently with haemophilia we were very careful about batches because hospitals always told you never to mix the batch. Very occasionally, I think maybe once or twice, even with more modern treatment, I remember having a new batch and feeling a little unwell for an hour or so, dizzy, hot, that sort of thing. So you were strictly advised not to mix batches. So back then it was even more tightly controlled and advised not to mix batches.

Q. Now, by the time you were given Factor VIII in November of 1984, and putting the case at its lowest on the basis of evidence the Inquiry has already heard, there is evidence to suggest that the risk of HIV from blood products was at least suspected.

A. Yes.

Q. What, as far as you know, were your parents told about the risks of the product they were giving to their

children?

A. I am not aware they were. I am not aware they were advised of any risks. I think probably, like many, the majority of the information came through the media. In a very different age to today, whereas obviously if something happens in America, you can find out within minutes here, that sort of information would have trickled through the print media, through television. So very little, if any, were they told about it.

Q. We have a statement from your mother that was made in earlier litigation. Perhaps we will put that on screen. It is 0125003, please, Henry. If we go to the second page, we can see -- if we go a little bit further down the page, please, Henry -- thank you -- we can see reference in that middle paragraph to there being -- towards the end of 1984:

"By that time we were becoming anxious about AIDS."

A. Yes.

Q. Then your mother makes reference to a meeting at Great Ormond Street. We don't know the precise date of the meeting from this statement.

A. No.

Q. Which says this: "My recollection is that we were

advised that the NHS unheated product was likely to be safer than the heated commercial product and it is correct to say that we expressed a preference for [you] to stay on the unheated Lister product."

A. Yes.

Q. That's on the basis of advice that was being given to your parents at the time, based on this statement.

A. Yes, probably based on the donor source that we knew -- in America where the donations were coming from, but in the UK it was felt that because donations were given on a more voluntary basis, it was likely to have come from a safer source.

Q. Now, how did your parents learn of your diagnosis after this test that was carried out in September 1985?

A. They were told very quickly. The end of September, I think -- in early October they were contacted by Great Ormond Street, by the doctors, and asked to come in. They said one of the tests had come back and there was an irregularity about them. They asked my parents to come in as soon as possible. My dad was working away at the time in Liverpool and he flew back to London and my parents went -- sorry.

Q. It is fine. Take your time.

SIR BRIAN LANGSTAFF: Take your time, and there's water if you want to drink it.

A. And they went to Great Ormond Street. They speculated as to which one of us it was who was ill. My mum knew that it was me, because she said my glands had been up all year, so she knew it was likely to be me that the irregularity related to, and when she got there and they were told, she was right.

MS RICHARDS: What were your parents told about your prognosis?

A. They were told I would be lucky to make my tenth birthday.

Q. Looking back, how did that diagnosis affect family life over the following years?

A. It's only with hindsight I can look back, because I wasn't told myself then. I was told later, which I am sure we will come to. Life was -- I suppose life was tough. Was it difficult? Yes. But my father worked. My mother didn't. Having three young boys with haemophilia was quite enough to cope with. So she didn't work and looked after us, because you never knew which one of us would be on crutches, in a wheelchair or need tending to at school, all those sort of things. So Dad worked. He was self-employed. Coming to around the 1990s, the recession hit. He worked in the building industry. So things were incredibly difficult. But I think, understandably, my parents struggled to cope, as anyone would.

My dad was diagnosed with depression and had some -- was given medication for that, but because he was driving to and from work and it made him nauseous, then he had to stop. That was back in 1986. You can imagine working in a male dominated environment it must have been impossible to talk about. We look now today and we talk about things like mental health and the fact it is okay not to be okay and the campaigns that are going on now. I can only imagine what my parents were dealing with back in the mid 1980s, not really being able to have any support. So they struggled and I think, having read their statements from previous litigation, I know that my mum said effectively they were living separate lives.

Q. I am just going to, if I may, read a couple of passages from those statements. Your mother in her statement said this:

"I have found it exceptionally hard to cope with the fact that [you have] been the unluckily one whilst his two brothers have mercifully been spared. After we found out about it, it had a devastating effect on our lives. My husband and I could not discuss it together and we had to deal with it as best as we could separately. I tried to keep cheerful and do things with the children and he had to keep going with his work."

She talks about isolation and the devastating effect on lives. At the point in time at which she gave that statement, you still hadn't been told yourself of the diagnosis.

A. That's right, yes.

Q. She says this:

"My husband and I very much fear the day when we have to explain to him about his infection and how he will be able to cope with it."

Your father in his statement talks about wrapping up all the problems internally and going through a very difficult time.

A. Yes.

Q. You also say in your statement, looking back, that you think your parents, having been told in particular that you might be lucky to see your tenth birthday, tried to make sure you and your brothers had a good time.

A. Yes.

Q. To go away and trying to give you the best of things.

A. That's right, yes. We always had -- so it was only my dad who worked. We always had good family holidays.

As I say, we weren't rich by any stretch of the imagination, but we had the best of what they could afford.

Q. How and when did you learn of your HIV diagnosis?

A. I learned in the summer of 1993. I was 12 at the time and I was just moving schools. I was going from -- the school system I was in had *[redacted]*. So I was at middle school and I was about to go to secondary school. My -- one of my other brothers and I went to a hospital appointment at Great Ormond Street, and my dad came, which was highly unusual. Dad never came to the hospital. As I have said in the statement, he struggled to cope, like so many that we have heard at the Inquiry, and many people buried their heads in the sand and I think that was largely speaking Dad's coping mechanism. Dad came to the hospital, so I thought something was up. As I said, he was the breadwinner, he worked, so coming to hospital for a day meant him not working.

I remember being in the waiting area with my brother and my dad. We were sat there for quite some time, I think probably well over an hour. My mum had disappeared for a time. Then eventually I was taken into a room with one of the doctors and my nurse from Great Ormond Street, and I sat down and I didn't know what was going on, quite frankly, but it all happened relatively quickly, so I didn't have too much time to think about it. So they sat me down and they explained to me that I was HIV positive.

Q. Can you recall what you thought and what, if anything, you said?

A. Immediately I burst into tears. I was -- it was a shock. I think my mum said in her statement that -- previous statement that she thought I was the brightest out of the three of us and she thought there might come the day when I worked things out and put two and two together and asked the question, and if I did, they would inevitably tell me. But I didn't, because I was relatively fit and well. So it was a complete shock to me. I broke down into tears straightaway, and when I eventually recovered my composure, I think the first thing I said was, "Am I going to die?"

Q. Can you recall what, if anything, by this time the doctors were able to say to you about prognosis?

A. Probably more than what my parents were told, but probably less than what one might be told now. I wasn't necessarily given a prognosis of sorts, but I was told that obviously there was more treatment available, and I think my first HIV doctor and maybe my second HIV doctor may have said similar things along the lines of, "The longer you stay alive, the more research and progress is being taken and the better your life expectancy will be". Obviously we are at a stage now where most people can expect to live a relatively normal and full life. So it was tentatively optimistic, I think, about my prognosis.

Q. You have said in your statement you felt very supported on the day you were told.

A. Yes.

Q. This had been arranged between your parents and the hospital that the news would be broken to you in this way.

A. Yes. It was no accident like others have found out.

Q. You said in your statement that after the initial response, you thought, "I haven't known for seven years and I have been okay, so why can't I continue to be okay?" and you just carried on.

A. That was largely my mindset. I did have a few difficult days. I would be lying if I said I didn't. And I don't know where that fortitude came from for a 12/13-year-old either. But, yes, that was my rationalisation of it, that I have been okay for seven years and why shouldn't I continue to be okay? So, in a way, the fact that I had not known to start with was a blessing.

Q. And you have explained in your statement that in the year or 18 months following the communication of the diagnosis to you, you started to look back on the time before your diagnosis and to make sense of some things.

A. There were lots of things that I started to join the dots in relation to. As I said before, my mum thought there might be times when I realised what my diagnosis might have been and asked the question, but I didn't. With hindsight, I can see where the opportunities lay. I started on HIV medication when I was about 8 years old. I remember vividly standing in the kitchen. I think it was AZT and it was in a syringe and it didn't taste very nice. I had to take it and I said to my mum I didn't want to, so she said, "If you take it, you can have a glass of Coke". So I did, and that was that. I carried on taking it. Then years later it turned into something else. But, of course, I was taking the medication and my two brothers weren't. So, as I say, there was the first opportunity for me to say, "Why am I different to the other two?" but it just never dawned on me.

I was given spurious explanations as to why I was taking it. For example, I had lots of joint bleeds. I think at one point I may have been told that as a result of that my blood got thicker so I was taking this medication to help balance it out. So I think I was told various white lies to make sure I didn't work out what was going on.

There were other things that, again, as I say, I join the dots. I remember going to see the GP at various times with my brother, my younger brother and I, and at the end of the appointment at times my brother and I would be asked to go and stand outside in the corridor and I could hear on the other side of the door my mum crying. Looking back, I realised that was because that was the only person she could talk to about it. That was the only other people who knew.

There were other situations, I think. Although a dark subject, it sounds almost ridiculous, but we would have quite lighthearted conversations sometimes in the car on journeys about, you know, if you died, what would you want to happen to you, would you want to be cremated or buried? I always said I wanted to be buried rather than cremated. I couldn't stand the idea of being cremated. As I say, it was quite a lighthearted conversation, but, you know, with hindsight, it was clear that my parents were planning my funeral in their own heads.

Q. You also mention in your statement a few occasions where your mum would ask you if anyone had asked you about being blood brothers at school --

A. Yes.

Q. -- because she was concerned there might have been a sharing of blood.

A. Yes.

Q. You say:

"She never told me why or told me not to do it, but it made sense why she asked in retrospect."

On one occasion you almost said yes just to see what her reaction would be.

A. Yes, to see what her reaction was.

Q. You also say you always would see two doctors when you went to Great Ormond Street in the years following your diagnosis. There was a haemophilia doctor. There was another doctor that was very nice but you didn't know why she was there.

