Friday, 7 June 2019

(10.33 am)

SIR BRIAN LANGSTAFF: Our first witness this morning is to be known as Mr L.

MS FRASER BUTLIN: That's correct, sir.

SIR BRIAN LANGSTAFF: In his case, as in others, as those of you who have been following the Inquiry closely will know, I am making a restriction order. This order prevents the publication of any details which might identify Mr L.

When he gives evidence, as it happens, there will be no transmission which shows his face although there will be audio transmission in his case.

Let me just read out the order so that you all know what it says. This is something which I do on every occasion when a witness has their anonymity protected by an order which has effect in the courts.

I order that the name and address of witness 0148 (that's Mr L to you and me) and any other identifying information such as the witness's image or a description of their appearance cannot be disclosed or published in any form unless express permission is given by me or by the solicitor to the Inquiry acting on my behalf. Witness 0148 must be referred to only as Mr L.

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. Indeed, those who follow the Inquiry closely will know that in Northern Ireland at the specific request of one person who had been granted anonymity protected by an order I did indeed revoke the order after he had given evidence and felt that it was safe and appropriate to do so.

So that's the order. It follows, please, that nothing may be published in any form, whether it's Facebook, social media, anything else which identifies Mr L and it does mean as well that if any of you are taking photographs in and around the vicinity of the Inquiry, please be careful that you don't by accident happen to snap his face or anything which might identify him.

Mr L.

MR L, affirmed

Questioned by MS FRASER BUTLIN

Q. Mr L, you probably want to pull your chair in a little bit so that the microphones can pick you up.

A. Is that better?

Q. That's perfect, thank you.

You were very unwell in February 1990 and were admitted to hospital. Can you tell us what happened.

A. I was very ill with a bad back which got diagnosed a little bit too late an was eventually admitted to St Helier Hospital with double pneumonia which turned into some very serious complications.

Q. It was complicated by septicaemia?

A. Septicaemia, complete renal failure, two collapsed lungs, dialysis, yes, and I was put in an induced coma for I think it was about eight weeks.

Q. Nobody was really very clear why you were so ill but you underwent considerable treatment. It wasn't clear whether you would make it through.

A. Absolutely.

Q. But you did.

A. Yes.

Q. You eventually came out of the coma but then became unwell again and had to have a lobe of your right lung removed.

A. Absolutely. The infection I couldn't quite get rid of. It seemed to be very, very complicated in hospital. I was a young man that had clearly burnt himself out very early on and the subsequent complications, I wasn't strong enough to get rid of the infection so they had to take my middle lobe out.

Q. During that treatment, you received a very large number of blood transfusions, both of blood and blood products, and the detail of which we're going to come back to later. There's a document we want to show which we've just received this morning and it's going to be uploaded any moment, so we will come back to that detail later.

A. Okay.

Q. But eventually you got rid of the pneumonia and left the hospital?

A. Yes.

Q. At that point, were you or your parents warned of any possible risks of infection from the blood transfusions that you had received?

A. Absolutely no information whatsoever. Everybody was very pleased that I was alive and that actually it wasn't even noted on my discharge piece of paper that had to travel around with, it wasn't actually noted that I had any blood products or bloods transfusions at the time, which I think we've got as evidence.

Q. Once you were discharged shortly after you went to France to recover?

A. I did.

Q. Then subsequently returned to the UK?

A. Yes.

Q. What was your physical health like at that time?

A. I went into hospital at about 12 and a half stone and I came out of that hospital three or four months later at 6 stone. So the doctors agreed that it would probably be better to get better and build my strength up in the south of France rather than South London. I was very fragile. I was emotionally wrecked.

I got read my last rites when I was in hospital both my parents came to say goodbye to me, so it was all rather shocking for a 19-year old man that was just beginning life, really.

So it scarred me both physically and mentally and it came to define who and what I am today really. It was a very important, yet tragic and painful, experience -- complicated.

Q. When you came back to the UK, you were you say focused on building a happy life, you got a job?

A. Went to university, job, family. You know it was about getting on and about actually being given a second chance actually. That's what I felt. I'd got my weight back. I got my health back. I was looking after myself and I was getting on, went to university and then went on to work in television after that, so ...

Q. In about 1999, you had by then had had persistently

raised blood pressure --

A. Indeed.

Q. -- since your admission with the pneumonia?

A. Yes.

Q. You went to a GP and you were having medication for that high blood pressure?

A. Mm-hm.

Q. Your GP in 1999 recommended a blood pressure research project that she thought you might be interested in?

A. Absolutely, I was diagnosed with high blood pressure when I was in Maidstone University. I think I was about 25, which is pretty young to be on blood pressure tablets, and my diligent GP back in south London said, you know, "What is all this. Let's try and get you off the drugs. There happens to be a research thing going on at St George's Hospital. I'd like you to get involved", so I joined it. I thought that would be a interesting, let's try and find out what this blood pressure's all about.

Q. What did that research project involve?

A. It involved a change of diet, lowering salt, lots and lots of blood tests and a lot of investigation of you know measuring and -- yes, regular visits and, you know, general overall of my health, really.

Q. One of those blood tests was actually a hepatitis C

test, wasn't it?

A. Yes.

Q. How did you come to find out you had hepatitis C?

A. Well, it was actually by complete accident. I was phoned up at home by Dr Rice from the path lab who literally took it on himself to say we've found some antibodies of the hepatitis C virus in your blood and I said, "Who are you? What are you calling me for? What's hepatitis C?" And I think he realised that I didn't know anything about it and immediately said, "Do you want to come over", I live very close to the hospital, "Do you want to come over", he met me at reception, took me kind of back stage, as it were, and sat me down and explained to me what hepatitis C was.

Q. How did you feel when you were told that by Dr Rice?

A. Well, I've always been pretty aware of my health background and that it was serious and he told me about how you get hepatitis C, blood-borne virus obviously. I said, well, I was at St Helier Hospital. I'd had loads of blood transfusions.

I was deeply shocked and terrified, to be honest. What it brought back for me after Dr Rice told me was essentially, "Oh, right, so I managed to sort of get nine years on from my pneumonia and nearly dying and I survived, and now you're telling me that

I've got a blood virus that's been eating away my liver for nine years", and big dark cloud, "Oh my God, what's, you know, how can this be happening to me again", I suppose.

Q. After that conversation, what happened next in terms of treatment?

A. Not very much actually. Not very much at all. I moved from the blood pressure research department to a liver specialist and I think had to wait, and you'll probably have to remind me, from diagnosis I then had a specific test for hep C, but from diagnosis and then waiting to see a liver specialist I think took four months; is that right? Does it say four months?

Q. You were formally diagnosed with hepatitis C on 22 June 1999 but not referred to the liver clinic until October 1999 and then your statement indicates you had the liver biopsy in February 2000.

A. Yes, all of that is true.

Q. While you were waiting, what was your mental health like?

A. Well, my GP who had recommended that I go and find out what the problem with my blood pressure was provided some counselling for me with a very nice lady, but I was just absolutely terrified with regards to the isolation.

The lack of information back then was very limited. I felt poisonous, I felt that I could infect anybody and anything. I was terrified and actually it's very difficult to -- it's very difficult to separate the original fears of the pneumonia and what I went through there and then suddenly having this again and they'd kind of merge together and become one and then they would separate and I'd go well I'd better get treatment for this. I got over something the first time. Just a dreadful mess really. A dreadful mess and fear, just fear and frightened of my mortality, actually.

Q. You have said you were having recurrent nightmares during that period as well?

A. Absolutely. Big dark horrible clouds of death, my own demise really.

Q. Part of the reason for that was because you felt you didn't really understand very much of what the risks of transmission were and what you should and shouldn't be doing in terms of drinking and alcohol?

A. I mean, there was no advice at all. I do recall at one particular stage, and this is a bit further down the narrative, but I had a nurse specialist and when I asked can I drink she said, "Oh, you can have a little bit, you know, cut down kind of thing", but

with regards to information, I mean, *[redacted]* --

MS FRASER BUTLIN: Can we stop the transmission.

(Pause)

We are fine to start the transmission again. I had asked the question that part of the reason you were particularly concerned was that you hadn't been given a huge amount of information about the risks of transmission.

A. Absolutely not. I mean, I remember going -- there was a little support group that was coming out of a place in South London that was full of -- it was set up by some intravenous drug users that had all been diagnosed and I joining that group, but I was the only one that got it from a blood transfusions and there was just a lot of misinformation even in that group, actually, and I became trying to get -- I think I got a couple of books and my wife did a lot of research and helped us and, *[redacted]* you know, I was, you know, what I understood was I was poisonous and I had to protect her and I had to protect everybody else that I was around really.

Q. You had your liver biopsy in February 2000 and then you wanted to receive pegylated interferon and get on with having treatment as quickly as possible.

A. Yes.

Q. Why was it that you were so clear that you wanted to receive pegylated interferon?

A. Actually there was a real dilemma at the time. Pegylated interferon, there were two brands, one had a better success rate than the other. Okay, actually the first time I did treatment it wasn't with pegylated interferon. It was normal interferon, okay.

The funding issue at the hospital to try and get it, there were no choices really. I had to wait for the funding to come through and pegylated interferon actually hadn't been trialled or hadn't been invented or was being trialled. I wasn't allowed to have that one. I can't remember whether I knew whether it existed.

Q. You said in your statement that the first time round your first lot of treatment, you wanted pegylated interferon.

A. Yes.

Q. It was available but more expensive.

A. Yes.

Q. So you were only given what you've called standard interferon because it was cheaper.

A. Yes, absolutely, and I had to wait for that too. Thanks for reminding me.

Q. At that time you wrote to your MP and asked him to

intervene.

A. Yes.

Q. The Chief Executive of the health authority responded. Please can we have document 0148004 and it will appear on the screen in front of you as well.

If we look at the third paragraph, this was a letter -- by now we were in September 2000 and the discussion around costs of pegylated interferon were still going and the combination of interferon with ribavirin and it's a letter to your MP from -- sorry, it's a letter from the Chief Executive of the health authority:

"Recently several trials have been published on the combination of interferon alpha and ribavirin drugs. Based on the evidence, the combination has been approved by the St George's Hospital Drugs and Therapeutics Committee and is included on their formulary. The combination has also been approved by the Merton, Sutton & Wandsworth Joint Prescribing Committee for consultant use only. The drugs can therefore be prescribed in hospital but at present no extra funding has been provided to meet the cost."

Your understanding of the situation was that the drugs were available to be prescribed but there was no funding to actually meet the cost of them.

A. No. I remember being actually infuriated and cross and sad and made some pretty bad taste jokes about trying to found out where the Chief Executive of the hospital lived and just demand, you know, sit outside her house and just try and get some funding really. I was pretty desperate.

Q. When you had your first course of treatment, what were the side effects for you from that treatment?

A. Okay, so I was quite keen to, having fought and waited for such a long time to get the treatment, I was pretty keen to get going. So I did the first injection myself with my nurse specialist and really I remember the first night immediately shivering and nauseous from the interferon. It reacts quite quickly in your body. Very weird out of body sensations but what was really horrendous was the ribavirin pills.

They take a few weeks to sort of kick in really and that involved, because the treatment was for a year, that sort of involved my whole kind of back seizing up, skin complaints, insomnia -- I mean, ridiculous insomnia as in you just don't sleep, you are hot and cold, shivering, kind of hungry but couldn't eat anything.

I remember a time when actually I'd be very, very sick, feel very, very nauseous in the morning and

I remember a particular time where I'd taken my pills and then -- sorry, everybody -- I was sick in the sink and I was sick -- I sicked up my pills and I then proceeded to pick the pills back out of the sink and then take the pills again because I didn't want to miss out on the treatment.

Q. What was the effect on your mental health?

A. My mental health, actually fortunate enough to describe it now, but depression. I was so low and so down. I'm normally a quite bubbly and airy person and like to see the good in things and make the best of things.

This was just horrendous really. I just feel like I was a couple of times monstrous to my wife because it affects your mood in such a dreadful way and it was a really horrible struggle of depression, sadness and doom. Just pending doom really, of just trying to get through.

Q. How did you manage that treatment with your work commitments at the time?

A. My work were extraordinarily supportive. It was a sort of top 100 company. They'd known I had got the blood from a blood transfusion so, of course, didn't have any stigma around. You normally get the, "Oh you got that from that, did you? That's really bad news",

so they were sympathetic. Some people did understand, some people didn't. A few really close colleagues did understand, actually, they allowed me to go in -- I wanted to continue to work because I thought staying at home for the first two weeks of treatment, which is what I did, I didn't want to end up rotting on the sofa and my mood was so low and it was all so dreadful anyway, I thought to have a bit of a focus and to have a purpose made me feel better.

So actually I remember, you know, going in for the first time after a couple of weeks of being on the treatment and sort of getting as far as Clapham junction on the train and then just turning round and coming back because just feeling so sick and awful and then finally sort getting to work, sitting there for an hour, doing nothing, and then getting back on the train and going home again. That was day's work, thanks very much. We'll just do that.

Essentially I, was doing sort of two or three hour days, little jobs at work as *[redacted]*. They were very good. But, you know, it had a purpose and to look out the window took my mind of a few bits and pieces. But they were very supportive, they were very supportive. I felt lucky about that, by the way.

