Friday, 21 June 2019

(10.30 am)

SIR BRIAN LANGSTAFF: Good morning. We have Pete, do we?

MS RICHARDS: We do, sir.

SIR BRIAN LANGSTAFF: Pete, please.

PETER BURNEY, sworn

Questioned by MS RICHARDS

Q. Pete, you received two blood transfusions?

A. Yes.

Q. One in 1975 and one in 1986?

A. Yes.

Q. Were you on either of those occasions told anything about any risks of infection associated with the blood transfusion?

A. No, no, not at all.

Q. Now, you found out many years later in 2010 that you had been infected with hepatitis C.

A. Yes. The date's a bit sketchy, 2010. I actually became aware of it in 2011 though it was documented on my medical records I was told in 2010.

Q. It was about 2009 when you started to feel really unwell.

A. Yes. I first went to the doctor's in March 2009. I presented myself. I was in jaundiced, I had ascites and obviously I needed to come out of work because

I couldn't function and I went to see the doctor I with a view to getting a sick note and, you know, that's how I kind of went to see him.

Q. In terms of the interactions you had with your GP in the course of 2009, you went more than once I think and you weren't given any test for hepatitis C.

A. Not initially, no. Basically, just issued the sick notes, he put on the sick notes, I'm pretty sure he put on the sick notes anxiety and alcohol, something to do with anxiety and alcohol. I did not really pay much attention because I only really needed the sick notes for work.

Q. Your symptoms of ill health continued. You began to feel very tired and you were experiencing itchiness?

A. I began to feel very tired prior to 2009. I couldn't understand why. I was anxious, I was showing signs of confusion but it all came to a head, as I say, in 2009.

Q. You described in your witness statements how you were having difficulty sleeping and you became very bloated and from a point in 2010 you started to have to have your stomach drained?

A. I suffered from ascites which is -- it's a noticeable, you know, signal for end stage liver disease and I used to have to kind of go in as an in-patient where

they would take maybe 15 litres of fluid off my abdomen. Each litre of fluid represents a kilo so I would lose 15-kilo overnight.

Q. By this time it was understood that there was something wrong with your liver but still no mention of hepatitis C; is that right?

A. Yes. The doctor did at some stage in 2009 he tested my liver enzymes. My liver enzymes came back high and he said cut back on your drinking, which obviously I did but I wasn't a massive drinker anyway. This is what I couldn't understand, you know. But I did and then I went back for another test and my liver enzymes was higher, so that didn't make any sense.

Q. In your statement you've said, essentially, looking back, you were being pigeonholed as someone who had alcohol problems rather than there being an investigation of what might in fact be wrong?

A. It only seemed to be pigeonholed by one GP. I think I got about six or nine sick notes. His sick notes always said anxiety and alcohol, something I can't remember, and the others that wasn't issued by him just said anxiety and depression so he was pigeonhole-ing me. I do not know why.

Q. The dates that you've given in your statement in terms of the blood tests which established the presence of

hepatitis C are that you were tested at Stepping Hill Hospital on 14 July 2010, that the results came back positive about a week later, a week or so later, 22 July, and then you were told of the hepatitis C the following month in August 2010.

Does that sound right?

A. Yeah, but I wasn't aware that they were testing me for hepatitis C at that stage you see, so that only became apparent from my medical notes which I actually got in 2011, so throughout the testing procedures I wasn't aware and then I seemed to be aware of a doctor coming to see me in Stepping Hill as I was an in-patient and I don't even remember him telling me that I had hepatitis C and I didn't really understand what hepatitis C was anyway.

Q. You have referred to there being at some point a casual conversation almost, "Oh, you have hepatitis C", almost as an afterthought.

A. Well, it to have been that way because otherwise if somebody said to me, "Listen, you know, you have got hepatitis C and it's not good", then I would have registered -- that would have registered with me. So he's obviously told me and I've noticed from my medical records that's probably one of the only entries that's initialled and dated, so it seems to me it was more of a -- not a cover-up, I won't use that word, more of him trying to cover his own back saying that they had told me, yes.

Q. Certainly whatever you were told, you said you didn't understand the enormity or significance of this information.

A. No, not at all.

Q. No-one explored with you the possibility that it could have been caused by the blood transfusions you had had many years previously?

A. Absolutely not, no.

Q. You weren't told anything about the risks of infecting others?

A. No, definitely not, no.

Q. And you put it this way in your statement, Pete, you've ended up finding out everything that you learnt from the internet yourself.

A. Well, yes, yes. That was obviously after I was aware that I had hepatitis C, which really only came -- I became aware of after I was placed on the liver transplant list after St James's, so. That would have been about March 2011, yes.

Q. When you did find out or understand that you had hepatitis C and you researched it yourself, you became terrified of the risks of infecting others, particularly members of your family and grandchildren?

A. I made a mistake. I'm not very computer literate, to be fair. I made a mistake of ending up on American websites and, wow, it was horrendous. It was like I really thought I was going to die -- well I was, but what I'm saying is it kind of drove home to me the enormity of it, yes.