A. No, not in that sense. And that was normal. Every appointment I went to, I saw two doctors. Now I know one was my haemophilia doctor and one was my HIV doctor. There was a special clinic downstairs at Great Ormond Street where all the boys who were infected with HIV would do. What Great Ormond Street had done is they had got an HIV doctor from Mortimer

Market clinic in London who came over and regularly held clinics with the boys who were HIV positive to make sure they got the best care.

Q. You also recall in your statement a time when you were about ten years old and you had headaches. You were admitted to Great Ormond Street and had a lumbar puncture. Your parents were very upset.

A. Yes.

Q. In retrospect, you understand why.

A. Yes. Obviously every parent is upset when their child is unwell, but I had had headaches for about a month and I couldn't shift them, and I was still going to school. Eventually they became excruciating. So we went to the hospital and they carried out various tests, and it resulted in a lumbar puncture. I think a small percentage of people then have back pain as a result of the lumbar puncture, and I had that back pain. I was bent double for about a week. I couldn't eat anything. Well, I could, but if I ate it, I would immediately bring it back up. So I was in hospital on a drip for a good week or so. I remember actually I went home for a time after the lumbar puncture. Then I think I had been playing in my bedroom with some Lego and I bent over. That's where the pain really started, so I went back to Great Ormond Street,

where I was an inpatient for a week or so.

I think my parents were always worried anyway because of my HIV, but that really caused them to worry.

Q. During your childhood and teenage years, in terms of physical symptoms, you have described having swollen glands, oral thrush, but that was all relatively minor.

A. Yes. Yes.

Q. But you recall that sometimes you would cry yourself to sleep thinking you were going to die.

A. Yes, a couple of times. As I say, I didn't come to that realisation quickly. In the first few months there were some dark times when I was worried. I think I said in my statement, I remember back to people like Freddie Mercury, who died in 1991, which was incredibly recent in terms of when I had just been told about my diagnosis. You would think if someone like that, who -- presumably with all the money he had, he could have been -- he would have been able to get private health care with effectively the best health care in the world, he still succumbed to it. That was something that was a constant reminder, and I suppose Freddie Mercury and Queen music generally, that it sums up I think what a lot of people feel

about what has happened to them. One of the lyrics talks about, "I have served my sentence but committed no crime". I think many people feel like that.

Q. You later learned that you had also been infected with hepatitis C.

A. Yes.

Q. Can you recall anything about that?

A. No. I don't know when I was told I had hepatitis C and neither does my mum, and neither does she in relation to my other siblings. I simply don't know when that happened. As crazy as that sounds, because, of course, if you were told, you would like to think you would remember, but I think in the scheme of everything, HIV, hepatitis, haemophilia, you would put it in that hierarchy. And later on, things like variant CJD as well would be some way down the list compared to everything else you were told about.

So I am not sure if it was something I was specifically told about at some point or my parents were and it paled into insignificance because of my initial diagnosis, but no, my parents don't remember and I don't remember. I remember when I moved my care from Great Ormond Street to the Mortimer Market clinic for my HIV, at some point having a conversation with my doctor about it and then receiving treatment later

on.

Q. You have since noted in your medical records in around 1984 a record of abnormal liver function tests.

A. Yes.

Q. As far as you are aware, nothing was mentioned at the time to your parents about hepatitis?

A. No. You saw from the UKHCDO record there are two hospitals mentioned, Great Ormond Street and Wexham Park, and in my medical records there's a letter from Great Ormond Street to Wexham Park hospital with my ALT level, which is significantly elevated, but that may or may not be an initial indication of hepatitis C at the time, and that was in April 1984. But as far as I am aware, there was certainly no conversation with my parents prior to them learning of my HIV diagnosis that I may or may not have been infected with what would have then been non-A, non-B hepatitis.

Q. At a later stage what, if anything, did you learn about the risk of vCJD?

A. I was written to, like most people, I think, in 2004 to advise, "You may have been exposed to variant CJD". I think from memory I probably was. But, again, it paled into insignificance with my other diagnoses.

Q. How was your health physically during your teens and adulthood? What treatments did you receive for HIV?

A. My health was good despite anything. If anything, my haemophilia has caused me more problems and issue than certainly my HIV and hepatitis in terms of joint damage. I can't touch my left shoulder and both my ankles are severely arthritic.

Initially we talk a lot about CD4 counts and viral loads for those people with HIV, and I had no CD4 count whatsoever, which is one of the reasons why my parents were so incredibly worried about me getting ill, things like chickenpox at school, for example. So I had no CD4 count whatsoever, so I wasn't able to fight off any viral infections. And my viral load -- I am not sure they were even testing it then.

I moved on from the liquid AZT to tablets in AZT, and then I think I went through several different medications. One was called DDI, which was a tablet which was dissolved in a bottle of water. Then I moved on to triple therapy, three different tablets I think twice a day then. I now take triple therapy once a day.

Around the age of 17 I started to develop a CD4 count. So rather than get ill, I actually started to get better. At the time I had a lot of warts, or a couple, maybe four or five on my hands, and a lot on one of my big toes and on my feet. I had been sent to

the dermatology clinic. I had had them frozen with liquid nitrogen and that didn't work. But I started on this new medication, I started to get a CD4 count and my warts disappeared almost overnight. So it was apparent to me that I was seemingly, with the medication, getting better.

Q. You did, I think, have a reaction to one HIV drug with a rash all over your body in your childhood.

A. Yes. 3TC. It was a little diamond tablet. Yes, it was either that or a jar of Chicken Tonight which mum cooked for dinner. Either way, we didn't have Chicken Tonight again for dinner, which was a bonus. But, yes, we think it was the 3TC.

Q. You had an occasion during your adulthood where you thought for a period of time that your HIV may have developed into AIDS. Can you tell us about that?

A. Yes. In around -- I think from memory around 2004 I had a mole on my back just by my right scapula, and I had been on holiday and it had started to hurt. Obviously I couldn't see it myself, so I couldn't tell whether it had got bigger at all, but it had started to hurt and be a bit painful, so I was again referred to the dermatology clinic. By this time I was at University College Hospital. I was referred to the dermatology clinic, and I was -- I went to have it

removed under local anaesthetic. The registrar who had removed it told me at the time when he removed it that he thought it was a lesion. I forgot -- you will be able to prompt me.

Q. Kaposi's sarcoma?

A. Kaposi's sarcoma, thank you. A Kaposi's sarcoma lesion, which meant nothing to me. I was then to go back two weeks later for a follow-up appointment.

Two days later I happened to be doing some summer work at a particular place and I was reading some papers in relation to something, and there was somebody I was reading about who also had HIV and also had Kaposi's sarcoma. The doctor had written in his notes that that meant his HIV had progressed to a diagnosis of AIDS.

I went home that night -- I was still living at home with my parents -- and spoke to my mum, who had been at the appointment with me. She had understood the import of what the doctor had said when he said it, but she had not told me so as not to worry me. But I then had 12 days thinking I had progressed from having HIV to AIDS, which of course was an absolutely petrifying time.

I went back to that appointment and I saw a different doctor, a different registrar, who told me

it was benign and nothing to worry about. But it was quite clear -- and the new doctor, as it were, the one I hadn't seen previously apologised to me because it was quite clear what the doctor had done is he had seen the lesion, seen my diagnosis and added two and two together and come up with five. But that didn't help me at the time.

Q. Did your parents tell many other people of your infection?

A. No. No. It was a secret. It felt like a dark and guilty secret. But no, it was our family secret and still largely is. There are very few people who know.

Q. That remains the case to this day?

A. Yes.

Q. This is probably the first time you have spoken publicly --

A. Yes.

Q. -- about what you are describing. You have explained in your statement that you

Yourself first told somebody that you had HIV as a teenager. You told your first girlfriend and your best friend around the same time.

A. Yes, I was about 16 when I told my first girlfriend and best friend.

Q. What was their response?

A. Didn't bat an eyelid. They were teenagers and just got on with life.

Q. In terms of your work life, you don't tell people you are HIV positive.

A. No.

Q. You explain in your statement that merely disclosing the fact of your haemophilia in early years had led to discrimination, to you not getting work.

A. Yes. My brother and I were both applying for weekend jobs. At the time we were teenagers and wanted a bit of part-time work and money in our pockets so we could go out with friends. We were both applying for jobs and we'd fill out forms, and under the disability section at the end we would fill out we had haemophilia, and you wouldn't get a thing back. You wouldn't get a phone call, letter, nothing. You might think once or twice that your application form got lost or there was someone better, but after four or five times you start to realise there's a reason they are not getting back to you.

So we both decided to apply for a job and not put on our haemophilia diagnosis, and two days later we both had a job.

Q. It is that experience and your own knowledge of the stigma associated with HIV and AIDS that has led you

not to tell people about that.

A. Yes.

Q. You have described in your statement an incident in the course of your working life when you overheard a discussion about someone with HIV or AIDS. What can you tell us about that?

A. Yes. There was a client I was supposed to meet in my working life and there were some other people who knew about that client and they were speaking about his diagnosis quite freely in front of me, not in front of him, but then when I was due to see him, they made various comments to me about being careful, et cetera, which I internally laughed at, because I obviously knew that my diagnosis was the same as his.

Q. And you have said this in your statement:

"My experience has done nothing to disabuse me of the notion that attitudes towards the virus had or were changing."

A. Yes.

SIR BRIAN LANGSTAFF: Did you mean attitudes weren't changing?

MS RICHARDS: Yes, I'm sorry.

SIR BRIAN LANGSTAFF: I think that's what you meant to say.

A. Yes.

MS RICHARDS: In terms of your personal and family life, you met your wife while you were still a university student.

A. Yes, I was at the end of my first year at university.

Q. You later married. Your wife was fully aware of your HIV diagnosis. There then came a time when you discussed having children. What process did you go through?