Q. Your treatment lasted a year?

A. Yes.

Q. But then on 3 May 2002 you received a letter which told you that you had relapsed.

A. Yes. After, I sadly can't remember the details but they did a check on me at the beginning of treatment and my viral load had gone down and it was all looking quite good. It looked as if I had cleared the virus whilst I was on treatment but three months after the end of treatment I came back hep C positive again. And that broke my heart.

Q. What was your reaction?

A. I just had to edit myself. This isn't fair. Why me, I thought I'd got rid of it. Devastated. Just devastated, I mean, devastated, absolutely devastated. I didn't ask for this blood. I didn't ... yeah, pretty broken actually from it.

Q. By then you were being treated at St George's Hospital and the consultant treating you was concerned that the hepatitis C had come back really quite aggressively for you?

A. Absolutely.

Q. So what did he and you want to do next?

A. I wanted the pegylated interferon next because that was available and I knew it existed and there was a better chance. I had genotype 1, which was the hardest one back in the day to get rid of and when I took the original interferon and ribavirin treatment I think I only had about 35/40 per cent chance of getting rid of it and, of course, it came back which is where we are in the narrative. But I think the pegylated had about a 50 per cent chance, so I thought I had a -- well, if I'd sort of shifted hep C in the first round of treatment, maybe the 10 per cent will, you know, absolutely get rid of it. That was what I wanted.

Q. *[Redacted]* agreed with you. He was very much on board that this was the treatment you needed.

A. Absolutely.

Q. But there was a wait for funding again.

A. Again, yes.

Q. During that wait, what did you do to get ready?

A. Fattened myself up, changed -- I kind of changed my attitude to sort of this idea of sort of pushing -- this idea of keeping pushing. So the idea of going to work the first time and, you know, keeping me busy and having a purpose. I changed that and I just thought you know what I'm going to give myself the best chance possible.

Yes, you know, I also you know had to get myself in the position of daring to hope that the next treatment would make a difference, would make a difference, really. Still determined to do it but at the same time taking a little bit -- taking the pressure off myself a little bit and just trying to get the treatment and let it do its work really, let it do its thing.

Q. You had the second round of treatment and finished it in 2004. How did you feel during that second round of treatment?

A. I mean, it is dreadful. The original pegylated interferon you would inject -- sorry, the original interferon you would inject three times week. Pegylated interferon you only injected once a week, but still the ribavirin seized my back up, still low moods, just another horrendous year.

I still had support from work which was very, very useful to enable me to do it for the second time, extraordinary support from my wife. Yeah, I mean, it was sort of as bad. It was horrible, it was just horrible. I wouldn't recommend it for anybody really.

Q. But at the end of the treatment you were told you had cleared the virus and nine months later you got an all clear for the second time.

A. Yes, that was -- I was slight wary about both of those results in the sense of it had happened to me before, getting bad news. It was almost -- the further -- you go clear of hep C and the further away you get from it the more pressure comes on you to -- because it can come back or it came back for me so, yes, even going to get results was terrifying, even though my nurse specialist was amazing, so supportive, and cried and hugged on the nine month afterwards but then, of course, you get another one a few months later and then you get a two year clear one as well so it carried on.

Q. You've said a little bit about the effect of the treatments on your relationship with your wife. Do you want to say any more of how that affected you both?

A. She was and is extraordinary with regards to strength and really understood what I was going through.

There weren't that many incidents I don't think but I remember one in particular where we were going up to town. We tried to live a kind of as normal life as possible. We use London to its maximum. We are out and about, rather ironically I took my last injection of interferon in a toilet in a theatre in North London. We kept going. You know, we were trying to go out, trying to keep everything as normal as possible and just taking it a bit easy, but I do remember being a complete monster to her on the tube, completely outside my character, certainly outside my love for her, and the person that kind of knew what I was going through and was closest to. You know, I was a monster to her on the tube. I think we got over it.

Q. She said to you since that she did question at times whether you were the man she'd married.

A. Well, I wasn't because the treatment bends and changes you. You know, I wasn't. It has a profound effect on how you think about yourself and a profound effect on how you feel physically about yourself. You're wrecked from it, you know.

Q. Did you *[redacted]* ever receive any professional counselling or therapy?

A. *[Redacted]* I had a ten-week course which the doctor gave to me from diagnosis but nothing was offered after that.

My nurse specialist had a counselling kind of certificate. She was very useful in a couple of respects. She offered me antidepressants but I didn't want any more drugs inside me. It was difficult enough to see clearly as it was so I didn't take those and I think she was really clever and really proactive because we ended up setting up a support group at the hospital, which I kind of ran with her.

So a bit like the couple of experiences that I named earlier, we set a support group up to kind of -- it was a once a month at St George's Hospital, for anybody that had been infected, and she had access to the people that had been infected so they were quite useful groups. So I found that more kind of proactive and important, plus I wasn't offered anything else other than from Lee.

Q. Now, looking back, how do you feel about having received the blood transfusions in the first place?

A. I suppose I have been extraordinarily torn for 30 years. I'm in this limbo middle ground with it because the blood has saved my life, okay, the original blood with pneumonia has saved my life and yet it ended up killing me. It's ended up killing me again. It's ended me up here.

I'm deeply grateful for the blood. I'm not sure what anybody else, you know, I was dead at 19, so I'll take it thanks very much, but at the same time the poison that it put into my body, the five years, six years between a chance diagnosis and treatment and then the subsequent, I mean, it's taken 20 years for me to be able to come and tell all of you, it's defined my life in both the most horrendous way,

because I promise you sitting here isn't easy, and at the same in the most magnificent way because I wouldn't be the man that I am now if it wasn't for all these horrendous things that have happened to me. So it's this extraordinary ambivalence about how it has affected me actually. Very, very complicated really, really complicated and I haven't circled the square. I don't think I ever will really.

Q. On 30 April 2001 you decided to apply for your medical records. Why was that?

A. My wife thought it would be a good idea and what had happened is that there was, I think there was going to be a legal case and I wondered whether or not to get involved in that, and my wife said, well, perhaps you need to get hold of your notes. I said that's a great idea, so I did what she told me to do.

Q. In those records there was a letter from Dr Patricia Hewitt dated 1999. She managed the hepatitis C look-back exercise for north London in 1995.

Please can we have on the screen document 0148006 and the first main paragraph which says:

"I have been in contact with Dr Jane Mircieca, the consultant haematologist at St Helier Hospital. She confirms that the laboratory records at St Helier have been located, but there is no record of [Mr L]

receiving a blood transfusion whilst a patient in the hospital. I understood from you that [Mr L] believes he was transfused in 1991 at St Helier Hospital and that no other risk of hepatitis C infection had been identified apart from minor surgery in France in 1985."

So it was said that -- and then if we look at the second paragraph:

"I'm copying this letter to Professor MacGregor as I think it's important that the patient is informed that he did not receive a blood transfusion in 1991."

Were you informed of that at the time?

A. No.

Q. You have also gone through the letters to your GP about the treatment you underwent for the pneumonia and none of those letters say you had a blood transfusion?

A. None of the letters say I had a blood transfusion.

Q. It may feel an obvious question but why does that concern you?

A. It concerns me because if I'd found out earlier, then maybe I could have caught it earlier and had less liver damage. It concerns me because who else is infected? Who else is going to die of this dreadful disease? The inconsistency of what I knew versus what

was on the paperwork. Frightening, who's in charge here, what's going on, why is there no information? I mean, it's terrifying. I consider that I found out by accident, so that letter that everybody has seen then, you know, that wasn't shown to me. I didn't see that.

Q. In relation to your GP not knowing you had even had a transfusion you said in your statement that:

"This means my GP had never known I had transfusions and, therefore, would have probably not considered me to be at risk of hepatitis C."

A. Absolutely not. If it's not written down, how could she? That there was obviously evidence of the blood pressure tests. That's what she sent me off to do but there was absolutely nothing in my medical records to say I had ever had a blood transfusion -- sorry, in the doctor's letters.

Q. In 2001 when you requested your records, what process did you follow? What did you do?

A. Well, I phoned up St Helier Hospital and I got asked to be put through to the records department and I asked for my medical records of the time that I had pneumonia back in 1990.

The lady at the end of the phone said, "Okay, I'll go and have a look for them and I'll call you back". She phoned me back a couple of days later and said, "Actually, I have found them, Mr L. There's quite a lot of them. What do you want", and I said, "Actually, I'd like them all please", and she said, "Well, it's £1 a copy. It's £1 for a copy and the limit is £50". I said, "Well, I'll have the lot".

She said, "Well, send me a cheque for £50", she photocopied me this *(indicated)*.

Q. A full lever arch of documents.

A. A full lever arch of documents, all my medical history from my time in ITU, intensive care, three months in a coma and everything else.

Q. In those documents, if we can have 00148008, the most recent documents, it must be 9 then ... what you found were pages and pages of labels like this, each label as you understand it representing a transfusion of blood or blood product.

If you scroll down, Paul, there should be more pages. You've counted them up. We can see on that page, on the right-hand side of the page, there's a 10 in a circle. You've counted up the labels in your medical records on each page?

A. Absolutely, yes, and there's more of those. There's 160-tabs, tickets like that, that I have photocopied that I have in that file. That's what came through,

and the corresponding notes match up with when you're in intensive care, it's I like to call it the best hospital in world. You get quite a lot all attention -- sorry, best hotel in the world. They write down everything, so those tags correspond to my medical files on that day at that time. So, you know, another bag of blood, another product, another bag of blood. So I recounted them last night and there's 160 blood tags there.

Q. Each tag has, as far as we know, each tag has a different bottle number, which is the specific reference for the products or the blood you have received?

A. Absolutely, yes.

Q. Dr Hewitt has responded to your statement and said this in relation to the letter she had written in 1999. She says this:

"It is, of course, a matter of regret that when his case was first raised in 1999 my enquiry to the consultant in charge of the blood transfusion laboratory at St Helier Hospital produced a negative response, in that they hadn't located any records of him receiving a blood transfusion. In the light of the information which [Mr L] subsequently obtained from his medical notes I would have expected the blood

transfusion laboratory to have located records relating to his blood transfusions as only nine years had then elapsed. I would not normally expect that laboratory records would have been destroyed after this period of time. I very much regret that I interpreted the inability to locate any such records as evidence that no transfusion had taken place. My letter in retrospect should have been more cautious as I was reporting back of second-hand information. I'm usually much more circumspect in correspondence when I'm relying on information provided by others."

How would you respond to that?

A. The information by others was from me because I got my medical records I think about seven months after she applied for them. So we have somebody of authority and experience that has got in touch with somebody at St Helier Hospital and asked to find out whether I had a blood transfusion, didn't get a result, proceeded to write to me the letter that everybody has seen, that I had never a blood transfusion, and I can phone up a few months later and get that file delivered to me with a contrary -- a different position basically. It's not true. I did have blood transfusions.

SIR BRIAN LANGSTAFF: May I just ask, the letter from Dr Hewitt, can we just go back to it. I think it is

006.

MS FRASER BUTLIN: It is.

SIR BRIAN LANGSTAFF: That talks about a transfusion in 1991. You I think described to us a transfusion in 1990. Do you know where the 1991 might have come from?

A. No idea whatsoever, a dreadful error.

SIR BRIAN LANGSTAFF: So nobody has suggested that it was simply because she was looking for the wrong date?

MS FRASER BUTLIN: No, sir.

SIR BRIAN LANGSTAFF: Thank you.

You would have been clear, I suppose, at all stages of the sort or operation that you had.

A. Absolutely.

SIR BRIAN LANGSTAFF: And the length of time you were in hospital.

A. Absolutely. I'm reminded every day from the scars on my body and the drain holes and the tracheostomy and everything else, absolutely.

SIR BRIAN LANGSTAFF: Thank you.

MS FRASER BUTLIN: In August 2004 your application to The Skipton Fund was rejected because the Blood Transfusion Service said you had not received any transfusions.

A. Yes.

Q. When you heard that, how did you feel?

A. Well, I mean, just dismayed and shocked because it's like somebody else is rewriting your history for you. I went and checked the file. I went to check the file. I went to have a look at those photocopies, I had to yet again revisit pneumonia and nearly dying, you know, and going, "No, I have had it. I'm not going mad. I have had blood transfusions, right. It's all there, God. Thank God for that. I've got the file. Thanks, I've got the file".

Q. In October 2004, your treating doctor wrote to Dr Hewitt querying her original letter?

A. Yes.

Q. If we can have 0148007, please, and if we look at the -- I'm sorry, my numbering doesn't match those on the system. Can we do 008. It should be a letter, thank you.

If we go across the page to the second part. I'm sorry, Paul, can we have 0148007. It should be something different. Yes, it was my fault, sorry.

If we look at the very last section of it, the treating doctor wrote to Dr Hewitt and enclosed from your records the photocopies of the labels of all the blood transfusions --

A. Yes.

Q. -- that you had had.

SIR BRIAN LANGSTAFF: Can we just remove that. It indicates the nature of the work that he was doing at the time.

MS FRASER BUTLIN: Thank you, sir.

SIR BRIAN LANGSTAFF: Can we please remove any reference to that from the transcript when it's published.

MS FRASER BUTLIN: Thank you. Thank you, sir, I hadn't spotted that.