Q. You became afraid of sharing cutlery and crockery?

A. Everything, yes.

Q. And your granddaughter would say, "Here, Granddad, eat this cake", and you would say no because you were so worried you might infect her?

A. Well, the one thing that stuck to my mind was my granddaughter kissing me, my eldest Granddaughter, she's 17 now, she would have been about 7 then. I said to her, "Look, what we're going to do now is when we kiss we're going to do it in the European way where we kiss on the cheeks", you know.

So, yes, I was trying to -- things like ice lollies, you know, and cake, as you say, you know, it was just really, it was really frightening you know the prospects, you know.

Q. In the autumn of 2010 you were admitted to Stepping Hill Hospital because your liver was failing.

A. Yes.

Q. You have described the symptoms in your statement in very powerful terms. You were in terrific pain, convulsing pain, vomiting, soaked in sweat. What can you tell us about that time?

A. Well, I've only kind of outlined one time, yeah, but there was many times like that and that particular time I think you are referring to is I was taken from the main ward and I was put into a side ward because it was obviously it was something drastically wrong with me and it was at the nighttime, and it was like there was -- I mean, I've never been pregnant but it was like there was a fist inside me trying to push out of my stomach but it was kind of like going all over my stomach.

I had terrific cramps, cramps -- I don't know whether you would describe them as cramps. My body was just convulsing. It was all up my back, it was up my sides, it was in my legs, it was in my neck, my hands, my feet. It was just all over me.

You know, I was vomiting, there was literally sweat just pouring out of me and the headaches were just horrendous. I really thought I ain't going to get through this.

Q. You also became incredibly itchy?

A. Well, yeah, again, that's a common sign, you know, it's a common sign with end stage liver disease, because my liver was at end stage at that time. You just can't stop scratching and the only problem is when you break the skin, then you're open to infection, you know, but it was on my feet, it was on my legs, my arms, it was on the tops of my legs, it was -- I know it -- to someone listening to this you'd think, okay, you've got a rash and it was itching. It was worse than that, it was a lot worse than that. I found that probably one of the most debilitating aspects of having the condition that I had at that stage.

Q. In December 2010, on 16 December 2010, a DNR, do not resuscitate, was put on your records at Stepping Hill Hospital.

A. Yes.

Q. You didn't know that at the time?

A. No, no, because I think I was only brought in as an in-patient on 13 December.

Q. You have identified in your statement a number of concerns you have about that. It wasn't discussed with you, your consultant's name or the consultant's name that's on it is not the consultant that was treating you and there's no mention of hepatitis C on the forms, and you've said in your statement you think that was -- could have been a deliberate omission. Why is that?

A. Well, my family was called into a room and the doctor kind of said to me before I went in, "Has the consultant spoke to you? Has Dr Das spoke to you and explained Peter's position, how serious it is?" And the family said, "Well, no", and he said, "Well, we'd like a family meeting", which was on the Thursday I think, and they went into the room and this doctor, when he was speaking to my wife originally turned round and said, "I'm covering for Dr Das. Dr Das is on holiday", yeah.

Obviously, then he kind of met up with the family but I wasn't present there because I didn't know anything about it. He met up with the family and then on the DNR, obviously I've seen the document, there's no mention of hepatitis C at all. There was also a nurse present I would imagine, because she was taking notes as well, I would imagine that she was witnessing what was said and she never mentioned hepatitis C at all either.

Q. What you've said in your statement is that had you died then, not having been resuscitated, your death would have just been registered as an alcohol-related cirrhosis rather than hepatitis C-related or related

to a blood transfusion?

A. Most definitely, yes. The coroner would have had no other option because the process on that DNR was futile and, you know, he was going to die.

Q. In January 2011 you developed hepatic encephalopathy. What can you tell us about that?

A. Well, okay, I thought I was fine, you know, I thought everything was normal and ticking along but some of the conditions that I had as a result of that was like I would go to bed and encephalopathy is a recognised brain disease but it's caused by your liver not being able to remove the toxins from your blood and the toxins then attack your brain, yeah, so it's a recognised brain disease. And I would go to bed at night and I would sleep for maybe 5 or 10 minutes, maybe 15 minutes, and I would think I had had my eight hours sleep. So I would get up and go to do my morning routine, so run a bath, clean my teeth, and the unfortunate thing is I was getting up four or five times a night and I was repeating my morning routine. So I was running baths four or five times a night.

Obviously, my wife was, you know, behind me watching me because, you know, this one particular time I filled the bath with cold water and that immediate my eyes water, kind of thing, and I jumped

out of the bath, you know.

Then I got quite aggressive with my wife and I said, "Why are you always behind me? Why are you following me?" Because I thought I was fine she said, "Pete", she says, "You're putting toothpaste on your razor blade to clean your teeth".