A. We went through the only process that you could really at the time, which was sperm washing. We were fortunate on the one hand to be living in London. The only place that I am aware in the country that did sperm washing was the Chelsea & Westminster hospital. We had to go to -- I spoke to my HIV doctor about it, who referred me to the GP because we then had to go and make an application to our local London borough at the time for funding. We eventually did get funding and we went through a round of sperm washing at the Chelsea & Westminster.

Q. That was not successful.

A. No, it wasn't, and one of the side effects of the HIV medication is it reduces significantly your sperm count. So, no, it was unsuccessful the first time.

Q. And then you had difficulty or you weren't able to obtain funding for any further rounds because of a change in NICE guidance. Can you tell us about that?

A. Yes. I think initially we decided that we weren't going to go through a second round of applications. I think the first time you apply it is almost a given that you will get it, but the second time it is I think a bit more of a battle. My wife and I took the decision that having children was never something that was going to make or break us. We were together for each other rather than having children necessarily.

It was around 2008 I remember going to see my HIV doctor. I think he mentioned it first or I may have read it in the press before, but at the time there was something that became known as The Swiss Statement in 2008, and The Swiss Statement was a statement by a number of Swiss doctors about the fact that if you had an undetectable viral load, then you couldn't pass it on. We are now of course talking about the U=U campaign. It was relevant I think mainly in Switzerland because of the law in relation to criminal law about whether or not you could consent to being infected with HIV, effectively, and people having sexual relationships. So it was of interest in that respect. The NICE guidelines changed and it felt contradictory in the sense that it still said that if one of you was infected, you should have protected sexual intercourse, but it also said that if you wanted to conceive children, then you should consider doing it naturally.

Q. And you understood that that would be problematic in terms of obtaining any further funding for any further rounds of sperm washing.

A. Yes, I think that was part of it. That was obviously a limiting factor in any consideration for any further funding.

Q. You have said this in your statement:

"It felt cruel that we were not able to conceive children naturally due to NHS treatment but then would have to fund anything more than one round of treatment."

A. Yes.

Q. You also in your statement, discussing the impact, practical impact of stigma, talked about issues relating to travel to the USA. What can you tell us about that?

A. I think that's probably where I have experienced the most stigma in relation to HIV. I think I have been to the US maybe -- as a child I went a couple of times with my family but knew nothing of what was going on.

Back then my parents would have had to apply for a visa for me to enter the country. When Barack Obama was president, he changed the law in America in relation to people with HIV having to apply for visas, so I no longer had to apply, but there was one occasion before the law changed when I was in my early 20s. My best friend had been off travelling around the world for several months. I was just about to start a new job and I was going to go out to meet him in Los Angeles for a couple of weeks for us to meet up and have a bit of a holiday before I sort of settled down with work. I had to go to the American Embassy for an application. It was just before the summer. When I got there, there were lots of other people in their early 20s. They were going on sports camps and the like, so they were applying for visas, and they were sat in the waiting room. I was petrified that people were going to ask me why I was there. Where was I going? What fun was I off to have? Why was I getting my visa and things. So I kept my head down. I think I might have had a newspaper with me and buried my head in the newspaper.

When I did go through, I had an interview with an immigration officer from the US. It felt like a police interview. They asked me a series of

questions, and then they started again and asked me the same series of questions to see if I gave a different answer.

I don't think I had any issues when I entered the US that time, but on other occasions when my wife and I have been, although I don't need a visa anymore, there is always a marker on my passport. So when I went to New York, I remember spending about an hour trying to get through customs. Immediately my passport -- they didn't let me through, I was taken off into a room. My passport was take away. They carried out various investigations. They didn't really say much, if anything, to me. I eventually said to them, "Is this why you are checking, because there is a marker on it?" They said there is.

I think the worst experience was when my wife and I were in Canada and then went to US. We had been travelling to see some family. We had been to Vancouver and over to Victoria Island. When we were there, we got the boat from Victoria to Seattle, and the procedure is that you clear US customs before getting to Seattle so you can get straight off the boat and get on with the rest of your holiday. My wife and I got there early because the boat trip itself is part of the journey, in the sense that there

are whales and dolphins and nice things to see, so we thought we would get there early and try to get a good seat on the boat and sit near the window. So we did, and I think we were one of the first ones there, but we were the last ones on the boat because, again, there was a marker on my passport. I was taken off, pulled into a separate room with my wife. There was another man sat there. He was Australian. In some sort of search he tested positive for gamma radiation because he had terminal cancer. He was on a round-the-world tour with his wife before he eventually died, so he was in the room as well. There was no privacy whatsoever. We both knew -- not that either of us were going to go and shout about each other's diagnosis, but we both knew exactly the other person's diagnosis. And we sat there like criminals in a police station custody suite. It was horrific. And having been, as I say, the first ones there, we were the last ones on the boat, and I don't think we got a seat if at all. It soured what had been otherwise a very good holiday.

Q. In terms of medical care, what effect has the potential exposure to the risk of vCJD had, if any, on medical care you have received?

A. It's had an impact. One particular example -- I have had two inguinal hernias. The first time I had the operation at the Royal Free Hospital it took place without incident. The second time I had it, I had been for my preliminary appointment and seen the consultant, and on the day I think his registrar was carrying out the surgery. I had gone in on the Thursday night. I am self-employed, and so I had deliberately taken time off work and managed my diary. Because of my haemophilia, I knew that, unlike most people who have hernia operations, who can go in and out on the same day, I would have to stay in for a couple of days to have my Factor VIII levels monitored. So I deliberately did it with the weekend in mind so as not to miss work.

I was woken up in the small hours of the morning by the phlebotomist and had a cannula put in me, which even as a haemophiliac, having injected myself thousands of times, it's never a pleasant experience, especially at that time of the morning. Then at 8 o'clock I had been nil by mouth since the night before. The registrar came round to inspect my hernia and said to me I was going to be first down the next morning -- that morning in terms of surgery, which I thought was quite unusual, because I think most other people at the Inquiry have talked about being

the last one down because of their infection. But for whatever reason I was put to the front of the list. He said, "You will be down shortly around 8.30".

So 8.30 came and went. 9 o'clock came and went. By this time I was starting to get a bit anxious and wondering why I had not been taken down to surgery. I spoke to one of the nurses. She said, "Oh, I don't think you are going to be taken down now". I said, "Do you know why not?" She said, "No, but let me try to speak to the surgeon". By this time I was getting quite angry, because I felt I was being fobbed off. I demanded to see the surgeon and I was told, "You can't, he is in surgery".

So in my gown, I think with the cannula in, I walked off the ward and I walked down to the Haemophilia Centre. I walked in and I spoke to my doctor there and I said, "I am being taken for a fool upstairs". I said, "You need to go and find out what's going on, please". It transpired the reason I wasn't being -- or at least the reason I was told I was not being taken down for the surgery is because the Royal Free didn't have any disposable equipment to carry out my operation that day, and so I would be sent home and my operation would be rescheduled.

I subsequently spoke to my HIV doctor about that

and he didn't accept that for a moment. He is a very mild-mannered man, but he said, "I don't believe for a second that a major hospital in London like that did not have the equipment to carry out the operation" on me. I suspect that the registrar -- he was struggling to find the hernia. The consultant had found it, but the registrar was struggling when he came to see me. My feeling is that he was scared to operate on a haemophiliac, not being able to find the hernia. But at least the ostensible reason I was given for the operation was they didn't have disposable equipment for the operation.

Q. Your treatment for your HIV over the years, you say in your statement, has been very good.

A. It's been excellent.

Q. And you have said you wished others had been as fortunate in that respect.

A. Yes.

Q. You have identified two particular respects in which your HIV care has been good. First, as you have already alluded to, you had specialist HIV care from an early age.

A. Yes.

Q. Rather than simply being cared for by a haematologist for your HIV?

A. Yes. The haemophilia doctors at Great Ormond Street, I understand from my mother, were incredibly proactive about getting that care. As I say, it wasn't just someone else from the hospital; they got a specialist HIV doctor in from the Mortimer Market Centre, and they set up a specialist clinic for all the boys at Great Ormond Street who were infected to be treated and looked after and to fight to get the first medication.

Q. And that's continued over the years; you have had specialist HIV care.

A. Yes. I have the option of having my HIV care at the Royal Free Hospital, but I choose not to; I go to a specialist HIV centre for it.

Q. A second factor about your care identified in your statement is the continuity of care you have had, especially for your HIV. You have only really ever seen two doctors.

A. Yes, and my second doctor is about to retire, which shows you how long I have been with him. So, yes.

Q. What was your experience of treatment for hepatitis C?

A. My hepatitis C treatment was also treated through the Mortimer Market Centre, through my doctor there, Dr Ian Williams, and the hepatitis C medication was horrific. I had my first injection at the clinic.

I went there on a Friday morning to be injected. I then went to work that day and I went out that evening. I had been warned about the side effects and how debilitating and crippling they were, but I had also been given several other warnings prior to other medication and none of the side effects had really materialised. So I think there was probably an element of naivety from me that I felt it is fine, you just have to tell me all these things and none of them or not many of them are actually going to be real. But it was horrific.

I was out in central London at the time, and it was about 8 o'clock when it just came over me. I was living in south-west London at the time. I just had to hail a black cab and get in the back of a black cab and get home. When I got home, I got undressed and I got into bed and -- it is impossible to explain to somebody who's never experienced it really. It's the worst flu you have ever had multiplied by ten. I was hot. I was cold. I felt sick. I felt suicidal -- all in one night.

I think it was quite a warm evening, but there would be times when I would be under the duvet shivering and then there would be times when I would have the duvet off and wearing hardly anything and I'd

be sweating. I couldn't eat. I struggled to sleep. My wife effectively nursed me, and on Monday morning I got up and went to work.

Q. You have said in your statement, and I think this was around 2006 that you had this treatment, you would inject the treatment at home after that first weekend on a Friday evening. You would be ill for the weekend.