Your treating physician wrote to Dr Hewitt with the blood labels that we've seen. She then responded didn't she, and we have the letter at 008.

A. Can I add a little bit?

Q. Of course. Please do.

A. Having gone back and checked in my file that I had had the blood transfusion, I then provided some photocopies to my liver specialist to then forward on to Patricia. I provided the evidence to my liver specialist who then forwarded it on to Dr Hewitt.

Q. Dr Hewitt responded and in the last paragraph of the letter, she does flag a confusion over when you had the treatment. She says:

"I admit to certain confusion as none of these relate to September 1991", because of course they were from the correct date of when you'd actually received them but more importantly when we go over the page to the final paragraph it says this:

"It appears to me that [Mr L] was exposed to at least 17 blood components during the period of March/April 1990."

That's a number that you dispute. You think that she was perhaps only sent some of the blood labels not all of them.

A. Absolutely.

Q. "These would not October have been anti-HCV tested as routine screening of blood donations was introduced only in September 1991. This being the case, it's possible that [Mr L's] hepatitis C infection originated from unscreened blood transfused prior to the onset of routine screening. We would not in this situation attempt to carry out any investigation into the donors, for more than 15 years has elapsed since these donations were given. If any of the donors had returned after the introduction of routine screening, they would have been identified and a look back carried out for recipients of previous donations. As [Mr L] has not been identified through the hepatitis C look back we can assume that if any of the donors were infected with HCV they have not returned to give blood and, therefore, their status remains unknown to us. There is very little to be gained now from attempting to contact such donors considering the long amount of time that has elapsed since the donations were given."

In your statement you've expressed your concern that the donor who infected you could well have infected others and that there's been a conscious decision not to trace those other people who may have been infected; is that correct?

A. Yes, that is right and also it's kind of clear to me here when I read it, when she's it written the 15 years has elapsed, we have to remember the time-line is four and a half or five years before that I put forward that I had hepatitis C from blood transfusions. So actually it's taken, you know, it's taken four and a half/five years for her to write that back which I would be under the 15 years elapsed point, wouldn't I, it seems to me.

Q. That when you originally had those letters with her --

A. 1999, yes. Dr Rice's letter.

Q. Dr Hewitt has been asked for her response and she has supplied a statement in that regard. It is a fairly lengthy explanation but for the purposes of putting it on the public record I will give an overview of what she says.

She says that her letter to the treating doctor set out the policy of the NHS Blood and Transplant at the time, that no recollection would be conducted into reported hepatitis C infection where individuals had received blood transfusions prior to the introduction of routine blood donation screening for hepatitis C in September 1991. She explains that there were two reasons for this, first, the difficulty in tracing donors if they've stopped donating blood, because people are likely to have moved house et cetera and, second, although NHS Blood and Transplant could trace the donations to the hospitals where the blood may have been used, the hospitals at that time didn't keep records to enable individuals to be identified.

Is that an explanation you accept or agree with?

A. I just completely disagree with it. I provided all the information from my notes to her to enable her to make some comments about it. She's never found my notes. She hasn't looked for my notes, she's not -- I've got blood tags with those numbers on. You know, you've seen them all. She hasn't bothered to investigate or they have not been bothered to investigate any of it and the only information that she has on my particular case is from the evidence that I have given her, which she's inaccurately, actually, written down in her letters, actually.

She's not even got that right, I'm afraid.

SIR BRIAN LANGSTAFF: The other thing which puzzles me a little is the use of the word "routine" in relation to screening, which suggests that there may have been screening done even if it wasn't routine to screen all and does she say anything about whether there was any suggestion that there had been any investigation as to whether any of the units supplied had actually been screened, whether routine or not?

MS FRASER BUTLIN: There's no reference to that in her statement. It's certainly something we can go back to her and ask.

SIR BRIAN LANGSTAFF: Thank you.

MS FRASER BUTLIN: Your wife has reminded you of a similar conversation with a nurse at St George's previously. Can you tell us about that.

A. There was obviously concern about who'd been infected by what blood and what blood products and we had some concern who else has got this, who else is going through this and *[redacted]* said to my nurse --

(Pause)

Q. Let me ask you that again. We're good to start the transmission again. Your wife has reminded you of a similar conversation with a nurse at St George's previously. Can you tell us about that?

A. Yes, we were concerned if other people might be infected by other blood, other blood products, and my wife said, well, shouldn't we be doing a look back or investigating who else has got this blood and the nurse very quickly said, "No, no, we don't do that. We're not going to do that".

Q. You felt she was very dismissive of that and defensive?

A. Well, you know, again, my wife thought it was very dismissive and very quick. When, it's a bit like being in this situation, there's so much kind of going on, you want the treatment, you're getting through treatment, et cetera, et cetera, but my wife certainly thought it was dismissive and very quick to say, "No, we're not going to do that, that's it. Let's just push that one under the carpet".

Q. After you had the confirmation from your treating doctor that you had indeed received blood transfusions, you applied again to Skipton and you received payments from them.

A. Yes.

Q. But you were required to sign a waiver. What were your thoughts about that and what was the nature of it?

A. The nature of the waiver is to never talk, never

think, never apply for any other support or funding ever again, a one-off payment to kind of shut me up, to not -- just forget about it, "Here's your £20,000, don't mention it again". It was almost like gagging order, in a sense.

Again, I'll remind everybody of the dilemma. I didn't join a class action because I didn't want to kind of get involved in the minutiae of the politics and the arguments and everything else. What I wanted to do was live. This is what I have been trying to do is live. We don't get much time. I found that out at 19. So I could have got involved in it. I just -- I signed the waiver. I took the £20,000. I left my job. I retrained, I used it for my benefit and to improve myself and start doing a job that I wanted to do and improving myself really. Took it as an opportunity to change something because of all the experiences that I had up to that point, you know.

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

A. I'd to thank everybody for finally being interested. It's become a part of me but at the same time it's identified me, made me who I am; so that's again part of the conflict. I'll thank my wife. She's been extraordinary and if she hadn't said buy the notes ... I just hope that I continue to listen to her for the next 20 years really because she's been amazing.

Thank you, everyone.

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

SIR BRIAN LANGSTAFF: No, I don't. Thank you very much, both of you, Mr L and ... nickname.

A. Wifey.

SIR BRIAN LANGSTAFF: We will take a break until 12 o'clock and at 12 o'clock we have ...?

MS FRASER BUTLIN: Maria Fletcher.

SIR BRIAN LANGSTAFF: Thank you.

(11.29 am)

(A short break)

(12.12 pm)

SIR BRIAN LANGSTAFF: I am told that the delay is due to some late documents.

MS RICHARDS: There's a couple of documents that the next witness would like to refer to, which I think are very useful documents and we're just arranging to have those redacted appropriately and scanned but we'll start the evidence first because we won't get to them until the end of Maria's evidence.

SIR BRIAN LANGSTAFF: Very well. She wishes to be known as ...?

MS RICHARDS: Maria.

SIR BRIAN LANGSTAFF: Maria, please.

MARIA FLETCHER, sworn

Questioned by MS RICHARDS

Q. Maria, you have a condition called beta thalassaemia major?

A. Yes.

Q. Could you tell us what that is?

A. It's a blood disorder. I've forgotten now. I was born with a blood disorder called thalassaemia major which requires me to have regular blood transfusions. I've had this since -- well, I was diagnosed at the age of one; so since birth. It's usually a Mediterranean Asian disorder that affects us people.

I'm *[redacted]* and, yes, basically, I was born with this disorder which requires me to have regular blood transfusions.

Q. The consequence of the disorder is that you don't produce enough haemoglobin?

A. Yes.

Q. That's why you need to have regular blood transfusions?

A. Yes. I can't, as you said, I can't produce red blood cells so I need -- my body -- well, I need blood transfusions to help me to move around, otherwise, if I don't have the blood transfusions my energy levels are very low, non-existent and I would probably die.

Q. So since you were diagnosed at about the age of 1 you have had blood transfusions throughout your childhood and adult life?

A. Yes.

Q. Very frequently, sometimes often as every two or three weeks?

A. That's correct.

Q. You also have to have injections to regulate the amount of iron in your blood?

A. Yes. Basically, because blood's got a lot of iron, it affects all the major organs in your body. So through over the years at the age of 5 I started having injections, and then from injections they were 24 hours long over a period of five/six days a week to get rid of the excess iron in my body because, as I said, it affects the heart and most of my other organs.

Q. You've also have regular liver biopsies?

A. Yes, I used to have regular liver biopsies. When I was young, it was to -- they wanted to detect the iron damage in my liver. So every few years -- well, every year it was, I would have to have a liver biopsy to detect the damage that was caused.

Q. You've produced a document that relates to one such biopsy. We'll have it on screen, please, Paul. It's 1876003.

We can see that this is dated 29 January 1986. It's headed University of Wales, College of Medicine, Department of Haematology and we can see it refers in the first paragraph to the biopsy and then in the final paragraph it says this:

"I've assumed that this patient does not have infective hepatitis and is not positive for HTLV3. Would you please make sure that this is the case in future?"

You're puzzled by this document, aren't you?

A. Yes.

Q. Why is that?

A. I didn't know anything about this. I didn't know -- I mean, all I knew that my liver biopsies were going off to be tested for liver damage but this also shows they were testing also for hepatitis C which I was unaware and my parents were unaware of this.

Q. You are also puzzled to the reference of it being at the University of Wales because at the time your care was entirely under University College Hospital to which the letter is directed.

A. Yes, that's correct.

Q. You have also in your witness statement attached some significance to the fact that this demonstrates a knowledge of hepatitis in 1986, not specifically in relation to you at that time but more generally?

A. Yes.

Q. You were indeed infected with hepatitis C in consequence of the blood transfusions that you've received?

A. Yes.

Q. If we have up on screen please, Paul, 1876007, we can see this is a letter from 2007 but we will just look at the first paragraph for the moment, please, second sentence:

"She first became aware of chronic hepatitis C in the early 1990s. She certainly acquired this through multiple blood transfusions since childhood, all of which were in the UK. She has no other specific risk factors for hepatitis C transmission."

So there's no doubt the cause of your hepatitis C and you understand you've said in your statement that the blood that you received for transfusion was all via the Brentwood Blood Transfusion Centre?

A. At that time, yes.

Q. Were you or your parents ever given any advice or

warning or information about any risks of infection associated with regular blood transfusion?

A. No.

Q. You were told of your hepatitis C diagnosis in early 1990, as far as you recall.

A. Yes.

Q. What can you remember about that?

A. I was feeling unwell, very tired, feeling sick, just didn't have the energy to do everyday things and I thought maybe it was to do with my thalassaemia because you get tired and out of breath, but it wasn't -- I used to have a blood transfusion, instead of feeling energised I was feeling very unwell and feeling sick and quite tired and so I went to my doctor, the haematologist, and was telling him that I'm not feeling right.

So they then started to do tests on me to see if there was anything else at the time, thinking it might be diabetes-related, so just feeling really not well and very tired and sick.

Q. You've said in your statement you kept going back to the doctor as you couldn't understand why you were so sick and that was unlike you because other than your regular treatment for your thalassaemia you wouldn't normally keep going to the doctor.

A. No. Just wasn't feeling right. Something, as I said, you know, having my blood transfusion and not feeling energised where usually I would be feeling energised and so I kept going back to my doctor and they decided then to do tests, random, all different tests to see what was the cause of it and then I was told I had hepatitis C through contaminated blood transfusions.

Q. We will just have another letter put up on screen, Maria. It is 1876010, please, Paul. We can see it's January 1990. The second paragraph halfway down says:

"I suspect that she's developed post transfusion hepatitis", and explains that the doctor has arranged for various tests to be performed to investigate the post transfusion hepatitis and also contacted Brentwood Blood Transfusion Centre:

"... so that we can screen all potential donors for hepatitis C."

That's January 1990 that that is being identified.

Your recollection, in fact, is not that you were told at that point that it was a possible diagnosis but that you actually had it.

A. Yes, yes. I remember went for a clinic appointment and was told that I had hepatitis C through contaminated blood.

Q. One of the concerns you voiced in your witness statement is why that took what you recollect to be about a year of you going to the doctor for hepatitis to be identified as the possible cause.

A. Yes.

Q. Now, how did you react? What do you recall the impact on you of being told this?

A. Well, I didn't know anything about hepatitis C. I didn't know any of the other patients had hepatitis C and I was in clinic appointment and it was like, "Oh, by the way, you've got hepatitis C", and sort of brushed under the carpet, didn't explain what it meant to me, what it would mean. I thought it was just something that I got with everything else and basically accept it and move on.

Q. Did you get given sufficient information in your view about the nature of the condition or any risks of infecting others?

A. No, I didn't get -- I wasn't told anything about what I needed to do, what the risks were to others, and it was over time that I started to understand more of what the risks were and I was, you know, 21 I think at the time that I was diagnosed and just basically it was as if just get on with your life and let's see what we're going to do about, you know, what's going to happen at outcome of it.

Q. You've said this in your statement, Maria:

"The fact that I had the infection was brushed under the carpet. I did not think it was serious because of the way the consultant dealt with it with me. He did say that if it came to it I could just have a liver transplant."