Q. Christine has described this period in her statement in this way:

"It was terrible, a nightmare. He was doing absolutely stupid things, ripping money up. I remember getting a call from a woman who asked who kept calling her phone. Peter, he kept trying to phone people and was calling her. I told her it was my little boy calling. Then there was the getting up in the middle of the night. He'd sleep for ten minutes then get up and start running the bath. I would hover round him. I saw him putting toothpaste on his razor."

Then she said:

"Sometimes I can still see bits of it now when he forgets things. He was never like that before. He has always had a strong mind. They have told him it will never go away and that's really hard for him."

A. Yeah, I still struggle with it now, to be fair, because it's really frightening because I can be doing

something, I can go into a room and I can forget why I'm in that room, and I can be in my own home, and for a couple of seconds you get that feeling of despair. You're panicking. You're not in control of yourself and that's happening now -- not now but you know still, yes.

My wife left something in the car and she asked me to go and get it, and this is going back that three weeks, and for the life of me I couldn't open the car and it was on a fob, you know, like it was obviously central locking and I just walked away and kind of -- I had that feeling of despair, you know, so you hide away, you know, and then she said, "Well, where's that ..." I said, "Oh, you get it", you know. Encephalopathy is an horrendous disease. I still have treatment. I have two forms of treatment for that now, you know.

Q. You were placed on the liver transplant list in February 2011.

A. Yes.

Q. You spent nine months waiting for that call.

A. Yes. That was in St James's in Leeds, yes.

Q. In November 2011 you did get a telephone call but it wasn't the one you were expecting.

A. No.

Q. What were you told?

A. Well, it was Bonfire Night, so the family was together and obviously, I'll be honest with you, nine months waiting for the transplant, it's really daunting, you know, because you know you're expecting these calls and yet you're dreading them. And I really, you know, I'm not the bravest soul, if you know what I mean, when it comes to surgical procedures.

We got this phone call on Bonfire Night and the family was together. So I put the phone on speaker or I think my wife put the phone on speaker and it was Leeds and I thought, God, they've got a liver, and he said, look, we're going to suspend you from the liver transplant list like that, and I says, well, obviously, I said, "Well why", you know. She said, "Well, if we got a liver for you this weekend you wouldn't survive this procedure". So I know it sounds selfish but secretly I was relieved because then I could kind of -- I didn't have that cloud hanging over my head and not being able to move too far from Leeds and having to take my bag everywhere I went. Obviously, my wife and family, they was distraught, you know but, again, I was secretly relieved because I guess I'm one of life's cowards.

Q. You continued with the symptoms you described and then

in March 2013 you started on treatment for hepatitis C, treatment which included interferon and ribavirin?

A. And telaprevir.

Q. Yes, and telaprevir?

A. Yes, yes.

Q. What were the side effects of that treatment? What was it like?

A. Well, the side effect of the treatment at first, I mean, by that time I was aware of what they'd done to me, yeah. So I had no trust whatsoever. I was quite hostile and I wasn't having it, you know. But then I had to inject myself, you know, every week and, you know, I wasn't into that either.

At first obviously there's trepidation but as the treatment started to kick in, it would send a lunatic mad. Everything was just exacerbated, everything was just made worse, you know. It's just affected every part of my body, you know. I had mad, crazy thoughts, you know, suicidal thoughts and, you know, I would be all right one minute and the next minute I'd be on the ceiling. I don't mean physically, I'd be -- I could be anywhere, you know.

It must have been horrendous for my wife and the family but, at that stage, I'd suffered so much with

the condition that I would have took anything.

Q. Your viral count was checked every four weeks?

A. Yes.

Q. You knew that the results weren't looking good.

A. Well, by that time I could talk to medical professionals and I could read between the lines, you know, and I knew it wasn't going good and on my second viral count, bloods, I spoke to the person who was doing it and it was in the specialist unit and I knew they were going to stop the treatment, you know what I mean. So I kind of said to her, I said, "Look, if you're going to stop my treatment I'd like you to phone me". She said, "I can't do that". I said, "Look", and I explained the position and she agreed to phone me, you know, rather than tell me in clinic because every member of my family was focused on this treatment, you know, healing me, kind of thing.

Q. They thought this was going to be the wonder drug?

A. Well, you do, don't you? I mean, it's like, you don't find too many atheists on a sinking ship, yeah, and this ship was sinking.

Q. You wanted to be the one to tell Christine the treatment hadn't worked rather than her learning in the clinic at the hospital?

A. And then having to walk through a crowded waiting

room. I got the call in the car and this nurse come on the phone and she said, "Look, I'm not happy with this", so I explained the situation and I said, "Look, this is at my request". I said, "I'd like you to kind on tell me what's going on". They said, "Look, we're pulling you off that treatment", so I thought ... you know.

But that gave me a bit of time to kind of break the news to Christine gently, you know. So it worked for me. I don't know whether it worked for Christine but it worked for me.

Q. It took you two or three days to tell her?

A. Yeah. It was like dropping hints, you know, this treatment ain't all it should be and, you know, there could be others things, even if this fails and then I told her and then ... well.