A. Yes.

Q. You'd just about start functioning by the Sunday and then you would try to get to work on the Monday --

A. Yes.

Q. -- and work through to the Friday again.

A. The nature of my work meant that I always had preparation to do over the weekend, and so on a Sunday I would need to prepare. As you say, I would be just about functioning. On Monday I would still feel ill, but I was self-employed. I had no choice.

Q. You took that treatment for how long?

A. About six months, I think.

Q. You did clear hepatitis C after that first round of treatment.

A. Yes.

Q. But you say in your statement that you realise, and it is only through hearing evidence that you have heard

during this Inquiry --

A. Yes.

Q. -- that you have continued to suffer with brain fog and memory issues.

A. Yes. Lots of people have spoken about that. I used to have an incredibly sharp memory, being able to remember names, faces, where I had met people, but now -- last night, for example, I went out to dinner with my wife and I can tell you what food we had and roughly where it was, but I can't tell you the name of the restaurant. Those sort of things just escape me. It is only after several times of maybe doing something or being somewhere that I will eventually remember the name of where I was or that sort of thing.

Q. To what extent has counselling or psychological support been made available to me?

A. I think there are probably two aspects to that. When I was at Great Ormond Street, again, Great Ormond Street had a counsellor, a lovey lady called Candy Duggan. For much of the time I didn't know she was a counsellor. I spoke to her, but it wasn't -- I wouldn't describe it as a formal counselling session where I went in, it was a case of, "Right, we are going to sit down and talk about things". It was

a general friendly chat to see how things were going, that sort of thing.

I know that -- I think one piece I haven't mentioned previously, but when I was at Great Ormond Street, I know I was monitored and tested because of my HIV. There were various psychological testing that took place with my parents' consent, obviously, and I had CT scans on my brain and things to monitor me.

When I had my hepatitis C treatment, I think I was offered counselling before that by my doctor, Dr Ian Williams, and I think once or twice afterwards, but it was never something I felt I wanted or needed.

I remember another witness saying previously that he felt counselling should have almost been something that was thrust upon you. I think I wouldn't disagree with that. I think it is something that undoubtedly does help, but it was offered to me, but not very -- not overly, not persistently, but it was there if I wanted it.

Q. In terms of your parents, who were told in the 1980s that their 4-year-old had HIV, were they offered any form of counselling or psychological or other support?

A. I don't think directly, no. I think they -- like so much of the NHS, one part was left to fill in for the other. I think the haemophilia doctors did most of it. I know when my dad was suffering from depression it was a conversation with the haemophilia doctor at Great Ormond Street that helped him to go and see somebody about it. So I don't think they were ever formally offered anything, no.

Q. Your parents participated in the group litigation, the HIV litigation.

A. Yes.

Q. What is your understanding and view of the way in which that litigation was compromised, having spoken, I think, to your parents about this issue?

A. Yes. My parents were at lots of the meetings in London and it was -- from what I understand, those meetings were incredibly difficult, because on the one hand you had young boys, and they were boys, who were dying, who were being promised this money from the government, and on the other hand you had people like my parents, who had a young son, for whom to a degree they could provide for and care for and look after, who wanted to go to court and seek a better settlement in relation to everyone's infections, and I think the words I am sure have been used before, but there was a form of emotional blackmail that went on in all of this. It wasn't just government pressuring the people into accepting it; it was because of that promise that

was being held out to those people, those people were indirectly putting pressure on the others who wanted to remain resolute and say "No". My mum firmly believes that if the waiver hadn't been signed back then, we probably wouldn't be where we are now.

Q. Then you I think a number of years later approached solicitors about the possibility of challenging the waiver.

A. Uh-huh.

Q. What were you advised?

A. Yes. The solicitor that represented my parents at the time -- I was going to be one of the test cases when the case went to court, because it was thought I was infected through British product rather than American product. The solicitor had since left the firm of solicitors and I think was teaching in Nottingham. I contacted him about challenging the waiver, but his advice to me was there was no way to challenge the waiver.

Q. You have termed the way in which the litigation was compromised in this way in your statement:

"A disgraceful sleight of hand".

A. Yes, especially with the hepatitis C infection, the fact that that was added so late on, seemingly, when people didn't know of the fact that they were infected

r the extent or the potential damage that would have caused.

Q. You applied, I think, only once to the MacFarlane Trust for a discretionary payment.

A. Yes.

Q. That was for a laptop for study or work-related reasons.

A. Uh-huh.

Q. What was the response from the MacFarlane Trust?

A. Reluctantly they gave me the money. They said that they knew how much people in *[redacted]* earned, so "Don't be asking again", effectively.

Q. You have described that again as disgraceful. You were made to feel guilty for asking for anything.

A. Yes, yes. Despite everything that had gone on, I had gone to university. I had studied, I had worked hard and I had achieved well, I thought, and despite all of that, they simply said to me, "Don't ask again", effectively.

Q. Your witness statement says that you have by and large been fit and well.

A. Yes.

Q. And that you have tried to live your life by looking forward, but also this, appreciating, as you do, that you are lucky to be alive, and fortunate, you say, in

some respects in terms of the care you have received.

A. Yes.

Q. "Living with my infection is like having a constant cloud hanging over."

Is that right?

A. Yes. I think despite everything, so many people have described themselves as lucky. I think I was discussing this with my parents and family recently and I described myself as one of the lucky unlucky ones.

MS RICHARDS: Those are the questions I have for you. I am just going to ask Ms Gollop if she has any questions.

No, there is nothing further. Is there anything more that you would like to say?

A. Just one or two bits. I won't be particularly long. It has become customary, Sir Brian, for people to

Make closing remarks. I don't want to shy away from that custom.

SIR BRIAN LANGSTAFF: It is not obligatory.

A. No, I know. I want to start by publicly saying thank you to

Several people. First and foremost my parents. I can't begin to imagine what you have gone through, and your strength and courage continue to inspire me.

I dare say you often ask yourselves if you did the right thing, and the answer to that is a resounding yes.

Next to my brothers. Growing up wasn't always easy, and at times we had to grow up a little quicker than others. It was always fun and continues to be. So thank you for being there.

Then to my wife. Many would have run the other way. You ran into my arms. I still ask myself why, and I am forever grateful that you did. Words can't express my gratitude to you, so I will simply say thank you.

There are many healthcare professionals that I would like to publicly say thank you to, but due my anonymity, they would never hear it. There are many doctors, nurses, physios and others who have got me to where I am. One of the great things about the haemophiliac community is because it is a lifelong condition, many of those people also become friends, and it is my privilege to know them all.

I want to turn then to what I call my piece of the jigsaw, and I hope you will forgive me for trespassing on what might be considered exclusively your territory, but something I have struggled with whilst listening to others give evidence is where my

piece of the jigsaw fits. I wanted to make some observations about how I feel my account fits into the bigger picture of the Inquiry generally.

So many people have given evidence of how they have been let down and the catastrophic impact it has had on their life. Whilst my story is not all good, overwhelmingly I have had a good experience in terms of the response to what has happened, which begs the question: what should have happened?

In my view, a comprehensive database of those infected should have been set up. Haemophiliacs should have been systematically tested and a comprehensive look-back exercise undertaken to ascertain those infected from the whole blood community. Specialist clinics should then have been developed with the leading experts treating those infected, experts in HIV, experts in hepatitis, counsellors, dentists and anything else the infected were struggling to cope with.

Had that happened, I firmly believe many more people could have ended up in my position, namely having been able to lead a fulfilled life, despite the devastating infection which had befallen them. I am not naive enough to think all could have been saved, but undoubtedly many more should be in a better

position than they are.

In terms of where I believe my piece of the jigsaw sits, I believe I am an example of what could have been achieved had a coordinated and comprehensive response been instituted. Instead, what happened was the most egregious dereliction of duty by a country to its citizens in modern times. The government made us more vulnerable with deadly infections. Whether that could and should have been prevented is a matter for this Inquiry. What is abundantly clear, however, is that of the government's response was worse than mere apathy. The government actively compounded our community's plight with campaigns, such as the AIDS tombstone campaign.

Much is talked about in relation to money and compensation. Many people who had money have spent it filling the gaps left by a lack of government response, on hepatitis treatment, for example.

But what we as a community want is about so much more than money. Day after day, week after week, the Inquiry has heard accounts of people's personal battles with their viruses. In reality, we have been waging a war, not just against our viruses but against government. Government has tried to subdue us. They continue to ignore us and continue to do battle with

us. Why? Where is their recognition of our struggle?

We today see the public health campaign U=U, meaning undetectable means untransmittable in relation to HIV. We all remember those tombstone adverts. We should now be celebrating the U=U campaign, and its principal champion should be government. They should be endeavouring to undo large aspects of the harm they themselves created, but instead it is left to charities like the Terrence Higgins Trust to promote such news. Again, where is our government in all of this?

We are tired of meaningless apologies. We are tired to platitudes in relation to this being something that should never have happened. As a community, in future we will judge you by what you do, not by what you say. If you want a list, here is a starter for free.

Start a public health campaign backed by government in relation to U=U.

Secondly, level out the support payments across the UK as a matter of urgency, by the end of this year at the very latest.

Thirdly, start a look-back campaign now. Do not wait until the end of the Inquiry. More lives will have been lost if you do.

Then I turn to my country and I ask: why have you forsaken us?

Sir Brian, you said last week in your opening comments that no-one could fail to be moved by what they have heard. Sadly, I don't believe enough politicians are listening. Why when Diana Johnson MP writes to the Prime Minister, Boris Johnson, is a letter received from Oliver Dowden MP? Is the death of over 3,000 of his country's citizens not important enough for the Prime Minister to respond?

I don't believe it is an accident that when David Livingston was Cabinet Office minister and attended the opening last September, he remained engaged. Politicians must engage now, but not just politicians. Our Royal family and celebrities. With some notable exceptions, politicians of all hues have ignored our plight for decades. But not just politicians. Why have our Royal family never acknowledged this immense tragedy. Haemophilia is known as the Royal disease. Why the dis-ease about acknowledging us?