A. Yes.

Q. "This shocked me but still I did not appreciate the seriousness of the condition. It was like I just had to accept it and get on with it."

A. Yes. I don't know if -- I was told and it wasn't -- you know, it was like, because I had heart failure at the age of 16, I was given a week to live and it was hard enough dealing at the age of 16, having to deal with, you know, heart failure and thalassaemia and only being given a week to live and, basically, it was just I pulled through that and it was quite an ordeal and as I was getting my life together and starting work, it was something that I just had to deal with, basically.

Q. You have also said in your statement you were given no information about the risk to others of becoming infected.

A. No.

Q. Then you have said this:

"Everything I know about the infection now I've taught myself through research and attending conferences and speaking to others who carry the infection. Some of my best friends have died from it. My very best friend passed away nine years ago."

A. Yes. Yes, basically, it was through the conferences, the thalassaemia conferences, that we had and that I learnt from -- I learnt about the hepatitis. We weren't given a leaflet to say, you know, the risks, the type of treatments, because it was a while after that that I started my first lot of treatment.

So it was through learning online, mainly at the conferences, and it was just as if -- it was another thalassaemia-related issue and basically not enough information and not enough information from the hospital, the doctors, to tell you more what, you know, what can happen and what the risks are.

Q. You've said in your statement that as far as you're aware you've been infected with hepatitis C only but you no longer have confidence about the possibility that you might have or not have other viruses and so you always fear that something else will be revealed.

A. Yes. You know, I've lived with thalassaemia, I've lived now with hepatitis, that I've cleared it up finally, but you don't know what's around the corner because there's always going to be something I fear that it could be either from having a blood transfusion or just something that my body needs, you know, the requirements that I need to go through in life, I think.

Yes I don't know what's around the corner for me, for my life and to do with illnesses.

Q. Do you continue to have to receive blood transfusions on a regular basis?

A. Yes. I go to -- I have two units of blood every three weeks at the moment and it depends on how I'm -- my body if I've got any infection or anything I might need to have blood more frequently.

Q. That's likely to continue for the rest of your life?

A. Yes.

Q. You were 21 or almost 21 when this news was given to you about hepatitis C. How did it effect you, first of all, physically?

A. Well, physically, as I said, very tired and, you know, living with two conditions, thalassaemia major and hepatitis, it was quite stressful for my body and the treatments that I've had to go through and the effects that those treatments have caused me, which were terrible, and I had to give up work because of the treatments, hepatitis C. You know, I had a very good job with a big cosmetic company and then being diagnosed with hepatitis C and then, you know, during the time that I was working I had to start treatment and treatment wasn't given to me straight away when I was diagnosed. I waited a few years. By that time, I started getting cirrhosis of the liver and the treatments affected my life.

Q. You've undergone five courses of treatment.

A. Yes.

Q. In the early 1990s, you had interferon?

A. Yes.

Q. For about six months and, ultimately, it made you extremely ill. You developed other infections and you could no longer tolerate it?

A. Yes, my first lot of interferon, I was working, it was terrible. It was injecting I think three times a week and the side effects, I mean, I used to put it in, inject myself, I just wanted to lie in my bed and curl up and just let time go by until the next lot of treatment. It just made me very ill, sick, shivers, temperature, my neutrophils used to drop which that could cause very bad infections, and doing the treatment and the first lot, and after I think three months results came through and it was the virus had come back. It was undetected during the treatment and then three months later it had come back.

Q. You embarked upon a second load of treatment, interferon and ribavirin, and you also had to stop that treatment again because of the side effects.

A. Yes. Again, the treatment mentally and physically my body couldn't take it. It was just very difficult. Neutrophils used to drop, I had to stop it, start it, stop it, start it. I wasn't getting the full lot of treatment to be effective for me and mentally the pain, the physical pain of the, you know, temperatures, body aches, flu-like symptoms all the time, all the time, and going to work and just it was very hard, very hard.

Q. You tried again a third time with pegylated interferon and ribavirin.

A. Yes and, again, and I think the symptoms and mentally I was getting depressed and this is when I had to give up work. You know, I remember crying as I was going home, I was talking to my manager at the time and saying to her -- I didn't tell her I was on hepatitis treatment. They knew about thalassaemia but I couldn't -- I didn't feel I was able to tell them that I had hepatitis C because of contaminating people.

And I just remember ringing her up as I was going home and I said, "Look, I can't work anymore. I'm just on treatment. It's really, really hard on me and I'm all over the place, not thinking right, and I think I need to take time off while I'm on this treatment and because I can't do both". You know, I'm not right mentally and physically and the stress it was putting on me.

Q. Having had to take that difficult decision, Maria, were you able to work again?

A. No, after that that was -- well, I still didn't clear hepatitis after the third lot of treatment. I didn't know how long it was going to take for the next lot of treatment. I wasn't able to go to work, no.

Q. It was a number of years, 2013, when you tried your fourth course of treatment. You persevered for 33 weeks.

A. Yes.

Q. But you had similar problems to those you had encountered previously --

A. Yes.

Q. -- and ultimately you had to stop it again.

A. Again, they put me on antidepressants. I had lots of bad mood swings. I remember my Mum was over and I was getting upset with her for no reason, shouting at her.

It was just hard to deal with everything around and plus deal with the thalassaemia and also with the hepatitis and also at the time of when I was diagnosed with hepatitis I was diagnosed with diabetes, so dealing with everything and having heart trouble as well, it was just -- it was too much.

Q. Finally, in 2016 you attempted your fifth course of treatment for hepatitis C, this time with Harvoni?

A. Yes.

Q. That treatment has cleared the virus.

A. Yes, it has cleared the virus. It was basically -- I moved to Leicester at that time, well, six years ago, and I moved hospitals. I couldn't keep commuting to London as it was too much. It was making me really tired, and I had to go to the hospital in Leicester for my thalassaemia and for all of my conditions, and had to go to the hepatologist department and, basically, I had to fight to get that treatment because at the time I was going -- before that I was going through IVF treatment for trying to have a baby and then that didn't work, and so I thought now I need to clear up the hepatitis because it was a big impact on my life, a big impact with my family life, my husband has a daughter and I needed, you know, constantly I was afraid that I might infect her,

because I'm diabetic I need to prick and blood, withdraw blood to check my sugar levels and I constantly do that 10/20 times a day sometimes, depending on how, if I'm feeling well or not, I need to check my sugar levels.

I was checking -- keep doing my bloods and I was always constantly aware that I might drop some blood and infect my family. And, so, yeah, going back to -- yes, so basically I needed to clear up hepatitis C and I went to see -- I was referred to the hepatologist in Leicester and he did me a fibroscan and -- which I've never had in London before and he goes, "Oh, we need to check, it's not as bad as having a biopsy", which I thought great, so I had a fibroscan and went back to see the doctor after the scan and he goes to me, "Well, I've got good news for you, your fibroscan shows that your 6 and you're not 12. Anything above 12, that's when we consider giving treatment, would give you Harvoni, but we feel that it's not needed because you haven't got so much liver damage".

And, well, I go to him, "I don't understand that because I've had a number of biopsies showing grade 1, genotype 1, grade 1 hepatitis, cirrhosis of the liver", and he goes, "Oh, your liver's, probably because you've been doing your DESFRA, the iron collation, probably because you've been doing that more it's made your liver better", and I go, "Well, no, because I've been diagnosed as severe cirrhosis of the liver", and then I went home, looked on about fibroscans and they're not as -- they're not -- the results aren't as great as a liver biopsy.

So went back to the haematologist at the time and she goes to me, "No, Maria, you need to have -- you need to go on this medication and I'm going to write to the hepatologist and tell them that you need to start treatment because you've got thalassaemia and because of the cirrhosis of the liver".

So she then wrote back to him and then when I went back to see the hepatologist, he goes, "Yes, we'll put you on Harvoni as soon as it comes available for you", so he had to put an application or whatever he had to do and then a few months after that they decided to start me on Harvoni.

Q. I should say that we received, as I think you know, but you haven't had the chance to look properly at them, a couple of statements from the hospital in Leicester in response to certain concerns you expressed in your statement.

A. Yes.

Q. I am not proposing to ask you about those but as

a matter of record they're there and will be published in due course.

Can I ask you, Maria, about the psychological and emotional impact of the years with which you had hepatitis and had to undergo these multiple treatments. How's that affected you?

A. Well, it's affected me in many ways because, you know, five lots of different treatments and it wasn't a simple treatment, it was going to the hospital all the time, every week, getting bloods done, on the fourth treatment I needed to be on a special diet, I wasn't feeling well, shivers, aches and pains, mentally -- it was very, very difficult and it had a lot of impact on my body and I believe it's still, after being cleared of hepatitis C, it still has an impact on my body because now I've developed a neuropathy and I get terrible pains in my hands and my feet, burning sensations, just not being able to sleep at night.

My husband not being able to touch me because of the pains that I'm in, and I think it still has -- it's still affecting me.

Q. You've said in your witness statement in terms of both the physical and mental impact upon you:

"Physically, I'm tired. I'm tired of it. It's

totally and utterly drained me."

You describe feeling drained for years, not having the strength for a normal life:

"It's like I've had my life sucked out of me", and then you have described your memory being affected, your concentration, feeling like you are in a constant daze, brain fog.

A. Yes and like now I can't remember a lot of things. My brain's all fuzzy and it's just, it's draining and being on the treatment is draining and, you know, needing blood, more blood transfusions because I used to get anaemic more so I used to have blood every ten days rather than every three weeks.

You know, my neutrophils going down to, like, next to nothing, you know, being scared that I might get an infection from someone that's just had a little cold and it's affected me mentally and physically and I still believe it's affecting me now.

Q. What's the impact been on your family and personal relationships?

A. Well, you're always scared to tell. It's bad enough you've got thalassaemia and it's a blood-related illness and that's bad enough to tell someone that, and because I live in -- *[redacted]* my community is, you know, thalassaemia was a big thing for them

because it's related to blood, you're classed as a disabled, shouldn't -- I shouldn't be alive, you know, them telling my Mum when I was a young age and the relationships, you know, moving on to relationships, telling my husband, I didn't want to tell him because, you know, telling him thalassaemia was easy but telling him about hepatitis as well it has a very big, big, big impact and influence in people's lives. People run a mile.

Q. You didn't feel able to share information about your hepatitis C beyond your immediate family and friends.

A. Yes. I couldn't tell, apart from my Mum, my Dad, my brothers and sister and my close friends that have thalassaemia, I couldn't tell someone that I've met that I've got hepatitis because it's a disgrace, you know, that I've been brought up that it's not a nice thing to have and that I shouldn't be here.

Q. You said in your statement it's also affected your relationship with your step-daughter because you felt the need to be on constant watch, super vigilant about razors, toothbrushes and the diabetes testing that you've identified.

A. Yes. You know, I had to be constantly making sure that she doesn't use my razor blade because, you know, but then now I move my razor blade so she can't touch it. You know, she might accidentally get my toothbrush.

You're always when blood testing and making sure I haven't dropped any blood on the floor, which it can happen, and I'm on blood thinners as well so you bleed more easily and, you know, you pick your finger and it hasn't stopped bleeding and you might just accidentally touch a glass or something.

You're afraid that, you know, that you might contaminate them.

Q. You've explained how you had to give up work because of the treatment but prior to that you hadn't felt able to share with the people you worked with your condition.

A. I couldn't tell them. I mean, they were wonderful with the thalassaemia and me having, when I needed time off, but I could never have shared that I had hepatitis C, especially because it was skin care that I was working with and touching people and if I had a little scratch or something, I can't imagine, you know, it's just -- it was very difficult to say.

Q. I wanted to ask you about the financial assistance that you'd attempted to obtain from the funds. You have identified in your witness statement a number of financial consequences of your condition, the having

to give up work. You say you got into debt because you weren't then able to meet the mortgage payments?

A. *(The witness nodded)*

Q. You've identified the expense of insurance and travel insurance?

A. *(The witness nodded)*

Q. What's your experience been of trying to obtain financial assistance from Skipton and Caxton, first of all?

A. Well, it's difficult. It's like you have to beg them for something. I tried getting financial support for IVF treatment and I got a letter, supporting letter, from my GP and they wouldn't. They didn't want to know. And it is part of -- I have hepatitis C and it's not easy for me to conceive, so they just didn't want to know at all; so that went out the window.

You know, I wasn't able to get a mortgage because hepatitis C. I wasn't able to get travel insurance because of hepatitis C. It was -- I wanted to go to Australia to see my friend and I thought I'd try to get travel insurance and once I told them that I had hepatitis C, they quoted me something ridiculous like £2,000 and I thought, no, I'm just going and whatever happens will happen to me.

So it was a struggle. I was living on my

benefit and I had because I sort of medically retired, I was getting paid from my work a pension but it wasn't -- I wasn't able to meet up payments that I had living on my own of a mortgage and the rest, so it was very hard.

Q. You have received some payments from the Skipton and the Caxton Foundation but you described feeling that you have had to beg and prove your entitlement?