Q. You had to wait until August of the following year, 2014 to start a second course of treatment.

A. Yes, sofosbuvir and ribavirin, yes.

Q. A consultant helped you access that treatment on --

A. Compassionate grounds.

Q. -- compassionate grounds?

A. Yeah.

Q. What was that course of treatment like?

A. Again, after failing the first course of treatment, you're waiting for the same to happen again, you know. The side effects -- I think the side effects was worse from the ribavirin than they were from the actual drug itself, you know. That's what I believe, yeah.

Again, it wasn't very nice. There was certain things that it was doing to me that I really don't want to go into on here, you know, and that was a three-month treatment and that was three bad months, you know, and I would say although it did clear the virus for which I'm grateful, I would say the effects of that treatment lasted a lot longer than three months, you know. I would, honestly and truthfully, I'd go into maybe a year before I actually kind of started to kind of get somewhere near normal, you know. I know it sounds strange but it's true.

Q. The impact of the illnesses and the treatments that you have described over these years from 2009 onwards on your family life and your social life, what's that been?

A. It's decimated it. Absolutely ruined it. I went from hero to zero.

Q. You've explained in your statement that you haven't been able to go on holiday with the family anymore. You take your wife to the airport and you don't go on the plane.

A. The thing is you begin to see yourself as a burden, you know, and you know like my wife will go away with her sister and I know that she'll have a relatively good time, you know, sisters generally do.

Whereas, obviously, I mean since they told me to kind of cut back on my drinking I haven't drank, you know, ten years I've not drank, you know. So I'm not saying drinking is the life and soul of the party. What I'm saying is my wife may want to have a drink or a bottle of wine or whatever but, I don't know, it's just -- it just seems to be one of the impacts of this condition, this hepatitis C, it does -- it affects you in so many different aspects.

I mean, don't get me wrong, I'm not looking for a reason to blame certain things on hepatitis C but it really is -- it really is life-changing, it's life-shattering having this condition.

Q. You talked in your statement how relatively recently you've gone on a flight simulator and that was one of the first things you've done as a family for a very long time?

A. We have three, grandchildren, obviously, and a son and a daughter-in-law and it was the first time that we've actually done anything together with the youngest grandchild, you know, since -- well, since she's been

born ever, you know.

I know it was only a flight simulator, and I know it doesn't seem like a great deal but to us it was, you know, it was a really pleasant experience.

Q. You found yourself avoiding the people you grew up with and avoiding trying to make new friends and acquaintances because the conversation turns to, "Why aren't you working?" And you don't want to say, "I've got hepatitis C"?

A. It's not only why are you working. It's silly things like it's if you're in a bar or because I will go in a bar and not drink, no problem, but you know you sit there they say, "What are you having to drink?"

"I'll have a water."

Don't you want a beer", you know? "No, no, I'm fine."

"What? Don't you want to drink or can't you drink", you know, and then, you know, again that probe's coming because you know what's going come after that. Regardless of whether you are clear of the virus a lot of people's lack of knowledge of it, even though you're clear of it, will to them probably still mean you've got it, so even though you've got rid of this virus, yes, you're still open to stigma and, you know, they can distance themselves from you.

Q. In terms of the stigma, you've described in your statement when you go to the hospital or at least one particular hospital, you very much felt the stigma when you had your bloods taken and there's a big yellow sticker with hazardous material.

A. Yes, that's exactly right and that was in Leeds, that. That was where you know when I used to go for my liver assessments and to meet with the liver specialists and they used to give you a bag, and it used to have, on the bag it used to have a big yellow thing like a round wheel but cut into bits and "Hazardous materials", you know.

I'd be sat there in the waiting room and I'd have the bag and it would be like that *(indicated)*. You know, I'd be covering it, you know.

Looking back on it, you know, I should have just turned round and gone, "You know what ... I'm not having this", you know. But, you know, at the time obviously I was with the wife and, you know, we was on the transplant list and I was potentially trying to save my life.

Q. When you were an in-patient in hospital the nurses' station on the ward by your name there would be written in big red letters "Hepatitis C"?

A. Yes, I flipped on that because there was people on the ward as in-patients that I knew because that was in Manchester actually, and I was kind of being pushed past it in a wheelchair and I seen it and I stopped the wheelchair and I grabbed the nurse and I turned round and said, "Listen, what does that mean?" She shown me and it was in big bold red letters. She says, "Hepatitis C". So I said, "Well, why have you got that on there?" So she says, "Well, it's because of what you're in for". I said, "Well, do you not think you should have a little bit more tact? Everybody that comes in here with any kind of enquiry", I said, "are going to approach that, look at my name, look at my bed number, and see 'hepatitis C' and they're going to look at the people that are visiting me." I said, "That needs to come off and that needs to come off now", and they took it off.

But that's one of the things that really stuck with me because I don't rightly know how long that was there and there was guys on that ward that I knew, you know, and -- well, I don't know. I got quite agitated by that.