Perhaps the Queen will see fit to mention it in her Christmas speech this year. Perhaps Princes William or Harry would like to meet some of the victims of this tragedy and gain a true understanding

of the stigma our community has endured. And celebrities who use their profile to try to end the stigma around HIV. Why has no-one ever championed our cause? We have no celebrities queuing up to write a song and raise money to support our community, or to highlight our profile to the public or to ensure we are at the top of the political agenda. Only last weekend Sir Elton John said, "The traumatic thing is still the stigma". As a community we seem to have a stigma all of our own.

Lastly, money. Since July I have been in receipt of the higher rate of payments from the English infected blood support schemes. I now work part time and *[redacted]*, and at the moment that is becoming somewhat of a part-time job, for which I am not allowed to be remunerated. The additional payments have given me a significant amount of breathing space in terms of being able to balance my work with the other demands on my life. The impact for others who have not been as fortunate for me is surely immeasurable.

Why then does government continue to ignore the plight of those in Wales and Northern Ireland in particular? What happened happened on the Westminster government's watch. Westminster must respond. Whilst

health may be devolved, responsibility cannot. It is further evidence of the government's lack of humanity, which is in stark contrast to that shown by you, Sir Brian, and your team.

The manner in which we have been treated by you and your team has been exemplary. The hearings themselves are so much more than allowing people to tell their personal stories. They have allowed people to come together and share experiences they thought only they had been through. Alongside the recognition it provides, it has allowed people to realise they are not alone. There will be more difficult times ahead, but I feel we are in safe hands.

So, finally, let me thank you, Sir Brian, and all of your incredible team.

SIR BRIAN LANGSTAFF: Can I, before I respond to your thanks to us, just ask you one question, if I may.

Despite the clarity of everything else you said, there was one expression you used which was a little Delphic. It was your mother's saying to you: "If things had been different, we wouldn't be where we are now."

What do you think she meant by that?

A. I think she feels that if people hadn't signed the waiver and things had gone to court, things wouldn't

be as bad for the community as they are now. I think she feels had the case eventually gone to court and been litigated, people would be in a better position now.

SIR BRIAN LANGSTAFF: So she would be looking to the litigation and success from the litigation, that's what she had in mind?

A. Yes, and of course it then wouldn't have barred any further claims in relation to hepatitis as well, which was one of the big issues which transpired after that.

SIR BRIAN LANGSTAFF: Thank you for that. It remains for me to thank you, and particular thanks, I think, because you have delivered a very clear account and, indeed, made at the very end those very clear recommendations, the comprehensive -- coordinated, compassionate and comprehensive response you are calling for. I have heard that and I shall remember that, even if I had difficulty in putting the words in the right order.

But particular thanks because it is obvious that you have managed to give us a very clear account despite the emotional rawness which this has to you, and despite what is obviously, as you put it, a very private family matter, although I see the front row, who are here to support you, and that makes it all the more courageous for you to feel, I think, that it was your responsibility to come, rather than your pleasure, to tell us about what you have. So thank you.

A. Thank you.

(Witness withdrew)

SIR BRIAN LANGSTAFF: We will hear our next witness at 3 o'clock.

MS RICHARDS: Yes, sir.

SIR BRIAN LANGSTAFF: 3 o'clock.

(2.36 pm)

(Short break)

(3.05 pm)

SIR BRIAN LANGSTAFF: Our next witness would like us to call him Robert, would he?

MS FRASER BUTLIN: That's correct, sir.

SIR BRIAN LANGSTAFF: May we have Robert, please.

ROBERT IVAN HODGKINS (affirmed)

Questioned by MS FRASER BUTLIN

MS FRASER BUTLIN: Robert, you were diagnosed with severe haemophilia A when you were a few months old.

A. Yes, that's right.

Q. As a child, you were usually treated at the Hammersmith Hospital --

A. Yes.

Q. -- needing treatment about once a week.

A. Yes.

Q. You were on cryoprecipitate until 1973, when you started to be treated with Factor VIII.

A. Yes.

Q. At that time, when you changed to Factor VIII, what were your parents told about it?

A. Nothing, really. My mother, who was the one that looked after me mostly at hospital, I apparently had a bleed -- and I have very little memory of this personally -- she took me into the hospital, Hammersmith, and, in fact, when I was going to be injected, they brought out this syringe of clear treatment, whereas before -- cryoprecipitate is in bags. It is literally like a bag of plasma, but it was a yellowy colour, but you had vast amounts. I think even as an infant I used to have about 60 ml, which is an enormous syringe, whereas the freeze dried is tiny by comparison. She was worried. She told me she said, "That's not enough, that's not good enough". They literally laughed and said, "Oh, no, this is new treatment, this is much better, he will be fine, this is all he needs", and that was it. There was no information, no leaflet or discussion.

Q. You went on to twice-weekly prophylaxis in about 1976.

A. Yes, I did.

Q. You have looked at your medical records and you think you received something in the region of 3,500 injections between 1969 and 2003.

A. I think so, yes.

Q. And your Factor VIII treatment covered the full range of products: Cutter, BPL, Armour, Immune, Hyland products.

A. I had it all, yes.

Q. In late 1974, you were on holiday with your parents and became unwell. When you got home, your father noticed your eyes looked yellow.

A. Yes.

Q. What were you then told?

A. Actually it was the local GP came out. I had started to get very sick, vomit. I wasn't a chubby child, and I wasn't fat, I was sort of in the middle. I couldn't keep any food down apparently. I had a cramping pain in my stomach, abdominal area. I was just really quite unwell. They called the local GP, who was the family GP and they had known me from birth. My parents had lived in the house for quite a long time. They weren't locals, but they were known. He came out and he said -- he looked at my eyes and said, "I think your son has hepatitis".

Obviously my parents were -- they weren't medical people, but they were both reasonably quite well read. My father had been in the forces, actually, so he knew a bit about certain illness, and he said "Hepatitis? But he's a kid. How did he get that?"

Obviously then they contacted the Haemophilia Centre at Hammersmith, went in. I don't really remember much about this, but they obviously did tests. I got pretty ill. In fact, I believe I lost over a stone in weight through vomiting and not being able to eat anything. For my parents -- a 4/5-year-old, that's a lot of weight. The hospital was obviously very concerned. Over the period, I think for something like six weeks, six/eight weeks, I was ill, really quite ill, but slowly started to recover.

I believe they told my parents then, the doctor at the hospital, that it was confirmed to be hepatitis. I thought hepatitis B. My parents were really pretty -- well, you know, pretty staggered and it became clear -- it was in treatment with the doctor at the time, who was actually quite angry. In fact, I believe she tried to take it further, actually, to her credit really. She made a complaint and even talked about compensation. My father was angry. My mother was angry. How the hell could this happen? She said, "It is completely unacceptable", I remember. But it is a long time ago. I don't have a clear recollection. But that's basically what happened.

So from Hammersmith it was taken up, but nothing happened. She was told, I believe, to the best of my mother's memory, that it couldn't go any further. Obviously being pretty naive then. We all know why now, but at the time it was just a horrible thing that happened. It was an accident. I don't think I really questioned that, really. In a lot of ways, I don't think I really thought about it. I was like five years old, so...

Q. You have looked through your records. At that point there is a diagnosis of hepatitis B. Your recollection in your statement is your parents were also told you had hepatitis non-A, non-B at around about the same time.

A. That's right. That's right, actually. Probably further blood tests. It was called -- there was something called Australian antigen.

Q. Which is the hepatitis B.

A. Right. So that is that. The non-A, non-B was talked about. Frankly, I don't remember a lot about it. My

parents obviously knew it wasn't good and my liver was being checked. If I went into the hospital for my haemophilia appointment, they would take extra blood, and they used to prod me like they do and examine where the liver is, and they would be saying things like "Oh, that's okay, you know, that's not a problem", that sort of thing.

Q. Your recollection is that in about 1995, you think you were told you had hepatitis C.

A. Yes.

Q. But until then you hadn't been told that non-A, non-B was hepatitis C.

A. No, no, I hadn't been.

Q. The connection was only put in place for you in about 1995.

A. Yes, yes.

Q. You weren't told you were being tested for hepatitis C at that point.

A. No. No.

Q. But then since then you've cleared hepatitis C naturally?

A. Yes, I did, yes.

Q. But then in about 2012 your liver function tests were abnormal, and the doctors ran further tests. What did they tell you about those results?

A. The doctor I was seeing at the time for my liver at Churchill Hospital, Oxford, said that my -- some functions, as you said, were not 100%. I wasn't -- I mean, I like to drink, but I didn't have a problem and I wasn't a big drug user, I wasn't anything that put me in say a high-risk category.

Again, to my recollection she said, "I'd like to run some other tests. I have obviously some thoughts about it". So I said "Fine", you know. She did run those tests, and I saw her again for the next appointment and she told me that they had come back and it confirmed what she had a suspicion, that I had another hepatitis virus known as delta virus or hep D.

Q. What did she tell you about hepatitis D?

A. She told me that it was a very unusual hepatitis and she said, "You are unlucky". She said, "Even in your community it is very rare". She had come across it as a hepatologist before, but it is a bizarre virus. To survive, it has to use hepatitis B. In other words, it is like a parasitic virus of a virus. That then damages your liver. There is no treatment. It is progressive, but it needs hepatitis B to survive, and I had been exposed to hepatitis B, as we were discussing. So in my liver, where some of the virus was, there was this delta virus doing what it

shouldn't do, basically. That was about the extent. I didn't get offered any counselling. It was like a routine appointment.

Q. And she told you there was no treatment for it?

A. Yes.

Q. There were no options?

A. No, she did, yes, yes, yes.

Q. You were also told in the early 1990s that you had received blood products from someone who had died of vCJD. Your recollection is you have not been told anything since then.

A. Yes. I don't have any letters at home I could find.

Q. Your statement has been provided to the Churchill Hospital and they have provided a response to your statement, which will be published on the Inquiry website in due course, but they have also provided some letters that they say were sent to you about vCJD. We are just going to put a couple of them up on the screen.