A. Yes.

Q. You had particular difficulties in relation to dental care and accessing dental care?

A. Yes. When -- in London during my hepatitis, when I was living in London I was going to Eastmans Dental Hospital and they were treating me and because of the hepatitis, I was getting lots of mouth ulcers and mouth problems and when I moved to Leicester, I have to pay for my dental treatment. So I asked if I can get -- because on the NHS or EIBBS they have got a one-off grant where they cover for dental, and all I want when I go and have a hygiene and see the dentist every six months if they could cover my cost but because I haven't proved that it's due to hepatitis they wouldn't pay for it.

Q. You have referred to the problems you have with pain in your legs?

A. Yes.

Q. You have described in your statement that they are restless and ache most of the time and you have insomnia as a result and you made an application to the EIBSS for a one-off payment to try and get some kind of specialist bed.

A. Yes.

Q. Could we have up on screen please, Paul, 1876011. It's one of the two documents that should have been sent while Maria has been giving her evidence.

This is a letter from your consultant haematologist in support of your application and it says this:

"Mrs Fletcher contracted hepatitis C from blood products some time ago and remains on treatment. As a result of the hepatitis C, Mrs Fletcher experiences constant leg pains and cramps. This is likely to be caused by hepatitis C-related neuropathy. Since starting treatment she has also been experiencing increasing generalised body pains. We therefore support her application for funding for a specialist bed that may help improve these symptoms as well as Mrs Fletcher's quality of life."

So that's a supportive letter you've got.

A. Yes. That's the requirement for them that you provide a supporting letter to state that my pains, my neuropathy is likely caused by hepatitis C, which I believe it does, because I've never had this kind of problem before and it's only since coming off Harvoni that I've started to develop these problems, and they're not little pains, they're quite, quite bad and anyway I sent that letter and they replied back with another letter saying that they want more specific details.

Q. We'll put that other letter, the response you received pretty recently, 29 May it is dated?

A. Yes.

Q. It is 1876012, please, Paul.

It says this:

"Thank you for your application for a specialist bed and mattress. I have reviewed your application and can confirm we would require some additional supporting evidence in order to fully consider it, that being a medical recommendation confirming the type of bed required due to the symptoms you having as a result of the infection. Although the medical letter you sent to us states that you suffer from leg pains and cramps it does not detail the requirements you have as a result of this. An application may be considered where the medical recommendation links the

need for a specialist mattress to your hepatitis C infection. The recommendation should detail which symptoms are caused as a result of the infection and what the requirements of the mattress would be to alleviate these ailments. The quotes you have provided may be acceptable, however, this would depend on any updated medical recommendation we receive. Any quotes must meet the requirements detailed in the medical recommendation."

So you've got to go back to a consultant haematologist and ask for recommendations about the type of bed that you might require and the details set out in this letter?

A. Yes.

Q. How does that make you feel, Maria?

A. Angry because I'm wasting doctors' time to write me a letter, where this letter should be more than enough stating that I'm having problems and I have problems sleeping and they want more information and I think that's so unfair because I wouldn't be here if I didn't receive contaminated blood. I'd be working, and I had a very nice, lovely job, but I'm asking for some help and they want more.

Q. The other concern you have expressed in your witness statement about the financial assistance schemes is

you say you:

"... don't know what assistance the funds actually offer, the extent of the help that they offer, this has never been made clear to me. I find the process of applying extremely difficult, especially because I'm sick. I always feel as though I should not ask. I think it is made purposely difficult so that people give up. When you do ask and when you do not ask for assistance I am confused about this, there is no clear guidance. I always feel like I'm made to beg for it."

A. Yes. I mean, that's how I'm feeling, that that's not good enough, and if I want a bed I need to ask for more and beg, basically, to get a bed. It makes me feel that I can't ask again.

Q. I understand from your statement, Maria, that in relation to your thalassaemia you have received over the years some form of psychological counselling and support.

A. Yes.

Q. Has that ever been made available to you in relation to the hepatitis C and the treatments you have undergone?

A. Never, never.

Q. Do you think that that would have been helpful?

A. Yes, I think, especially at the time of doing five lots of treatment, that I should have had some support there. You know, I was quite upset, a lot of pain and taking it out on the people that I love and also the stigma behind it all, dealing with it and dealing with others, to telling them that I've got hepatitis C and it was okay to tell others that I've got hepatitis C. It wasn't -- you know, counselling would have helped.

Q. You made reference earlier in your evidence to when you were going through IVF and you've explained in your witness statement that the issue of your hepatitis C infection played a large part in that?

A. Yes.

Q. That the way in which it was dealt with was very clinical. What did you mean by that?

A. You know, you're contagious. They have to be careful and, you know, if I did happen to fall pregnant and what they would need to do in delivering the baby. So, yes, it wasn't -- I wasn't made to feel, oh, you know, I'm going to try and get you to have a baby and nice, it was like all very clinical and had to be probably put in a sterilised room or something. It was quite hard.

Q. You've also said in your statement that when you attend the hospital, you feel that there are constant reminders of your infected status.

A. Yes, even now.

Q. Infectious diseases unit is where is you have to go, risk of infection is something that's stamped on when you have your tests?

A. Yes. Basically, when I had hepatitis C my blood form had in bright yellow writing "beware" or "can cause contaminated -- contamination". It had a bright yellow sticker basically saying "infected", and the departments that I had to go to was infectious blood -- infectious diseases.

So it was a constant reminder that I'm infected and it wasn't -- it's not that I'd been out sharing a needle with someone or I'd been sleeping around. It wasn't my fault that I received contaminated blood and Leicester -- and it's only been in Leicester that I've had blood forms saying "infectious" and "infectious disease department".

Q. Has that continued after you have cleared the virus?

A. On my blood form it doesn't say that but on my appointment letters it says "infectious" in bold writing "infectious disease department".

Q. Now, again, I think you know that there's been a statement from the hospital which says, well, they have to call it that and they have to have the stamps

for public health reasons but as I understand your evidence your point is about how it makes you feel?

A. Yes and I disbelieve that because I didn't have that in London and the last -- I've only been in Leicester for five/six years and they have that. Why is the two hospitals different in that? Why does it have to be -- well, my letters "infectious disease" or "infected blood" on my blood form. I don't understand that.

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

A. I just want to say that at Leicester hospital especially, that they need to see that I'm a person that has various problems and that I'm treated as differently, like, basically, you've got hepatitis and this is how we treat hepatitis patients.

Well, no, I'm treated -- I've got thalassaemia that has problems that make hepatitis have more problems and I'd like to be treated as a whole person rather than a person that's got hepatitis.

So I feel that they're not doing that.

Q. Maria, I'm just going to turn my bank and ask Mr Lock if there's anything further he'd like to have asked.

Just one question, Maria, that Mr Lock suggests. Once the hepatitis virus had cleared, how easy was it

for you to ensure that you received regular check-ups after that?

A. At the beginning when I was told that I was undetected, the consultant didn't want -- he wanted to take me off his books, basically, and didn't need to see me again. I've had to say to him, "Look, I want to be -- I want to have scans every six months. I want to make sure that my liver's okay because I've got cirrhosis of the liver", and I've known others that have had the hepatitis cleared but they have passed away because of the hepatitis, and I just want to have constant care to make sure that I'm treated as a patient with other problems that can, basically, with hepatitis that I've got care all the time, every six months to have a scan basically and to be, you know, to show that it's all clear.

MS RICHARDS: Thank you.

Sir, do you have any questions for Maria?

SIR BRIAN LANGSTAFF: No, I don't. Thank you very much indeed, Maria.

A. Thank you for listening to my story and I'm sorry it's not as how I wanted it to come out but it's just very difficult. Thank you.

SIR BRIAN LANGSTAFF: We meet again at 2.15 and then we have ...?

MS RICHARDS: We have the evidence of Graham, Graham Manning.

SIR BRIAN LANGSTAFF: Graham Manning, 2.15.

(1.07 pm)

(Luncheon Adjournment)

(2.18 pm)

SIR BRIAN LANGSTAFF: The next witness would wish to be known as Graham, would he?

MS RICHARDS: Sir, yes, Graham Manning.

SIR BRIAN LANGSTAFF: Graham, please.

GRAHAM MANNING, sworn

Questioned by MS RICHARDS

Q. Graham, when you were nine years old in 1978 you fell over and you were taken to hospital.

A. That's correct.

Q. Can you tell us what happened?

A. Well, I was in the playground running around playing football.

Q. Can you speak a little closer into the microphone, please?

A. I was in the playground, playing football and I fell over in the playground and my knee started swelling up and it started to ache and it wouldn't go down, and I remember distinctly coming home from school and I was limping and it just wouldn't stop. It just burnt, really, really burnt and I knew there was something wrong, my parents knew there was something wrong.

So my Mum and Dad took me straight down to A&E the Brooke Hospital in South East London and that's when they did a test to see exactly why my knee had swollen up and they thought, first of all, I had water on the knee and then they realised that I had a blood clot in the knee.

Q. The doctors thought at first that you had a deficiency of Factor IX?

A. That's correct, yes.

Q. And you were treated with what you've described as four bottles of Factor IX initially followed by another three bottles the following day.

A. That's correct, yes.

Q. What were you told about where those products had come from?

A. Well, this was in 1978, May 1978, and the doctor, *[redacted]*, he was a very nice man, quite a young guy, and I had -- my Mum had Dad had bought me a Star Wars poster. I was a big Star Wars fan then, as I am now, and basically they said -- well, the doctor said, "Oh, great Star Wars poster. That's fantastic", *[redacted]* said, "let's put this up on the wall here", and he put it up and then the turned round and said to me, "I love Star Wars", I said, "I do as well, it's fantastic", and I said -- he then turned round and said to me, "Well, this new medicine you have, this new treatment that we're going to give you it's from America". That's why I remember it.

Q. You said you were really excited about this being products from America because you loved all things American and particularly at that point in time you loved Star Wars.

A. Yes.

Q. There aren't any batch numbers or any details in your medical records which show the particular Factor IX products that you were given?

A. That's correct.

Q. But it subsequently became clear that you didn't suffer from a Factor IX deficiency. What do you know the position to be?

A. Well, that's right. They'd given me the seven bottles over the two days and, basically, they were still doing tests to see what was going on. It turned out that I was Factor VIII deficient, which meant I had haemophilia, but I was so mild so that's when they gave me the cryo-Factor VIII which was, of course, produced here in the UK.

Q. So you were given the Factor IX concentrate but entirely unnecessarily because you didn't have a Factor IX deficiency?

A. That's correct, yes.

Q. Do you know whether any advice or information or warnings of any kind were given to your parents about any risks associated with that?

A. Not at all, not at all. I was in hospital. Why wouldn't they not trust the doctors for what they're doing for me? They are there to make me better. There was note kind of choice. This is the procedure, this is what we're going to give him and that's what they did.

Q. You said in your statement your mother raised a concern when it became clear that they treated you with Factor IX when you didn't actually need that product and she asked if it was dangerous, and they assured her it was nothing to worry about.

A. That's right, that's exactly what happened.

Q. But her concern was not about any risk of infection --

A. Oh no.

Q. -- but about whether there was any danger to you from having been given the wrong clotting product?

A. Correct, yes, exactly, the actual Factor IX itself because they thought I was deficient in Factor IX and actually given me Factor IX, somehow that would be dangerous because I didn't need it.

Q. Do you know whether you had any particular reaction to that treatment?

A. I did, I did. I remember being ill. I remember having terrible stomach pains and that lasted for a couple of days, yes.

Q. You've said you recuperated at home with your parents. They noticed you'd become very tired and you looked a bit yellow.

A. That's right. I was very, very tired once I came out of hospital and I looked yellow. My parents put that down to me having an operation and being in hospital and recovering from having the procedure, taking the blood clot off my knee.

Q. Had there been any family history of haemophilia that your parents had been aware of at that stage?

A. No, not at all. My grandfather we worked out, actually, when I was diagnosed with mild haemophilia it worked to be that it's what made sense sort of going back in the past really because my grandfather he had actually died of a haemorrhage. It was an ulcer that burst and they couldn't stop the bleeding. This had been in 1970 I believe and they didn't understand why he wouldn't stop bleeding.

So once I was diagnosed with mild haemophilia, of course, they worked out that basically he must have had haemophilia as well and that's how, basically, we found out about my grandfather when I was diagnosed with haemophilia.

Q. From 1978 to 1988 you attended the Haemophilia Centre in Lewisham on a couple of occasions but you didn't have any treatment with Factor VIII in that period?

A. That is right, yes.

Q. Then the second occasion on which you received a factor product was in May 1988.

What can you recall about that?

A. In May 1988 I'd hurt my elbow and I basically had a haematoma and they gave me Factor VIII and, yeah, it cleared it up pretty quickly which was like -- it was like a miracle kind of drug because it would work really, really fast. It was incredible how quickly it got rid of a haematoma.

Q. Your UK haemophilia database records show that that was Factor VIII BPL is how it's recorded in those records.

A. Yes.

Q. But the UKHCDO database records don't have any record of the Factor IX treatment you had received a decade before?

A. That's correct, yes.

Q. Since 1988, when you have required any treatment what treatment have you been given?

A. Since after 1988 I did not have any treatment at all until I had my gall bladder removed. Then, of course, again it was all UK-sourced Factor VIII.

Q. In August 1992 you received a letter from the Haemophilia Centre and that's going to come up on screen in front of you, Graham.

It's 1367003, please, Paul.