Q. You've mentioned in 2009 going to the GP for the sick notes because you weren't able to work and you had to give up work.

A. Yes.

Q. That obviously had a big financial impact.

A. Massive, massive financial -- I went from £800 a week to £80 a week after six months plus housing benefit. I had a mortgage to pay, had a house to run. Luckily I've -- well, I've been quite prudent. I'm the youngest of seven children. I come from a council estate and everything, you know, as far as I've got a bit of a squirrel attitude.

Q. You'd been the provider for your family since the age of 15.

A. Yes.

Q. And no longer being able to be the provider has upset you?

A. Getting back to that from hero to zero, you know. I think it's the same for everybody. It's indoctrinated in you. You know, you have to provide for my family. As I say, I was the youngest of seven children. My parents -- I was brought up with a Victorian attitude, you know. The guy should provide, the woman should kind of cook, you know. I know it sounds a bit strange but that's my parents instilled that in me because they was quite old when I was born. I think my mother was 45.

You know, I adopted that attitude and that kind of got me through life and we were going quite well, to be fair. We was okay. We could holiday when we wanted and we could do whatever we wanted. We didn't have any financial -- you know, we had quite a nice home, quite a large mortgage, and that all kind of went rapidly wrong, rapidly quick.

Q. What obstacles, if any, have you faced in terms of accessing dental care?

A. That's a strange one, you see, because you have to declare it. When you go into the dentist they will ask you, like, what conditions you've got and, obviously, my platelets being low I have to declare that, then liver disease and hepatitis C because they could inject you with something that will go to your liver. Yeah, it's not good.

I had a problem with some -- with a tooth I think and they kind of said, "Right, well, we can't treat you for that", you know. "You need to go to the hospital". I said, "Why do I need to go to the hospital?" She said, "You've got three teeth there all the roots are twisted and they combined and we can't take them out". It was a lie. I went to the hospital and they said, "There's nothing wrong with your roots", and they also said to me that they'd put me to sleep. They couldn't do it because of my liver. When I got to the hospital he said, "We can't put you to sleep", you know what I mean. "You don't need to go to sleep. There's nothing wrong with your roots. We're just going to take them out".

Then the guys was there swinging on them and, you know, I went back to the dentists and I said, "Look, you know I need an extraction", and he said, "No, no, no, we don't want to extract it. We'll fill it", and then they'll say, well, okay, they filled one and then I'd go back and then they'd say -- or my filling would come out and they'd say, "Well, we'll temporary fill it". I've got temporary fillings in now that I've had in for over a year, you know, and all my family go to that dentist, you know what I mean, and they don't want to treat you. They just don't want to treat you. I know I've heard stories about people coming in masked up to treat you. There was none of that but after having said that you know, you know when you're not welcome at a party, you know that. I wasn't welcome.

Q. You made applications to The Skipton Fund and received payments. You didn't face obstacles yourself in accessing Skipton but you've been helping others over the years who have had difficulties?

A. Yes.

Q. What is your view or impression or experience of The

Skipton Fund from that work you have done helping others?

A. Well, The Skipton Fund, to be fair, right, you had a criteria that you had to satisfy. If you satisfy that criteria you sail through, yeah. If you didn't, then a brick wall came up, came up against a brick wall.

There's a person in this room that I helped obtain payments from the Skipton and she was a blue baby and she applied to the Skipton for funding, yes, and because she was transfused at birth, they had no medical records, so I kind of -- I met her at a support group because I'm the chairperson of the Liver Support Group at Manchester Royal Infirmary and I met her there and I could see she was distressed and I said, "Look, you know, what's up", and she said, "Well, they won't give me any money. They are saying I can't prove I've been given contaminated blood". So I got the story anyway, she signed an authority and I could liaise then with The Skipton Fund on her behalf.

So she got some documents but, basically, I did it as we got the birth certificates of the children, got the medical records from the father and the mother and it showed that the mother was rhesus negative so,

basically, she had to have a transfusion at birth otherwise, she would have been dead.

So I presented that to the Skipton. They asked me two questions. They said, "Well, look, she hasn't even got cirrhosis because her platelets are too high." I said, "She's SVR. She's cleared the virus. The platelets are right." So they said okay and they awarded her the money.

That woman today wouldn't have been getting a penny but because of these, I won't say obstacles, the criteria are so black and white for them, there's no grey area, there's no hang on a minute if she's got this or she's got that then she must have had this. They don't work that way. They don't want to pay you because they want to kind of minimise the magnitude of this problem. They just don't want to give you the money, simple.

Q. In terms of EIBSS you asked EIBSS about counselling, funding for counselling.

A. Oh, yes.

Q. Can you tell us about that?

A. Well, EIBSS, yeah, I applied for counselling from EIBSS and actually getting from EIBSS the criteria gain that I had to satisfy was like pulling teeth. They have no template letters. They have no letters

to say what criteria you have to satisfy. You have got to kind of do this and you've got to go to a GP. They are asking me, who's now hepatitis C clear, to go get a letter from the GP saying its due to my hepatitis that I need counselling. I haven't got hepatitis, yeah.