A. Okay.

Q. Henry, please can we have 3063002, please. It's a letter from 3rd December 1997 and it sets out some information about vCJD. Then if we go over the page to the final paragraph, it says this:

"We would have preferred to have been able to have spoken to you personally about this issue. However, we hope you appreciate that the requirement to inform so many people in a short period of time does not permit this. Should you wish to discuss this further do not hesitate to call the centre to speak to us at the numbers above. In order to ensure that patients have the fullest possible information on all the issues and the reasons that we have taken this step, we have arranged for a meeting in lecture theatre 1 [and the date is there] to present the evidence and discuss the matter, to which you are invited."

Do you have any recollection of receiving this letter?

A. No, I don't.

Q. And you have obtained your medical records and substantial quantities of them. Is this letter in your medical records?

A. No, it is not.

Q. A further letter they say was sent in 2001. 3063004, please, Henry. We can see in the third paragraph that the records show that you had received some of the implicated batches. Then the final paragraph:

"It is regrettable that the Department of Health did not follow the unanimous advice of the UK

Haemophilia Centre directors' organisation and adopt the use of recombinant Factor VIII some years ago as this problem could have been avoided. It remains a matter of concern to us that recombinant Factor VIII and IX are still denied to most patients with haemophilia in England, although these products are now available to all people with haemophilia in Wales, Scotland and Northern Ireland. We shall continue to lobby on your behalf to obtain these products for all of our patients."

Again, do you think you ever received that letter?

A. I have no recollection of that letter.

Q. And is it present in your medical records?

A. No.

Q. You are also HIV positive.

A. Yes, I am.

Q. And I just want to look back at some of the documentation in the early 1980s to look at when you were told and what you were told.

Could we have document 0009002, please, Henry. This is a letter from August 1983. If we look at the third paragraph, we can see that the haematology registrar to your GP is telling them:

"We have decided to see all our haemophilia

patients more regularly in the routine clinic, and particularly those on home treatment who do not often get seen by a senior haematologist, as they have few problems. We are concerned about the acquired immune deficiency syndrome which has been seen in haemophilia sufferers in America and has now been documented in one patient in England with haemophilia who was treated with imported American Factor VIII. The main signs of the syndrome are fever, weight loss, rashes, diarrhoea and repeated infection."

They have noted earlier in the letter that you had some enlarged glands, lymph nodes. If we look just above the last paragraph:

"I rechecked his serum virology, but do not have the results yet.

"I am uncertain as to the significance of his slightly enlarged lymph nodes, but otherwise he seems to be extremely fit. We shall see him again in 6 months' time for another routine check, though if he should have any further infections, I would be grateful if you would get him to come up and see us earlier."

Were you aware of them checking for HTLV-III?

A. No.

Q. Were your parents aware of it?

A. No.

Q. You recall seeing a letter in your records in the context of the American litigation, a letter later on in 1983, saying you had tested positive to HTLV-III?

A. That's right.

Q. But that's not in your records anymore.

A. Well, it was in the original records I got a few years ago from the GP, and it was from the Department of Health. It was a letter to my GP saying basically that I'd been exposed to a virus called HTLV-III and that I was not a significant public health risk, but they were obviously informing them that this had happened. But I think it was October 1983. I had a copy. Because I, like a lot of the people involved, didn't think it was going to have the chance -- didn't think we were going to have the chance to have a public inquiry, I got rid of the letter. I don't remember getting rid of it, but I got rid of it. But it was a definite letter that existed.

The reason I remember it was different from this letter is because it actually stated on there HTLV-III and it was from the Department of Health. It wasn't from the Haemophilia Centre, but the Department of Health saying that I wasn't a severe health risk. I don't know what that meant. Presumably they would come round in hazmat suits to collect me, but they were not going to do that now. I had no idea the letter existed, that's why I kept a copy, because I showed my mother, because at the time I would have been 15, and they had no information from anybody about that whatsoever. I mean, I had never heard of HTLV-III. I didn't know what the hell it was or didn't want to know what the hell it was. You know, I was fit and hanging around with my friends at the time.

SIR BRIAN LANGSTAFF: May I just ask you how sure you are about the date being 1983. Let me tell you the reason I ask. My general understanding is HTLV-III was labelled in that way after the virus had been isolated for the first time in April 1984, although there had been a similar virus identified known as LAV about a year previously. So if you perhaps might be mistaking October 1983 or October 1984, that --

A. The thing is, I don't have the letter, but it definitely did not say HIV.

SIR BRIAN LANGSTAFF: No.

A. It definitely did not say HIV.

SIR BRIAN LANGSTAFF: But it is the date I was really asking about.

MS FRASER BUTLIN: Sir, it might assist to look at the next document that we were about to go to in relation to dates, if I may.

SIR BRIAN LANGSTAFF: Please.

MS FRASER BUTLIN: 0009005, please. This is a medical record from 15th January 1984. It will come up on our screens in just a moment. We see in the top left corner the date, 15th January 1984. If we go down towards the bottom, there is in brackets:

> "Started heat treated Factor VIII (HTVL-III antibody positive)."

SIR BRIAN LANGSTAFF: And the date?

MS FRASER BUTLIN: The top of the letter says 15th January 1984.

SIR BRIAN LANGSTAFF: Yes. Can you just scroll down again. Thank you very much.

MS FRASER BUTLIN: In the margin, which is highlighted -- just above that, Henry, if we go up a little, we can see, "FBC profile", full blood count profile, "virology and store HTLV", what I think is shorthand for "antibodies".

SIR BRIAN LANGSTAFF: Yes.

MS FRASER BUTLIN: Again, in 1984, were you or your parents aware of this?

A. Not at all. I think the first I have ever heard or remember hearing was off -- which I know others have said -- a TV programme, documentary. I recalled it was Panorama, but I can't -- I think it was the BBC and it was about the infections for HIV in America. That was in the '84. So I heard that for the first time. It caused -- obviously it was pretty overwhelming. My parents were obviously shocked, and then got a call from Hammersmith saying, "We just want to give you a call. A lot of people are worried. It's been on TV". The irony is they were actually angry at the BBC. They said, "We are thinking of taking an official complaint about the BBC because they are talking about a virus in America and being infected with it". So obviously they were angry that that information had come out.

Q. In your statement you have placed that at about November 1985, when you then went in for an appointment with your parents.

A. It was -- yes. I found out from the doctor at the time, who basically had done a test -- I thought it may have been actually 1984. It could have been the '84, but I --

Q. If we look at 0009007, we can see an entry from 26 November 1985, which says you were advised of your status then.

A. The reason I say that is because my -- the doctor that was looking after me at the time had a colleague who had been training or partly trained, if I can remember, at Professor Robert Gallo's laboratory at -- in the American Cancer Institute, which is partly credited with discovering HIV. The test had become available, and that was in the '84. What I remember is that they took mine and so many others -- I think about 12 people's blood and flew the blood sample to America to have it tested at the laboratory to confirm whether it was HIV and then the results would be faxed back, and that is what happened.

I went to Hammersmith Hospital with my parents. I thought it was the '84, but it might -- I thought it was, because the tests had only just become available, and I know officially, or what I believe was officially, it wasn't really recognised until the '85, but I got an early window, as it were, on it, because this colleague had done a favour to the doctor, which is possibly why there isn't any direct record, because it was a bit under the radar.

Q. Whenever that appointment was, what was your understanding of what you were being told?

A. That I had been exposed to HIV. That was basically it.

Q. What did your parents understand that they had been told?

A. My mother -- by the time I was told, I was 16, so my mother wasn't in the room. The doctor said to me -- I can remember she said, "We are not asking anybody to say do you want to know, but if you'd like to know, I'm prepared to tell you", and I said, "Well, there isn't much doubt that I've been exposed to it, is there?" and she just smiled and said, "No, you have been exposed". And then I said, "Well, I think my parents should be told", and because she had known, obviously like a lot of haemophilia doctors, the family and knew my mother, she just nodded and said, "Okay, that's fine". I said, "Can I go and get her?" and she said yes. So she went and got her.

My mother sat there, and we had obviously been talking about it, and the doctor said, "I am afraid Robert -- it's come back and he has been exposed to HIV". Unfortunately my mother, I don't think she understood what that meant. She did not understand that I was HIV -- she just thought I had been exposed to it like you have been exposed to a flu virus and that was it. I had a pretty good understanding what she was talking about, so I did realise that that was pretty catastrophic.

Within about a year, with an incident at home,

I told my mother and she found out, which was -- obviously it was an emotional moment, but it wasn't as emotional, because she knew of the virus, but she hadn't any idea for about a year, maybe a year and a half, that I was actually positive, and the same for my father.

Q. You have said in your statement that the doctors didn't tell you very much about what it actually meant and what you should be doing.

A. Not really, to my recollection. There wasn't any great advice. I do appreciate there wasn't a lot anybody knew about HIV. But I wasn't offered counselling, and actually neither were my parents offered anything.

Q. You were registered at the Oxford Haemophilia Centre from 1987. Were you given any treatment for your HIV from the time of your diagnosis until the mid 1990s?

A. No.

Q. How did you come to start treatment in the mid 1990s?

A. I was going to a routine haemophilia appointment, which for a lot of people would be the normal thing and where you seem to find out everything, routine appointment. There was a six-monthly house doctor there, who was obviously finishing her training, who I used to see generally. I didn't really get to see

the consultant that much. He came in -- or I came in and he said -- he was an African guy, actually, very black skin. He was training. He was going back, so he wasn't here permanently, and he said -- he looked up and he said "Oh, hello. Sit down. I am very sorry for your situation".

So I thought, okay, that's good of him, but I have been living with it for quite a few years, and he obviously saw my expression that was sort of puzzled and he said, "Haven't they told you?" I said "Told me what?" He said, "Your immune system is very low. I am very sorry about that. There isn't a lot that I can do for you, but we will try and do what we can", or something like that.