We can see the date of that letter, Graham, 4 August 1992, it's addressed to you from the consultant haematologist at the Lewisham Hospital Haemophilia Centre and it says:

"Although you may not have attended the centre for a considerable period of time your name still appears on the register of patients. I am writing to you to offer an appointment to attend the centre for a number of reasons."

Then we have three reasons set out, one is about assessing your present condition, the second is about hepatitis B and then the third says this:

"People who have received blood or blood products, particularly in the past, may possibly have been exposed to infections. Some of these infections

can persist for very long periods and may require treatment. We cannot know for sure whether people who have received blood products in the past are now free from such infections unless the appropriate blood tests are performed. We would like to offer them the chance to discuss these issues, and if they wish to perform these tests."

Then you are invited to let them know if you would like an appointment.

What can you recall thinking when you received this letter?

A. Well, as you can see there, it's not very specific to anything really. Again, I was such a mild haemophiliac that I had hardly been to the centre. Because I hadn't been to the centre for so long, I was thinking this is more aimed at severe haemophiliacs rather than myself.

Again, it's not very -- it can't be me. How can this be me because I hardly had any Factor VIII?

Q. You have also noted in your witness statement that the letter doesn't in fact explicitly refer to hepatitis C at all?

A. That's correct.

Q. So you thought it was a standard letter?

A. Yes.

Q. Really concerned with people who had had regular blood products?

A. Yes.

Q. You had received them only twice in your life and you didn't really think it was sent with you in mind.

A. That's right, exactly, that's corrected, exactly, yes. It didn't register with me that this would be something that I would have been exposed to because I just hadn't had enough of this Factor VIII. Had severe haemophilia, of course, you were having to inject yourself every day, and it just wasn't like that for me. I got to nine years old without a scratch.

So, again, you know, even after I'd been to the Brooke Hospital I hadn't been then to the centre for years.

Q. You've obtained for the purposes of the Inquiry your medical records and you've seen in there a bulletin that was apparently sent out to you in 1993.

Paul, if we can have that on screen, please. It is 1367004. If we just go to the page before that, please, this should be a letter. Thank you.

So we can see it's a letter 28 May 1993:

"Dear patient, the accompanying bulletin contains important information. Please read it carefully. If there's anything you wish to discuss further please contact the centre."

Then if we go on to the next page, please, we can see there it is called:

"Patient information, the Haemophilia Centre, this bulletin contains important information. Please read it carefully."

Then if we go on a couple of pages please, Paul, that's it, halfway down that page we can see hepatitis C update and it says:

"All patients treated with blood products should be tested for hepatitis C infection? If you attend regular review clinics this should already have been undertaken and the result made available to you."

Then there are various matters other matters set out, including matters relating to the risk of sexual transmission. You've got no recollection, as I understand it from your statement, of receiving this?

A. No, I haven't, no.

Q. In your statement you say, effectively, you can't be certain you didn't.

A. Exactly, yes. Again, I can't be certain but it's quite a lot of information there and really that would have really stood out. Even, literally, the business

with that being -- you would do -- if you saw that I would have done something.

Again, if I somehow -- I wouldn't have thought I would be at risk because I've hardly had any Factor VIII.

Q. Now, in October 1995 you did visit the Haemophilia Centre and what can you recall about that visit?

A. Yes, because, basically, what it was, my sister was pregnant with my niece, *[redacted]* and they turned round and thought, "We were trying to get hold of your brother. We've been trying to get hold of your brother. He needs to come in. He needs to come in", and my sister thought that was strange. My Mum and Dad thought that was strange. "Okay, all right, I've got to go in, got to go in", so I was tested for hepatitis C.

I remember going in for the test. 100 per cent confident. Absolutely no way could I be infected with hepatitis C.

Q. Were you told if any other tests were being undertaken?

A. No.

Q. If we can have up on screen, please, 1367005, this is an extract from your medical notes, Graham, 23 October 1995, it's a reference to haemophilia A,

Factor VIII, and then if we look halfway down the page it's got HIV, hep A, B and C.

You were obviously aware that you were tested for hepatitis C. Were you aware of or were there any discussions about any testing for HIV or hepatitis A or B?

A. Not at all, not at all.

Q. You then returned for the test result. What can you remember about that?

A. I remember going back for the test results. I'm never going to forget it. Again, I felt very confident. Went in there, it's impossible. It just couldn't, I'm not going to be infected. This is crazy. I'm not going to be infected. I sat down, sitting down, and the doctor turned round said, "Unfortunately, I have some bad news for you. You have been infected with hepatitis C. You have contracted hepatitis C", and my whole world well apart.

Disbelief, anger. I was in shock. I remember saying how could this happen? How can I be infected when I've hardly had any factor? And that really -- and I wanted answers and all I got back was, "I'm so sorry, but I'm afraid it's just happened".

Q. If we go back to that same document please, Paul, 1367005, the bottom of the page, we can see that it

there says:

"Patient told hep C positive result, counselled, very angry because has had minimal exposure to blood products."

What information were you given. We can see that it suggested there advised re curtailing alcohol intake, top of the next page:

"Sexual transmission, need for regular follow up, repeat hep C, letter re result", and you were subsequently sent the letter with the specific genotype. What, if any, other information can you recall being given at that consultation about the condition?

A. Sharing toothbrushes, basically with the sexual transmission I was told to use condoms but they said that it was a very -- they didn't feel that it was a very -- that way, you know, there's more of a chance of other ways, so they said really for main thing toothbrushes, alcohol intake as well, yes.

Q. You have said in your statement you were told nothing about the prognosis of the infection other than you could get liver cancer?

A. Yes, that's right, yes.

Q. What can you recall about your immediate reaction when you walked out from the hospital that day?

A. Well, as I was being told I had a brand new company car and I could hear the alarm going off in the car park and I just didn't give a damn because I was in shock. I was like I was -- been hit by this, something that I never expected to be told. I remember getting to the car, sitting in it for a while and driving off. I was in Lewisham. I worked -- at the time, we worked, offices were in Greenwich so it wasn't too far to Greenwich.

I remember crying in the car, I think I'm going to die. I'll never get life insurance, I'll never get a mortgage, I'll never have children, I'm going to die before I get old.

I remember pulling up at the side of the road and ringing my Mum and I remember saying to her, "Mum, Mum, I've got it, I've got it, I've got it", and her disbelief on the other end of the telephone. I look back at that now and I feel -- I feel guilty that I did that. It doesn't make any sense but I feel telling my own mother that out the blue and shocking her as much as I was shocked and terrified.

I then -- I still can't work out to this day why I did it, but I then drove back to work. Of course, I can't tell anybody. Nobody even knew I had mild haemophilia. It was something that just get on with

my life. So it was kind of the way I deal with a lot of things.

I remember my general manager, a wonderful man, wonderful man, and well he had no idea, of course, where I'd been and I said, "I've been to the hospital to see my sister because my sister's having a baby and making sure everything was okay". He said, "You okay, what time you -- what's going on? You're late, you're late." I said, "I know, I'm sorry."

"You, all right?"

"Yeah, yeah, yeah, it's just been some complications."

"Right, okay", which is just awful when you think about me saying that but it's the first thing that come into my head. I then sat back down at my desk staring at my screen and I thought -- I can just remember looking at the clock as well thinking, "I just want to get home. I just want to get home". I got back home, fell to pieces, was angry, had to tell my Dad. He took it really hard.

It was either that night or a couple of nights afterwards I had this nightmare and this nightmare -- it was so vivid. It was a beautiful sunny day. I was in a graveyard. There was a funeral going on and then I found out that it was actually my funeral and

everyone's dressed in black and I'm in the coffin and I can see down the sides of the grave as they've been lowered me down and I'm scrambling to get out, "I'm alive, I'm alive, I'm alive, get out, I'm alive, I'm alive".

I just -- I woke up on the landing. I'd actually scrambled out of bed thinking I was getting out of the coffin and landed -- just, obviously, on the landing and to my parents, "What's wrong? What's wrong? You okay? You okay?

"Yeah, yeah, yeah. I had a nightmare, I had a nightmare. I'm sorry, I had a nightmare, nightmare."

Q. You were obviously unaware until that point of your infection. Looking back at that point, had you experienced any of the physical symptoms of hepatitis C, do you think, by then?

A. No, not at all.

Q. You have said in your statement that you did have tiredness and confusion and muddle sometimes at school. Do you know whether that's attributable to the hepatitis C?

A. I believe looking back now, yeah. At the time -- well, I didn't know and I used to struggle with just the simplest things, get things round the wrong way, mess up, brain fog, feeling really tired, I mean,

exhausted tired. But do you know I used to think to myself other people must feel like this. I can't be the only one who feels like this. Other people must feel like this, and, yeah, I felt different in a way. I can't explain it. I did. I did feel different.

Q. How did you react then? You had told us of the immediate reaction?

A. Yes.

Q. And the reaction you experienced a day or two later. In the months and years that followed, how did the diagnosis impact upon you?

A. I fell apart. I fell apart. I drank a lot. I just thought, "Why me? Why me?" I felt incredibly selfish because if I look back on my life then and I thought this was just happened to me. I just thought it happened to me. It didn't happen to anybody else. It just happened to me. You felt you were on your own with this. It was a secret I couldn't tell anybody but, of course, my family were the only ones who knew. We did it from the outside world. I didn't let any of my work colleagues know. I didn't let any of my friends know because I felt that they would look out me differently, made me feel like a leper on the fringe of society. I was different. I was tarnished. I was dirty. The terror of me accidentally infecting someone was from the start. I was very, very conscious of that.

I remember having my -- I was at my Mum and Dad's and we had toothbrushes in this thing and my Mum had separated it, mine, from my Dad's and my sister's and hers and just I remember seeing that and I thought, "No, no, I'm going to put it back with the others". I just remember that.

It's not -- it just made it so real, you felt that you were so different, you were tarnished, as I say, you were this leper. It was something that controlled my every single day and when I looked in the mirror every single day that thing was there.

If I cut myself shaving, I'd be terrified of getting blood anywhere. If I had nose bleeds, even now, if I have nose bleeds now I'm terrified of getting the blood anywhere. It's like that because you think you could then spread this and give this to somebody else and the thought of me giving it to somebody else then killing them is something that plays on my mind.

Q. You explained in your statement that even whenever you brush your teeth or shave you will disinfect the entire sink?

A. That's right, exactly. I literally wash everything

down with disinfectant, bleach. In that routine after I've brushed my teeth or I've had a nosebleed or anything like that, then I do that, I clean it all up.

Q. You started drinking heavily, as you told us.

A. Yes.

Q. You were convinced you wouldn't get married and that you would die extremely young?

A. That's correct. It was very, very difficult. I met what was going to be my future wife, she was -- I met her and I didn't tell her for around about two months that I was infected with hepatitis C. I was very careful but it was something that was eating away at me. I thought how can I tell her this? Eventually plucked enough courage up to tell her and she fell about crying, "Oh no, this is terrible", but she stuck -- then, right then, she did, you know, she stuck by me then.

And it was a secret again that she couldn't tell her parents or her friends or anyone else. So this is what we were doing, just living this lie, trying to get on with your life, going to work, doing everything you can as a normal situation, but it wasn't normal. It was always there.

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

"Every single day I would think about having

hepatitis C", and you'd be at work and you'd think about it.

A. Every day.

Q. You couldn't tell anyone at work.

A. No.

Q. And you were turning down offers of things like private medical care at work because you would have to disclose the condition.

A. That's correct. We had -- I'd had a pension when I was -- from when I was 21, a private pension, and the company decided that what we're going to do is have a company pension and that's great, I was doing well at work, blotting out the secret, putting everything I can into my work, and this scheme was to start, and then they said about life cover, part of the pension plan was life cover, and that's when I got really, really anxious. I was really upset, because I thought they're going to find out. They're going to find out that I've got hepatitis C because they won't give me the life insurance policy, they won't insure me.

I had had the pension going, my personal pension, which is basically it was all combined into one in the company pension, so they did give me life cover for what I had in the pot but it was lower than

everyone else in the company and I remember the financial adviser turning round saying, "It's strange that. Yours is lower than everyone else's." I said, "It must be my age, must be my age".

"Oh yeah, yeah, you're right, must be your age, yes." The reality of it was I had to go, and see the GP because the company actually wrote to my GP and I had to have a test and everything else and I remember going to see him and I literally fell to pieces in his surgery saying I'm terrified of my work finding out about this. I cannot -- I can't have that happen. It would destroy everything. Because I'd used -- my work was a way of I could just feel like I'm normal and to have that secret out I wouldn't -- and everyone could see I wouldn't be normal and so, yeah, that really was hard.

Q. From 1995 onwards you described in your statement you were seen at the Lewisham Haemophilia Centre, you had regular blood tests, liver function tests, and you said in your statement you were made to feel like cattle being herded through the system. What did you mean about that?

A. Yes, it was like that. I'd go along for another liver function test. It was a blood test. You'd go along, you have this test, go on to the next one, you have the other test and it was like that, like you were being herded through a systems, and sometimes they actually went, "Oh, what are you here for again?"

This is the haematologist actually saying to me, "Oh, what are you here for again?"

"Liver function test."

"Oh right, yeah, okay, oh last time. We got your results from last time. Yeah, they're fine, they're okay, they're fine."