So I turned round and said, "Well, look, I'm not going to do that. I don't have hepatitis. I'm going to turn round out and say I need counselling because of my cirrhosis". After a load of umming and ahing, they agreed, yeah.

So I got the letter from the GP, wonderful letter, and forwarded it to these guys and then they come back with this other criteria that you have to get an estimate as to how many hours you're going to need, an estimate as to how much per hour they're going to charge, and we want to see the public indemnity insurance, and we want to see the qualifications, and they have to be registered with such and such a body, and then no funding for the assessment, so you've got to fund that yourself.

You get on the phone to these guys and say, "Can you give me a quote for ten hours", they are going to say, "Well, how do we know you are going to need ten hours? You need to come and be assessed. It will

cost you X and X amount of pounds". I go back to EIBSS and I say, "Well, look, are you going to pay for this assessment or if I pay for it, can you knock it off?" "No, we can't do that. We can't make retrospective payments."

Everything that EIBSS try to do is never in your favour. It's always to stop you obtaining any kind of funding.

Q. In addition to having to locate counsellors, get prices, get estimates, get the registration and insurance details of the counsellor you would also have to get confirmation you said in your statement that all other sources of support available such as local authority grants have been exhausted?

A. Yes, of course.

Q. And give them two quotes for that, and then you might get up to £900 counselling if you went through those various stages.

A. Yes, yes. That is for -- they are giving this counselling, you know, because they've given you a terminal illness, you know. It does really beggar belief and I mean, to be honest, I mean, it's the English Infected Blood Support Scheme. I think they've got some cheek calling themselves that, to be fair.

Q. You have made number of observations about that scheme from your own experiences. You have said it's got echoes of the Department for Work and Pensions. What do you mean by that?

A. Massive, massive, massive echoes goes of the DWP. In fact, I have to say this, and I'm not a lover of the DWP, I'm on a working group with the DWP and we meet in Caxton house in London, and I have to say the DWP are more understanding than EIBSS and I don't know anybody -- I don't know anybody that's had dealings with the DWP that would say that, unless they have had dealings with EIBSS because EIBSS, if you want to become a stage 1 recipient, basically, they ask you questions which are identical to the questions that are asked on the ESA 50 fitness to work form, and when EIBSS, before they came into power, kind of thing, they turned round and said, "Look, these medical examinations and these assessments for stage 1 payments will be light touch, they will not be anything like the DWP". They're identical, you know, and, "Can you sit? Can you stand? Can you walk so many metres", even 50 metres. It's the same, you know. It's a tragedy what stage 1 victims have to go through.

If they've got hepatitis C and they've been

given hepatitis C for whatever reason, either a factor reason or a transplant, give them the money. That's what they are there -- they are there, to support you but honest to God they just put obstacle after obstacle after -- it's probably one of my worst pet hates.

Q. One of the observations you have made in your statement is your sense that the scheme, you put it this way, always want to distance themselves from giving help by signposting you to others.

A. Yes.

Q. Citizens' Advice, DWP, mobility schemes and the like.

A. This is exactly right because they'll turn round and say, I mean, the previous schemes like the Caxton they used to say, right, well, you know, if you do need money or you do need financial help and there could be a case of mismanagement you need to see a financial adviser. If you have a problem with benefits then you can go and see Mr Neil Bateman. We will pick up the bill.

These guys have kind of said, look, go to the citizens' Advice Bureau, Signposting, welfare rights adviser. Never mentioning Neil Bateman, you know, and Neil Bateman, okay, he's quite good at what he does and he does help you and he does listen and he does

get back to you promptly, but these guys pay him but they don't advertise the fact that he's there. So for the new person joining the scheme or a new person that's ever had any interaction with EIBSS wouldn't even know; understand me? So everything that they seem to do is designed and aimed at not engaging with the victim or the affected, you know. Everything that they seem to do, and it is quite frustrating.

If you go to EIBSS with a request I'll guarantee you this: if you are sent three emails in reply to that request you will be dealing with three different people. There's no continuity, so then every time you get on the phone to them you have to go through your application process, what you want it for, then another person will answer that email. It's like they are just trying to play games with you and we're vulnerable people, we're all vulnerable people.

Q. At the time you signed your first statement, Pete, you were having regular six-monthly liver scans?

A. Yes.

Q. You talked in your statement about the anxiety of waiting for the next scan?

A. Yes.

Q. You concluded your first witness statement by saying that you considered yourself one of the lucky ones.

A. I did consider myself to be one of the lucky ones for the simple reason being is that I wasn't HIV infected.

Q. You described in that first statement you and your family living in fear of a diagnosis of cancer.

A. Well, yes, because statistically 1 in 4 people with cirrhosis will go on to encounter cancer, yes, which is 25 per cent.

Q. A few weeks after you signed that first statement in February of this year, you got a phone call asking you to come for an MRI scan.