Q. At that point you asked for your care to be transferred elsewhere.

A. Well, yes, that's right. So I spent -- at that time obviously I went back home. It was pretty devastating. I think I then actually went back again and there was a doctor that saw me who realised my CD4 count was very low and immediately suggested that I go -- because by this time it had gone down to -- when I went back again, it had gone down to about 50, and anybody that knows the immune system knows the normal count, which I have heard other people say should be

800, 1,200 is normal, below 100, as one of the doctors said, there is not much point counting really. The count was 50. The doctor I saw there was quite shocked and said, "Why haven't you been put on antibiotics to stop the disease PCP?"

At that time I felt taken aback and I was quite angry, and that's actually when I went back and decided to take my care elsewhere because I thought these people aren't taking care are of me. This is -- because I had also got -- additionally to that I had been having a newsletter from a group called the National AIDS Manual called Update, and it was a very, very good publication. It gave you a lot of information largely about diseases. It was a bit depressing, but it then also started to talk about how to prevent yourself. There was a very good straightforward antibiotic you could take to prevent PCP. So I thought: I am out of here. There is no way they are going to look after me properly.

I went to a local clinic I had read about in another bit of information. It is a GU clinic run by a Dr Stephen Dawson, and that was the best bit of decision-making I made for my health, because they were great.

Q. And in their response, the Churchill Hospital have said your CD4 levels were good until October 1994, but they then failed to check your levels in April 1995 before noting they had dropped very substantially in November 1995, and they have apologised for the failure to check your CD4 count in April 1995.

When you went to the new clinic, you went on to experimental treatments for the HIV.

A. Yes.

Q. And you suffered quite significant side effects.

A. Yes. I mean, over the years -- the thing about -- I made a decision to take some of this early treatment, because my CD4 count was low. The drugs that were then available, the antiretroviral drugs, were about stopping the virus replicating in you. They weren't about rebuilding the immune system.

With HIV, the thing at that time particularly that everybody understood was that you died and became ill because of the lack of immune system, not because of the virus. With my CD4 count -- I think it went down to about 20-something -- I knew that probably that was going to be it. The drugs were not going to rebuild my immune system, but I felt that I should do something. I felt I wanted to do something.

So I had the chance to try some of these early drugs. They were quite toxic and subsequently they

have given me various problems. I mean, one of the problems that continues now is the lipid fats in your blood. It destroyed a process in the liver that allows you to metabolise properly, so it gives you higher blood fats, basically, which is not a good thing.

Q. You also had problems with your kidneys, which continue.

A. That's right. I mean, in the longer term, the very first -- one of the drugs that has done this blood lipids is D4T, which is one of the very early drugs, which was really quite toxic. One of the other drugs a bit later on, I think you would probably call them the second generation of drug, gave me what they called kidney grit, which was really like kidney stones, pretty painful, uncomfortable. I had to come off that. I have had quite a few -- I mean, later on I had a drug that gave me neurological effect or damage. So over the time, I mean, there's been quite a few, quite a few.

Q. You have also -- some of the medications affected your bone density.

A. Yes, that's very recently.

Q. Causing osteoporosis.

A. Yes, I was diagnosed with osteoporosis quite recently

because of a drug that I have now changed from again. I am currently awaiting an appointment with the renal team specialist to look at my kidneys again, because there is something not quite right.

Q. You have struggled with severe fatigue and depression?

A. Yes. I am not a naturally depressive person, but I have had -- it has obviously worn me down, yes, and definitely I have had fatigue, which I know is an effect of perhaps not a liver that's very good and kidneys, yes.

Q. In terms of your mental health, you have had help from a psychologist for about the last three or four years.

A. Yes.

Q. And you have said that has been a great help.

A. Yes.

Q. Were you ever offered any support before that time?

A. No, not in the early days, to my recollection, no.

Q. And you have had to actively seek out that support --

A. Yes, yes.

Q. -- over the last couple of years.

A. Yes, yes.

Q. One of your main concerns is about the effect of the hepatitis D in the future.

A. Yes.

Q. What can you tell us about that?

A. For a lot of people, the hepatitis C -- which I did obviously get exposed to, but I was very lucky. I seemed to clear it myself, which a small portion of people do. The effective treatment there is now for hep C at least gives people something. Unfortunately for me this delta virus, there doesn't seem any effective treatment at the moment. The only chance I have to really deal with that is if they have more effective treatment for hep B, which is what this virus actually uses to survive on. So there isn't anything at the moment. Possibly in the future they may be more effective. If I could get the equivalent of treatment for hep B that people can for hep C, it would be much better for me, but there is nothing at the moment. That is an anxiety, because it is progressive.

Q. And you are having regular liver biopsies and tests to see what's going on.

A. Yes, I am.

Q. In terms of your education and work life, you were obviously diagnosed with HIV as a teenager.

A. Yes, I was.

Q. Can you tell us what impact that had on your education?

A. Pretty severe, really. I mean, I was at the age where

I was right at the beginning of deciding what I was going to do. Obviously finding out that you've got that problem, I mean, it's hard to -- lots of people have been talking about it, but for me it was really almost just like -- I don't know -- falling into a bottomless pit, you know. There was just no way of dealing with it. There was just -- the media, the opinion of what people were that were positive, the social effect as well as the medical effect was pretty devastating.

So it did make me feel really what is the point of doing -- in a lot of ways I didn't -- I have never stopped having ambition and doing things. What it really did almost is make me I think panic, and that is I thought to myself: how much time have I got left? There are things I want to do. Do I really want to waste so many years training for this, so many years studying for that, get to the end of that and then start to get ill? It sort of shortened my life view dramatically.

I mean, in the mid 1980s, when you found out, I mean, this is the era of Rock Hudson dying and people that were in the public were literally dying. Psychologically, obviously, it affected me a great deal. I didn't just stop, but I did think, "If I go back in" -- at the time I had actually left education and what I wanted to do was to go back in to do some additional training, which later on I did do. For those first two or three years, I mean, my career was blood tests and urine tests and hospital appointments. It wasn't really feasible -- if I had been in education at the time, I don't think I would have come out. I want to say that. But I do think it made me think, "What do I really do?" I mean, there wasn't anything you could do.

Q. So from about 16 to 21, you weren't in education and you weren't able to work particularly?

A. By the end of the 1980s I had gone back into full time -- I did a full-time college course. Before that I had done some additional training for the creative stuff that I really wanted to make a career of, but it was very disruptive. It was not a good time.

Q. And ultimately those plans and hopes of doing creative work didn't --

A. Well, I have done some things. My thing was filmmaking. I had a relative who was a cameraman. I had an interest in writing and directing. In the 1980s, actually, that was one of the first bits of training -- I managed to get on a course that involved basically filmmaking, and I subsequently then did

other training as well, as well as some other educational stuff through that time.

But obviously when people get the knowledge about the fact you were positive in the 1980s, and this was something that people living with the problem will understand, I imagine, is that when somebody knew about you, you could never tell what that person would be like, and in a community, one of the difficulties is although I am fit and I put a lot of effort into that, I couldn't go so far without telling somebody about the haemophilia. I mean, you can't not say about that, because it's severe. For insurance purposes, for all sorts of other reasons, you need to say. At that time, people connected it quite strongly. So that in itself gave me problems.

Later on, I was in Hollywood, I was in America, and I met with a producer. I talked to a guy about a collaboration. I couldn't stay out there, because of my positive status, and in America, that's where they gave it to me or it came from.

So in a practical sense, yes, there are lots of places and lots of opportunities that I've lost, but I think above all it is the -- as other people have been saying, it's the knowledge. You can't tell what somebody is going to be like. Once they know that, it was potentially pretty devastating.

Q. So your paid work life has been very limited.

A. Yes.

Q. But you have been able to do a lot of charity work.

A. I have. I mean, having severe haemophilia, I mean, I was getting -- because I wasn't on prophylaxis, I was getting a bleed probably every week, and trying to do regular -- I mean, my big ambition was to do filmmaking, but trying to do almost like the intermediate work was where it was a problem, because if you turn up to apply for a job and they say, "Have you got any problems?" and you say, "Well, I have a few" and then you say you have severe haemophilia, then they say "What's that?" and they say, "Do you have to have any time off?" and you say, "Probably a day a week", they say, "Oh, yeah, that's not a problem", then you never hear from them again, because you're going to be -- I mean, I was making sandwiches at one point, like a lot of kids do. For me, I have ankle damage, so I couldn't do something that was involving a lot of standing. Obviously, having severe haemophilia, I couldn't do anything like go and work on a building site. So the intermediate thing was pretty difficult.

I went along to the careers service. She was a specialist with people with problems and she just said, "I don't really know what to suggest". I thought "I don't know what to suggest either". So she made me a cup of tea, and I used to go back every three months. That was about it, really. That was about all anybody could do.

Q. In your statement you said your illness has proved a real challenge for you and it's been difficult to form any long-term relationships.

A. Yes. If you are a teenager in the 1980s and you had HIV, that was not a great calling card. Obviously for people that are adults, I mean, I don't really need to explain that much further. It was not fun. It was very difficult. I mean, when I found out, I was 15/16. I hadn't really seriously considered about being married, about having a family. Everything was what I wanted to do.

But over -- it is funny, actually. I have never had a long-term relationship past very intermediate stuff, and as I've got older, the last I guess 10 years, maybe 15, I wish I had been able to have children. I wish I had been able to have a long-term relationship. I am heterosexual. My parents were married for 50-plus years. I grew up in a household like that. It is what I wanted to do. But I wasn't

a good bet, really. So that didn't ever really work out.

Q. In terms of finances, you participated in the American pharmaceutical litigation.

A. Yes, I did, yes.

Q. And signed the settlement agreement in that.

A. Yes.

Q. You have also received a lump sum payment from the MacFarlane Trust and annual sums, but you have said in your statement you have not found them very helpful to you because you don't own your own home. You live with your mum.