Even in the early days I was always concerned when they are going to turn round and say it's not fine. You always had that anticipation of something they are going to find something else, because I think as well combined with not thinking I even had hep C that going to go at see them again I was going to be given even worse news. So it was very like that. It was very sort of methodical. It was always the same kind of thing. You went in there. It was always the same laborious process.

Q. You describe your then wife used to come to the consultations with you and you would sit in the waiting room and no-one was speaking to each other and you felt like a leper.

A. Yes, because you felt you were on your own. You felt you were on your own. You didn't think that anyone else had been tarnished with this and, it's interesting, I used to go that thought in my mind when you used to see people sitting in the waiting room, I used to think to myself, "I wonder if they have got hepatitis C", because it was a Haemophilia Centre so people went there for all sorts of things and so that was, yeah, that was something I used to think of a lot.

Q. You were desperate for treatment that would rid you of the hepatitis C?

A. That's right.

Q. In the autumn of 1996 you underwent treatment?

A. Yes.

Q. What can you tell us about that?

A. Well, the first interferon treatment that I had was very, very difficult -- very, very difficult, indeed -- but again I had that kind of mentality to, "I'm going to give this my best shot. I'm going to get rid of this thing and I will take any treatment I can to get rid of this thing out of my life", and they said would be hard and I thought okay, but the flu-like symptoms it gave you and the fever I felt, the sickness, the headaches, it was just awful.

But they took me off the treatment early because it hadn't been working.

Q. You weren't responding?

A. That's right, sorry, hadn't been responding.

Q. So it came to an end and you said in your statement you were very angry because you still had the virus.

A. Yes, yes.

Q. So you started in July 2003 a second course of treatment. This was pegylated interferon with ribavirin. What can you tell us about that second treatment, Graham? If it's easier for me to read it from your statement.

A. That's okay.

It's a living hell. The first six months were very, very heard -- really, really hard. You had to get through to a checkpoint, the first six months and then you were tested to see if the virus was still active. I had some great news, I got to six months and they said that, "No, Graham, it's working. There's no sign of the virus. It's affecting the virus. There's no sign of it". I was over the moon. I was like, "Yes, this is great, this is brilliant, this is fantastic. Come on, you can do this, you can do this".

The last six months of that treatment was the hardest thing I have ever done in my entire life. I was holding on to the fact that the virus itself had gone but it was so awful. I had scabs on my head, my mood swings were terrible. I turned into this monster. The flu-like symptoms, and when I say flu-like symptoms, it was like a raging torrent of you feel ill all the time. I'd find that getting worse actually in the afternoons after I had something to eat. I would be at work. I'd feel absolutely terrible. I was sitting at my desk feeling absolutely lousy and, of course, no-one knows what's wrong with me.

I remember having a go at my boss and screaming and shouting at him and years later I had to apologise to him and said, "Look, I'm so sorry, *[redacted]*. The reason I was like that is because I was on the treatment for hep C and I wasn't myself".

With the treatment itself when I look back now, there was a Graham before the interferon treatment, the second interferon, and a Graham after. I was a completely different person.

So I got through to the last six months, got through to finish the treatment. I remember the doctor turning round and saying to me, "Well done, well done, you've done it", because some people were sectioned while on the treatment because they wanted to harm themselves. And he said, "You've done it, well done".

I mean, I actually had problems with my teeth as well which was unusual and I remember telling this to the doctor and he said that's unusual, not had that before. So he said, "You've done it. You have completed the treatment, but I'm afraid" -- I believe it was -- I can't remember now, I think it was a month or two after I had to go back then for the final check after being off the interferon treatment to see if it, actually, had eradicated it and, unfortunately, it came back, so I did all that treatment, feeling lousy, for nothing.

I got to a very low point after that and I just said there was a Graham, a different Graham, after that treatment.

Q. Physically how was the hepatitis C or indeed the treatment over these years impacting upon you?

A. It really did. Every day, as I said earlier, that every single day I look in the mirror and I knew I was infected. I knew that I could pass this on. By now I was married. It was hard living with this thing in the marriage. Again, it was a dirty secret that we never told anyone about. Through the interferon treatment as well it -- my marriage actually failed in the end but it didn't -- I wouldn't say it was all

down to the treatment or the hepatitis C, but let's put it like this: it certainly didn't help having that in my marriage.

So it was very, very tough, very, very difficult to keep going with that and not telling anybody and it was very hard. When my marriage started falling to pieces, I thought I'd look into how I got infected and through social media, Facebook, I found other people and the campaign groups and it changed my life in a positive way, because I found out I wasn't on my own anymore and that I was with people who understood and people who had gone through far terrible things as well than myself.

That really, really opened my eyes to it. From being so selfish before that I felt, when I actually see what this had done do to other people, I remember going to my first demo at Westminster and I met amazing people, absolutely amazing people. You know, it's incredible. I met a man called *[redacted]* who I really respected *[redacted]* a lot. We were quite similar, about a year older than me. He was a mild haemophiliac like myself and I remember walking through Westminster, through Parliament, and the main entrance hall, and we were talking and he said, "Graham, you did two lots of interferon treatment",

and I said, "Yeah, yeah, I did. How did you do that?" He said to me, "How did you do that?" And I just looked at him and I thought this is a man who's had a liver transplant and he's asking me how did you get through that interferon treatment and it just totally changed my outlook of rather than me looking inside myself but looking at what had happened to other people.

And another incident as well at the same demo. I've never -- actually, I don't really know the lady's name and I can't really place her in the campaign now but I was standing outside and she came up to me, "You look, my God", she said, "you look so much like him. Have you been here before?" I said, "No, this is the first time I've been here". She said, "You look so much like him. You look so much like him", and then her daughter came up as well, and said, "Oh my God, you look so much like him", her son. I looked like her son who died of hepatitis C.

The pain in that lady's eyes I will never forget. I will never forget the pain in that woman's eyes. It changed me again. It changed me and fired me up to, this -- we are going to right the wrongs of what happened.

Q. Graham, you started taking medication for your

depression in about 2008?

A. Yes, that's right, yes.

Q. How has your health psychologically, mentally, emotionally been since then?

A. It's just got worse, it's got worse. As I said earlier I'm a real fighter. That's how I've been brought up. You keep going. You get up next day. It will be a better day than the day before. But it's very hard to keep getting back up again when you've been kicked in the teeth, you keep getting back up again, you have to face it, you get hit again, you go down. It's very, very difficult.

I've been on different antidepressants. I've been seeing a councillor which helped. I was going through troubles with my marriage as well, so the counselling helped with that as well as I felt with the hepatitis C. But it's just, as I say, my marriage fell to pieces. I got divorced.

My ex-wife, I think what it was was the -- I had my own fears of infecting anybody, especially with my sons, terrified that somehow I might accidentally infect them. I remember this happened so many times really where my ex-wife, if the kids had hurt themselves and I'd go up to see them, "Look, it's okay.

"No", she used to say to me, "Get away from them. Get away from them. Get away from them. Don't go near Daddy. Don't go near him".

Because, you know, that's how I felt anyway. You know, you look and you think that's what I am. I can infect them. I can infect the people I love. I could -- you know. That was very, very hard. Just the mental thing of it all is the thing that's hit me the hardest than anything else. It's the flu-like symptoms that I still get. It's the constant madness. If I'm brutally honest with you, it's the constant madness. I feel like I'm screaming inside.

I'm trying to be strong, you know. I keep saying, "You can do it, pull yourself together, you can do it", but the screaming inside is very hard and, as I said, with the campaign it helps because I'm with people who understand and I can fight for the cause we all believe in and for justice, and that has helped me but it has been getting worse and I'm under Brighton Mental Health as well, and my GP's very good and given me antidepressants and, hopefully, as it say, it's something that's ongoing and I'm hoping that I will get it resolved.

Q. Amongst other things that you went through, you had a serious pain in your rib cage in mid-2001 and that

resulted in your gallbladder having to be removed.

A. That's right, yes.

Q. Do you understand that to be related to the hepatitis C?

A. Yes, it's related to hepatitis C.

Q. You in 2004 received the first of various letters about vCJD.

A. Yes.

Q. Suggesting a possible risk of infection. What, if anything, can you recall about that and how it impacted upon you?

A. Again, it was -- I'd just come off -- I remember seeing one of the letters and I'd just come off the treatment for -- interferon treatment, the second one, and I was messed up anyway. I was different, a different man. I was a broken man, I felt inside, and I couldn't even bring myself to look at that. What is this? No. I'm not looking at it, not looking at it. That's how I dealt with that.

I can't remember seeing the second letter but I looked at my notes and it's from, not sure, 2008/2009, not sure, but that's when my marriage was falling to pieces anyway, so if I had seen it or it had been -- I wasn't in a right place, again, to even look at that.

Q. We've got the letters and I am not going to put them up on the screen but you got letters in 2004 and again in 2009. What you have said in your statement is you don't really understand from them where you stand in terms of risk.

A. No. It's insane. There's nothing there to state that there's a test. You have been exposed to it. You've been exposed to it.

I mean, in the actual letter I mean I looked at and it says, "If you want to know please indicate here and send this off to us and we'll let you know. If you don't want to know, that's fine, please state you don't want to know or if you don't, don't reply". So it's a very bizarre kind of letter because again there's no kind of test for it, as I say, so it's all sort of up there in the air. So, yeah, it's -- and I didn't know I mean last year I started getting my medical records together and I contacted the haemophilia database and, strangely, on the database itself it did say, "If you wanted to know that if you've been basically exposed to variant CJD then please indicate yes or no". Strange, years later they seem to be saying the same thing. So I put on there, "Yes, I want to know", and it came back and my haematologist said, yes, I'd been exposed and the date

that I think it was 2001, I think, I might be wrong, 2001 I think it is, and that does he know and it says no.

So that was another bombshell last year. Subsequently I found out there was 840 of us who have been exposed to it, as in haemophiliacs.

Q. You have started a further course of treatment for hepatitis C in September of last year?

A. Yes.

Q. How did that affect you in terms of side effects?

A. Yes. Now I was very -- after the unsuccessful treatment, the last interferon treatment, I was apprehensive of taking any more treatments but also then I was then transferred to St Thomas' from Lewisham. Again, this is not about haemophilia. This more to do with the hepatitis C. There was nothing about the haemophilia, it's all to do with the hepatitis C.

So I went to St Thomas' and I can't remember the consultant's name now because there have been a few of them, but he turned round and said to me there was a trial about to happen for like an antiviral treatment's coming in. He said there's one here looking at your response to how you were on the interferon we feel that you have got a good chance of clearing the virus.

So I thought, mmm, okay, all right, there's side effects, not as bad as interferon at all. You know, "We've got problems.

"What's that?"

"The problem is it's not licensed yet. You have to wait until it's licensed", which she found incredibly frustrating. So I was on this list. They asked me would I agree to have blood taken so they could work out why I'd responded so well with the interferon, the virus going, but then why it came back and they didn't understand why it did that. I said, "Listen, that's fine, I agree to that. It can help others and let's do that", so they did that for me.

Years went by. I was still having the test. This time you have a fibroscan once a year and a normal scan every six months, as well as the liver function tests.

So you would then, the day of the scans, even now it scares me, again, is this the day I'm going to find out I have liver cancer. Is this the day they're going to find something? So you have all that worry. This went on for a number of years. The drugs, antiviral drugs, had been licensed but it was all down to the cost and the budgets.

I can distinctly remember at St Thomas' there were budgets and they were giving it to people who, you know, really did need it right there and then. We're talking about different stage liver cancer -- chronic liver disease, cirrhosis. I was very, very aware of that. I felt that, no, that's only right that people who are in that situation need to be treated now and so -- but it was a bitter pill to swallow. As I said, it was like a waiting became for me for when it could happen. I believe it's in 2016 I was given the green light to have the treatment.

But leading up to 2016 my mental health had got even worse. I was not in a right place. It was horrific. I can't tell you how dark a place can be, how dark a valley can be with no sides, you're just stuck in this terrible place just feeling ill, just feeling despair, sick and this is all in my head. It was just getting worse and worse and worse and so I felt I've got to do something about this. I was scared because the interferon treatment I had before which made me feel terrible, the doctors had said to me these new antiviral drugs, they're not as bad as interferon, the side effects are nothing like interferon. I'll be honest, I looked at that and I thought, "I don't trust what you're saying", and

I spoke to the guys on the campaign and I said to them, "Listen, look, they've had the treatment, Graham. It's not like interferon."

"Okay." I was then concerned about after seeing reports that there could be a relapse where you clear the virus but then the cirrhosis starts.

But it got so bad that I thought, right, I've just got to take this treatment and so I said yes to that and I was one of the last ones I believe in St Thomas' to have it. I think there were about three or four of us left. I think we had all been on the interferon and we didn't want to go through that hell again.

Q. How was it?

A. The actual treatment itself was tablets, Zepatier, so you take one tablet a day and it went on for 12 weeks. The side effects were, how can I put it? Nothing like interferon, absolutely like interferon at all. I would have like -- you could tell between the flu-like symptoms I'd been having for years and when I was actually on the Zepatier treatment. It was different in that respect but the only biggest thing I noticed was the heart problems I had.