A. Yes, I did, yes. What it was was I'd been on -- I'd been to the hospital and I'd had my usual CT scan and then they asked me to go and have an MRI scan which was unusual, it was irregular. It was not normal.

Q. You had that scan on 20 February of this year?

A. That's correct, yes.

Q. In April, you went back to Manchester Royal Infirmary for your six-monthly liver review.

A. Yes.

Q. You were expecting to be told the results of that scan?

A. Of course, yes.

Q. Were you told those results?

A. No, they didn't have the results.

Q. So that's roughly two months on from the scan and the consultant you saw in April didn't have your scan results.

A. No, no, no.

Q. You then on I think 10 May you had been attending an Inquiry hearing in London and then you got a phone call from the Manchester Royal Infirmary to say that the consultant wanted you to come in on 15 May?

A. That's right, yes, yes.

Q. You didn't want to wait five days.

A. No.

Q. You had a conversation. What was the conversation that you had?

A. On the 15th or ...?

Q. On the 10th when you phoned?

A. Basically on the 10th I got a phone call and this woman said, you know, "You have to come in and see *[redacted]* so I turned round and said, "Why do I have to come in and see *[redacted]*? What's going on", kind of thing. She said, "Well, it's a problem with your scan but he'll explain it to you when you come in". I turned round and said, "What are you thinking of doing", kind of thing, I said, "because I need to know". She said, "Well, we may do a small procedure", so I said, "Okay, that's fine. What's the procedure?" So she said, "We may stick something in your neck and

go down to your liver and then take a biopsy and then do something else". I says so it's really an investigative procedure and she said, "No, it's a curable procedure". At that stage, I was aware I had cancer.

Q. On 15 May, nearly three months after your scan, you saw *[redacted]* --

A. Yes.

Q. -- at the Manchester Royal Infirmary.

A. Yes.

Q. What did he tell you, Pete?

A. Well, I knew I had it you know because of the conversation, yeah, but what *[redacted]* did do is when we went into the office I was expecting all kinds of doom and gloom, because that's what doctors do generally, they paint the blackest picture and then anything else is a good thing, and he expertly delivered my prognosis and my condition, my diagnosis. But he had all the answers ready, you know, he was saying, "This is the plan moving forward. We'll be okay here, you know if we get on with it", kind of thing. "Your nodule is 2.2 cms. If we take that away, you know, we can get you on the liver transplant list. This is not all bad news", you know.

I thought, "Oh God, that's great", you know,

because that gave me a foundation that I could work on with Christine because, obviously, my concern really is Christine, yeah, but yeah we walked away not confident or happy but I walked away quietly relieved because I was expecting a lot worse than that and the way that he delivered that diagnosis was so professionally delivered it was -- I applaud it. I honestly applaud him for that.

Q. You said in a supplemental statement that you signed on 10 June, you said this:

"I'm scheduled to go into hospital on 16 June for a liver biopsy and ablation. They found two problem areas in my liver. One they are going to try and remove, a second one is difficult to get at."

A. Yes.

Q. "I think that means they can't get at it. *[redacted]* hasn't discussed options like chemotherapy or how long I have to live. I look upon that as a good thing because they haven't mentioned it."

A. Yes.

Q. "As I said, *[redacted]* did mention the possibility of a transplant but that's only if the cancer has not got into a blood vessel in my liver or spread from my liver to any other organ. I'm hopeful it hasn't."

A. Yes, all positive -- well, as positive you can be with

a diagnosis of cancer.

Q. You went in for your appointment on Monday of this week, Pete?

A. Yes.

Q. 17 June. What was the outcome of your appointment on Monday?

A. Well, we went in and what they do is they do like a CT can, yeah, and the radiographer will do the ablation and, as I say, I went into the scan and he came back out after the scan and he said, "Look, the circumstances have changed". So I said, "Well, you know, how have they changed?" And he said, "Well, *[redacted]* will come down and speak to you about it". I says, "Well, has the nodule grown?" He says, "Yes, it's grown". So I said, "Has it gone into the vein?" He says, "Well, yes, it's gone in", you know.

So we waited for *[redacted]*, my wife and I obviously were discussing it and, you know, I said "Look, Chris, this is getting a bit, you know, it's getting a bit warm now".

Anyway, cutting a long story short, *[redacted]* came in and he kind of said, "Well, look", he said, "This isn't good". He said, "From February your nodule has grown quite rapid and you now cannot have a liver transplant and we can't take the nodule away and we can't really treat your condition because your platelets are at 53" and it's below the cut-off period for any kind of chemo or anything like that, so it's changed from a curative procedure to a terminal condition now, yes.

Q. What prognosis were you given in terms of life expectancy?

A. Time. Again, he wasn't too forthcoming with that because I don't think they like to kind of take a punt on it, if you like. I said, "Well, I've been discussing this with Christine. Sometimes you have to do reverse psychology with these guys. I said, "I've been discussing this with Christine. I think I've got three to six months to live". He said, "Oh no", he says, "you're wrong. You've got maybe a year, maybe two". He said, "You haven't got three to five". So -- and that's it, so I am one of the people that won't see the end of this Inquiry, you know.