A. I do, yes.

Q. Can you tell us what the issue with the MacFarlane Trust has been?

A. How long have you got? The person that was on before me I think spoke very

Well and they said a lot about some of the things that I feel, and that is that really for a community of people like us, who were vulnerable -- not that I like to think of myself like that, and I don't think anybody else does, but we were vulnerable -- I think really in a country like Britain, which at the time was something like the fourth wealthiest country in the world, they could have done a hell of

a lot better than they did.

On a personal note I, because of my HIV status, even if I had been able to find regular work, I couldn't get a mortgage. That's what everybody knew that was positive. It was made clear. So I was stuck at home, which is not what I wanted. I had to obviously tolerate that and I was quite lucky, really, because my parents owned their own home, they were stable. At least I had a place to live. But I never had the chance to own my own home.

It is a little bit complicated. My father became ill. He had a stroke, which is in 1990. He developed Parkinson's and dementia, which for my mother was very difficult, because both of them knew about me, so she had to give up her work really to look after my father. Then it went to another level and we had to have nursing staff coming in day and night.

Slightly ironically, my parents were worried about me and I wasn't getting ill, but my father was, who had no health issues before that time really, he had always been strong and fit.

When my father died at the end of the 1990s, we needed a new boiler, which is not a sexy thing but it is quite important when you don't have much of an

immune system and your mother is of retirement age. I thought: I know, there is this MacFarlane Trust. I: had never really asked anything of them because they had always said, "If you are a homeowner you can get this, if you're a homeowner you can get that" and I thought there is not much I can get out of them anyway.

I contacted them and said, "We need a new boiler. Can you help out?" They said, "Well, you are not the homeowner. Do you pay rent?" I said, "It is my parents' home. No, I don't pay rent". They said, "I am really sorry, no, there's nothing we can do". So the first major application I had was turned down.

In part, some of my problem with the MacFarlane Trust is the fact that I didn't make many applications to them, because they didn't give me the impression I could get anything out of them. The only thing I ever remember getting out of them was a grant to get hold of a computer and a payment for a massage, which I did use, but I am not explaining that any further. That was it. Literally, that was it. They weren't very helpful.

The criterion -- you know, there are other people here and other people are probably going to speak that can spend a lot more time explaining the technicalities of it, but they were not an organisation that was very helpful to anybody. I have never -- because I have been connected with this community for a long time, some guys I have known for 20 years, I have never met anybody of the infected, the affected, ever that has ever had anything good to say about the MacFarlane Trust or Skipton Fund or any other organisation that was meant to be there. They were useless, worse than useless.

Q. In terms of the Skipton Fund, because you had cleared the hepatitis C naturally --

A. Oh, yes, yes, yes.

Q. -- you couldn't have any payments from them on that.

A. Right.

Q. And they also didn't recognise hepatitis D.

A. That's right. Well, I am not a trained scientist, though science was quite an interest of mine. So I had a test that said you are PCR negative for hepatitis C. I was very relieved. I didn't need any of the therapy that a lot of people have had to tolerate. I thought: God, that's something good. I was then told that, because of that, I didn't qualify for any payment whatsoever from the Skipton Fund. So I didn't receive the initial £20,000, no recognition at all or anything.

I felt angry about that, because any of the other guy's I know, I think everybody was sort of puzzled, because we all thought that everybody that got exposed to -- what that initial payment was, was saying, "This is to help you deal with the fact that we basically infected you with a virus". I didn't expect recognition at the same level as some people have had with severely affected livers, but I expected some recognition and got nothing.

What is really puzzling is a few years later I was told I was PCR negative for hepatitis B, but apparently PCR negative wasn't good enough to stop the hepatitis D, which they had also passed into me, and still no recognition. So on the one hand I was PCR negative and excluded, but on the other hand I was PCR negative and had a virus because there were still traces of it in my liver.

The Skipton Fund Trust don't recognise hep D. I know it is very rare, but I have it. They don't recognise if you have PCR negative tests, so I didn't qualify for any help there. That is the end of it. I applied for it and they simply turned me down. And I got one of the doctors to back me up, but it wasn't enough, so I have no relationship with them whatsoever.

Q. Robert, those are the questions I have for you. Is there anything else you would like to say?

A. Yes, there is. There is. I have written down a load, but I am not going to be able to say it all. There are others that have said it very well as well.

You know, one of the problems is that for most of my life, and I know for a lot of people that live with haemophilia in my generation, we have been seen as essentially a failure, and it makes me angry because in my generation, when I was born in the late 1960s, the revolution that gave me everything that I have now -- and I have been able to do many things, I have been able to travel around the world, I have been able to pursue interests, I have been able to walk here and walk out -- all because some remarkable people developed a treatment that solves my dilemma. But unfortunately those people got betrayed I think as much as we did, and that is they perverted this treatment for profit.

The original discovery of cryoprecipitate I believe was done in America at Stanford, and it was done by public money. It was people that cared enough to do these things. The drug companies got hold of this stuff and it has been a nightmare.

In the press they always say -- which I know we

all understand -- it was one of the greatest disasters in NHS history, but to me it was one of the greatest successes that became the greatest disaster. That adds to the problem. It adds to the catastrophe, because it was all good. When I was born, things were getting better. For the first few years of my life, I had a treatment that my parents couldn't believe even existed, and it gave me the ultimate achievement, which is normality. I can walk around and people don't even know there's anything wrong with me. I went to a local school. I played with my friends. I rode a bike. I climbed a tree. I even competed in sport. And I could not have done that without the treatment.

So I can't say anything else anybody else hasn't already said up to now. I mean, one of the things, I have done training as a filmmaker, and somebody else before me mentioned it, and I don't understand why we haven't had in this community our Philadelphia. We haven't had our Dallas Buyers' Club. We haven't had any recognition within culture really at all apart from a disease of the week, where a load of us get sick and everybody gets sad.

If I had to pitch an idea, a script, I would say our story is somewhere between Watergate and a financial film like Gordon Gekko's film. He would be a character in that story. Because it is far more than just a sad story. It is a catastrophe, and it involves a level of political scandal that is as deep as Watergate, and Watergate was one of the big political scandals in America. That's the calibre of film we should have. That is the calibre of story we should see, and it should have an impact.

I mean, recently they have done a show on Sky, I think it is, called Chernobyl, and it got a lot of acclaim and it was very tragic. We can match what happened in Chernobyl, because if you were positive in the 1980s, you were radioactive. Nobody wanted to come near you. And it would make a powerful story, and I think one that would help the community, for us, and also to explain it. So few people even understand what this catastrophe is about apart from now, and that is because of the limited press coverage. I mean, having like, you know, 35 seconds on Newsnight is powerful for the person there, but then somebody watches Love Island and it's all gone away. It should be something more than what it is. So that is I guess the main part that I want to say.

I also feel as I have got older how awful it must have been for my parents to see their child being

made ill by a country that they had been a part of. I mean, my father fought in the Second World War and he ran a factory. He made a lot of contributions. My mother worked. And all they saw was me getting worse and worse, and I should have been getting better and better.

As I have got older, if I had had a child that went through what I went through, I would have found it very, very difficult to cope with. I think that that should be recognised, as other people have said, as well.

So I have a lot of other things, but that's basically, I think, pretty much what I want to say. So thank you very much.

MS FRASER BUTLIN: I am just going to turn to Mr Snowden, who as you know represents you, to see if he wants to ask anything. No.

SIR BRIAN LANGSTAFF: You are the first person who has made a plea for a film. Some have given me poetry, some have made recommendations. Yours is the first to deal with what is obviously your great love.

A. Yes.

SIR BRIAN LANGSTAFF: Can I thank you very much for what was a fascinating account, a pleasure to listen to.

A. Thank you.

SIR BRIAN LANGSTAFF: I suspect, with your rather relaxed manner, it is telling a tale which is somewhat understated. That may be part of its power.

A. Well, I have a lot of emotion, but, I mean, one of the other things that actually I was talking about just before I came on is that, you know, in some ways, this is a huge event and I feel a bit edgy about being up here, because it would be unnatural not to be, but it is almost rehearsed, and that's what the tragedy of it is. I mean, I have been talking about this problem -- so many people have -- for 35 years. It's difficult to feel fresh.

The fact I can talk about it without really getting that emotional is probably a measure of how damaged maybe I am or it's almost -- when you write scripts, it is like first, second person. It is almost talking like a second person. It is like I am detached about what happened.

It happened to me in the early 1970s. I can't even remember that period really. It has gone on for so long. I have never had any period of my life where there has not been any infection there. It is tragic, but if I could get more emotional about it, I would, but I am just burned out. I don't have any left. I am like an actor that's burned out, really.

I haven't got anything more to feel about it anymore.

My father died in the late 1990s and, you know, he never saw me get better. He never saw any of that, which makes me sad. But I'm still alive. So I feel -- I haven't stopped wanting to do things. I haven't stopped pursuing things.

One of the other things is that it's a bit like in a way a civil rights movement. With bigotry, you can't take that bigotry away, but you can match what it is. So if you can pursue what you want to do, you have made that contribution in and you have not given up, and in that way maybe that's a victory for me.

So thank you very much for your efforts too, and, I mean, you know, it is an amazing experience that this is actually happening, because I have waited and my parents have waited and everybody else I know has waited for at least 30 years, and now for me 47 years or whatever. So I hope we get the conclusion.

Thank you very much.

(Witness withdrew)

SIR BRIAN LANGSTAFF: Tomorrow we start at 10.00 again and all our witnesses tomorrow are anonymous, are they not?

MS FRASER BUTLIN: No, sir. The first two are anonymous and there will be no live stream. The third witness after lunch is Amanda Beesley.

SIR BRIAN LANGSTAFF: Ah, thank you very much. So anonymous in the morning and those who wish to follow us on live streaming should tune in, if that's the right expression, after lunch.

MS FRASER BUTLIN: After lunch.

SIR BRIAN LANGSTAFF: Thank you very much.

MS FRASER BUTLIN: Thank you.

(4.05 pm)

(Adjourned until 10.00 on Wednesday, 16th October 2019)

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