Now, I've never had a heart problem, I've never had palpitations like this. It happened the moment

I started the treatment. I had an ECG before I took the treatment, which I thought was a bit odd, why they give everyone an ECG before you start the treatment. When I took the first tablet it literally happened within the second or third day I started getting palpitations.

I started getting out of breath. It got so bad that I started getting a pain in the middle of my chest, my heart felt like it was coming out of my chest, my left arm went numb. I had a pain in my arm and thought right now I think I'd better ring up St Thomas' and tell them this is just not right and I had been speaking to them already about it saying, "Look, I'm having these things." They said, "Well, look, you know, we'll check you", they checked me out. Everything had come back fine, but when I was having this thing petition my arm and the middle of my chest they said, "No, we're going to -- we want you to stop the treatment now". This was on the Friday.

So I stopped the treatment on the Friday for the Saturday and the Sunday, sorry, and then I went up to see them on the Monday. They then asked me, "Do you want to carry on?" My test results from then had been brilliant. I'd gone from like 800,000 viral count down to 6. I incorrectly thought that was 6,000 but

I found out it was actually 6. So 800,000 viral count down to 6 in the space of I believe it was a week and a half to two weeks which was incredible -- something I've had for 40 years. So it was an incredible thing.

So they gave me the choice to carry on and I'm glad I did it because I then re-took the tablets. I did have palpitations again but it was nothing like it had been before, which is strange. Having that break for two days, something happened. I'm not sure what it was but I didn't get back to where I was before. But I'd had a lot of ECG follow-ups, I'd had a scan on my heart, everything had come back normal. I'd had all the blood tests on my heart, everything come back normal. Whatever it was, as I say, it was strange.

But after I finished the treatment, while I was on the treatment the thing that got me the most was not having the flu-like symptoms in my life anymore. I recognised that within the first week-and-a-half I was taking the treatment. Not having the flu-like symptoms was like a break in the clouds for me. It was a different -- I cannot tell you the relief I had not having that in my life anymore. You did have little symptoms of the drug itself but I could actually tell the difference between that and how I'd

been feeling for years. So that was a real eye-opener.

Unfortunately, I'm afraid the symptoms have come back again over the last month-and-a-half or so.

Q. In terms of the treatment itself, you finished it and you went back in February 2019 this year?

A. That's right.

Q. What's the outcome in terms of the clearing of the virus?

A. That's right. So in February of this year I was given the thumbs up that there was no sign of the virus at all and that really -- yeah, that was fantastic. That was really, really good. My blood pressure had been high while I was on the treatment and it had been high before and they were looking into that, and they still are looking into that. But, yes, that's basically where it is with that.

Then I had to go back every six months which I'm doing now. It's in the programme every six months to have a scan and a fibroscan to make sure everything is okay.

That could peter off, though, as time goes on. I'm not happy with that and I do still want the regular checks but, as I say, that's something that hopefully will be resolved going forward.

Q. But in the last four to six weeks -- is that right -- you've started --

A. About that. I've been feeling just lousy again. The flu-like symptoms have come back. I've had a pain now. This is the second time I've had it. I had it a few weeks ago and I've had it this week. Underneath my ribs, it's a dull ache that I recognise because I've had that for years because it's a sign of the virus. And I've had the tiredness has come back as well which is -- which is -- I'll say annoying because it is annoying. It's if you can come out of anywhere and you're just absolutely exhausted, me being me I fight against, it but it is a real -- it's just something that just happens and you can't control.

However, the worse thing without a doubt is the flu-like symptoms. I feel that I'm at a crossroads with that. I cannot stand that anymore. Having that break from not feeling like that and then to have it again now is -- yeah, I will admit to you it's shattering. But again I am going to do something about that and hopefully I'll get some help with that.

Q. You mentioned you had had some counselling?

A. Yes.

Q. As I read your statement, Graham -- but correct me if I'm wrong, please -- that's because you have accessed

the help of local mental health services?

A. Yes.

Q. And that's the reason you have had counselling?

A. Yes.

Q. Has any counselling ever been offered to you specifically in relation to your infection and the treatment that you have undergone for it?

A. Since I've been at St Thomas', yes, but again they're overstretched. There doesn't seem to be resources for that. It's also as well -- it sounds crazy, but I've got my job. I've got a job and I've got to work for my job and having the help. It's not just something I can do after work and everything else. I know that sounds crazy again but I don't want -- I want to carry on. I want to keep doing what I'm doing. I want to be able to run a normal life as much as I can but it has got progressively worse over the last few years.

So st Thomas' have offered it but it's not something that I feel that is going to be that easy to access all the time and, as I say, because they're overstretched.

Q. You've made applications to Caxton, Skipton and EIBSS?

A. Yes.

Q. What's your experience been of the process?

A. It's just a long-winded, laborious process which is heartless in a way. It's just heartless. It's something that we shouldn't have to be jumping through hoops for or having hurdles put in front of us. It should be able to access it so much easier. I mean, I needed help with a car, just, you know, so I could get to work and they were -- the whole laborious thing. I had to get different quotes. Okay, send that off. But then they had to have a meeting once every -- I'm not sure how many weeks it was now, and depending on what they say at that meeting that's when, you know, they give you the yes or no. So yes, it was a very long-winded kind of process.

Q. You've put it this way in your statement: you wouldn't hear back from them for six weeks as they had a meeting to decide if you worthy.

A. Yes.

Q. That's how you felt about it.

A. Yes, that's how it felt. That's exactly how it felt, and it also felt that you're cap in hand as well and I've heard that several times through the Inquiry. It is so true. You feel -- you lost your -- they damaged our health and they lost our sort of pride in a way as well because you're made to feel that you're some kind of charity case for something that wasn't our fault.

And that's the real thing here. None of this

was our fault for us guys with a bleeding disorder. We're born with haemophilia but we weren't born with hepatitis C or HIV. So it's a very cruel way we've been dealt with. It's just a real -- something just added to the disaster really, you know.

Q. Graham, those are the questions I have for you but do you have anything you'd like to add?

A. Yes, if I may.

I'd like to thank, first of all, Sir Brian and to the Inquiry. Thank you for letting the victims and families talk. It's something we've not been able to do for decades. To live in our world, in our community, in silence for so long because we're scared of basically what people think, what loved ones think, people, friends. But we sort of work together. We had that bond together and I'd just like to say thank you for everyone giving their statements because it takes an awful lot of courage, it really does.

I've met some amazing people in the campaign groups. I mean, they're incredible people. These people are like brothers and sisters to me and that's what we're like. We're like a band of brothers and sisters against something that should never have happened. It should never have happened.

When you look at how we got infected and you

look at the mistakes that were made, the whole political ideology, if I can put it that way, which led to the disaster, where self-sufficiency producing Factor VIII and clotting factor from UK-sourced blood, those plans were scrapped again because of one thing: because of money. And money has been at the heart of the disaster. It's why it's never, ever been resolved.

I would just like to quickly quote something. This is from a book written by Simon Garfield, an extract from a book called The End of Innocence. He attributes this to Edwina Currie:

"Because there are a lot of them and it was expensive. Simple as that. It is not Government policy to compensate people who are the subject of medical accidents. We looked very seriously at compensation possibilities to avoid poor souls having to take cases to court. But the cost of doing it was horrendous because compensation usually in this country takes into account loss of earning power and potential length of life. So you're talking about settlements of 1 million. Another less public argument received much support at the Department of Health. Payments would have gone to people who ain't going to get better, whose medical circumstances are

not going to improve, Currie says. Many of the more recent compensation cases will pay money during the individual's lifetime rather than a lump sum but the practice then firmly was to give a lump sum based on a calculation and then your haemophilia patient might die three weeks later and, hey presto, you've got a very wealthy family. They haven't got haemophilia, they haven't got AIDS but they've got a million quid of public money which could have been used to help treat other patients. And on the whole that continued to be my feeling. If people are hurt inevitably by treatment that in fact has made their lives better, it's awfully difficult to see where the legal position might lie."

I think that just sums up why not just this present Government but previous governments have not looked at it. It has all been down to money. It's all been down to political people held responsible for what they did.

It's also the pharmaceutical companies. 1970s, 1980s Cutter was the biggest producers of Factor VIII and Factor IX in the world. Bayer, as I know now, basically took over Cutter. They have a responsibility, as well as the other pharmaceutical companies, as well as the Government, to do something now.

What really worries me is we had over 107 people die so far since the Inquiry was announced back in Parliament in 2017. More people are going to die by the end of this Inquiry. That's going to happen and I know that plays on everyone's mind in this room. And we have a duty -- we have a duty -- to those people who aren't going to be here by the end of the Inquiry to do the right thing and do the right thing now.

And I think that the Government need to realise that. We need to stop the games because there's been a lot of games trying to get the Department of Health, for example, off at the Inquiry has been -- it's been awful how the games that they have played and the people -- they just don't seem to care and I think I can say that throughout the whole of the disaster, that people don't seem to care from Government officials, pharmaceutical companies, even some haematologists.

And that's the thing with the tragedy. It's just been a -- and still going on. The disaster is still happening. It's not it's over 30 or 40 years ago. It's still happening right now. It is up to the Government to say enough's enough and do the right thing. People have suffered for too long and it's

been -- and just do the right thing in society because we owe it to the people we've lost, we owe it to the ones who are alive, and we owe it to generations so this never, ever happens again because it could happen again. We have pharmaceutical companies -- again, profits are more important than people's lives.

The people who died, if you hear all the figures, and it's the numbers. These aren't just numbers. They're people. They are real lives, real families destroyed, smashed to pieces. It was genocide total genocide.

We deserve to have the people who have questions to answer to appear in front of the Inquiry, not to write letters, not to try and dodge out of things, not to try and say the same old thing, "Oh, there's nothing else we could have done" because the people we've lost deserve answers. The families deserve answers. We deserve answers so, as I say, it never happens again.

I just wanted to quickly say this about this form which is the EIBSS form for funding for certain things for people who are infected. The thing that I could not believe when I saw this is to apply for a funeral prepayment plan payment, the applicant must send this in: a completed discretionary one-off

payment application form and a quote for the prepayment funeral plan. A quote for a pre-paid funeral plan. It says here a copy of the funeral invoice or receipt.

We're not talking about double glazing. We're not talking about something that is trivial. A widow gets that and has to go through that. Haven't they been through enough already? There doesn't seem to be any thought, there doesn't seem to be any humanity and that's the thing that was lost with what happened to us. Humanity lost in madness and chaos; as I say, political ideology; pharmaceutical greed.

There are people who have to answer for what happened no matter how difficult this is, they must answer for what happened. We cannot -- we cannot have closure until that happens, sir. We cannot have closure until that happens. We have lost too much and we're going to lose even more.

This thing has consumed so many. Even in the campaign, we lose people and we keep going and we lose people, we keep going, people get ill, you don't see them anymore. It's just ... why would people in authority allow this to continue? It's just wrong and, as I say, it's something that the Government needs to look at now and act on.

That's all I wanted to say.

Q. Graham, I'm just going to ask Mr Snowden if there's anything he would like me to add.

Thank you, there's nothing.

SIR BRIAN LANGSTAFF: Graham, thank you very much for coming to share your evidence and your thoughts with us.

A. Thank you, sir. Thank you.

SIR BRIAN LANGSTAFF: As you will probably know, this is the last day of our hearings in London until October. The Inquiry is a UK-wide Inquiry. It takes that seriously and, because it is more difficult for those who live in some parts of the United Kingdom (Northern Ireland, for instance; parts of Scotland; the north of England; Wales) to get to the Inquiry, as people ought to be able to do -- this is a public inquiry, it seeks to put people at its heart -- and so we go, as best we can, to where we are going to serve more people and better able to take their evidence at their convenience.

Next week if you happen to be in Leeds -- you may not be, but if you are -- you are very welcome to come to the Inquiry where we sit again on 11 June. We shall be in Leeds for two weeks. Then after a week spent in preparation, we shall be two weeks in

Edinburgh and, after a further week of preparation, a week in Cardiff.

But I can tell you now that we have been reviewing the needs to accommodate as many people as we reasonably can. As I've said a number of times, we certainly can't take oral evidence from everyone who would wish to give it; we have to make a selection. That's inevitable and I think all of you who are here and those who may be listening have understood that, even though it may mean that their own wishes to give oral evidence have been disappointed. I'm sorry if that's the case but it's, to an extent, inevitable.

However, we are going to have a third week of evidence from those infected and affected in October or November when, as you know, at that time of the year we had originally been planning to have two. There will be further opportunities, I should add, for those who have been infected, those who have been affected by the infection of others, to give evidence throughout the Inquiry from time to time and, as I promised at the outset, at the end as well as at the beginning. I say that because there are still those who are hesitating about giving witness statements. There are those amongst them who may feel that they would wish to give oral evidence but may be feeling

that they have missed the boat. They haven't. There is space for some. As I've said, it won't be all. I will be dishonest if I said that. But there will be space for some throughout the Inquiry until it closes.

But for now, thank you for your attendance here in London. We sit again to hear evidence at 10.30 in Leeds on 11 June and I look forward to seeing some of you when we meet again either there or here in October when we are due currently to start on 8 October. If there's a change to that schedule, then you will be told of it in good time. Thank you very much.

(3.40 pm)

(Adjourned until 10.30 am on Tuesday, 11 June 2019)

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