Q. Pete, those are the questions I have for you. I think there's something more that you wanted to say yourself.

A. There's plenty I want to say. I would like -- because this prognosis has come so recently, yeah, I haven't had time to kind of come to in terms with it so I'd like to read something that I've written because

I don't think I would be able to talk and forgive me if I've got to refer to this, because it's not that I'm daft or anything it's just that I think it's better this way. I might get my point across, yeah, so I'll have a go.

As you were aware I was due for an ablation procedure on 17/6/19. Before the procedure they scan you. The scan doctor came to see me and said the circumstances had changed and the consultant would come to talk to me. *[redacted]* arrived. My wife and I was obviously stressed. After a lengthy conversation the upshot was the nodule was too close to the portal vein and it had grown so, as it stands, no removal of the nodule and I am no longer suitable for a transplant.

There may be another treatment but because my platelets are so low, I more than likely won't be suitable for that. My platelets are low because of the cirrhosis I have been given because of the hepatitis C, which is a result of being given contaminated blood. If my platelets go below 10 there is a good chance I will have a bleed on the brain. That's not good. When I went for the MRI can there was, I would say, a 40-day delay in the hospital receiving the scan results. Their time allowance is

32 days turnaround from the date of the scan. The scan was done on 20/2/19. I got diagnosed on 15/5/19. I would say that delay has created a delay in treatment which in my case could cost me my life. I have registered a complaint with PALS in May this year citing my concerns.

My condition should not have got this far. I was referred for a standard scan. Victims of this NHS scandal should be fast-tracked for every procedure. From February to June my nodule had exceeded the limit for the transplant. This, in effect, has given me a death sentence. There is a victim dying because of this contaminated blood tragedy every 96 hours, while the Department of Health stand by and watch.

There is a system in place in Ireland where victims are fast-tracked. Why are we always behind other members of the Union and having to follow their example, which the English never do. The reason for this believe is they are happy and proud at the speed and the rate victims are dying.

There is one voice less with every passing. I could use the word to describe them as animals but I can't as that would be unfair to the animals, that they at least look after their own. I am definitely

a victim who will not see the end of this Inquiry. I am one of the many who won't see justice. At this stage you won't even know my name but when I am done, you will remember it well because the difference with me is I will not pass quietly. I will scream from the rooftops and document every part of my passing and show you for what a bunch of lying, murdering criminals who have stood by and watched a victim die every 96 hours without any kind of remorse and knowing many of these victims are dying in poverty leaving thousands of affected families in poverty and having to rely on the means tested hand-outs from the very people who covered up this mass murder, the Department of Health. You really are not fit to be called human beings. You need to start taking notice of the death and the blood of the innocent victims you have on your grubby little hands.

As regards the apologies we have had, they are welcome but worthless if we are living in poverty. Again, you need to follow the Republic of Ireland's policy of making an interim payment at the beginning of the Inquiry again this seems to be a situation where the tail is wagging the dog.

That's about my terminal illness that I was given on Monday. That isn't my closing remark.

I feel as though I had to get that out there because I'm living proof -- at the moment -- but I don't know how long, you know, so I have to get that out and I don't apologise for any of the words I've used in it.

In fact, I think I've been quite conservative. But I would now like to move on to my closing remarks, if I may.

Q. Go ahead.

A. This inquiry has been a long time coming. I think if we put together all the years of individual victims campaigning and total them up, we would be left with a total figure of thousands of years. That's years of governments not listening in denial and more focused on covering up the deaths of thousands of innocent victims.

Many of the campaigners and the victims are sadly no longer with us. This includes haemophiliac victims where they were used -- where they used children referred to as PUPs to try out new medication on them and observe them in clinical trials, thalassaemia victims who had to receive authorise of transfusions per year. Many of those transfusions was contaminated, sickle cell victims, whole blood victims, people who suffered traumas, mothers given

transfusions during child birth, blue babies transfused at birth, von Willebrand victims and victims misdiagnosed with von Willebrand and infected, victims who were misdiagnosed as haemophiliacs and given factors.

All the above have been infected for a variety of different reasons but we have one thing in common: we are all victims of this contaminated blood tragedy and as victims we must try to work together as one to make sure this tragedy is (a) never allowed to happen again and (b) the voices of all the campaigners who have passed are heard again and never forgotten, because it's their voices who have gotten us where we are today and they who paid the ultimate price, and authority need to understand one thing, this tragedy will not go away, regardless of the outcome of this Inquiry, until we have justice and some kind of closure for the victims and for the families of the victims who paid that ultimate price.

I would like to say thank you to the Inquiry team for all their efforts to date. They are doing an excellent job under extremely difficult circumstances.

I would also like to thank my wife Christine who has to suffer the effects of all my conditions alongside me for the last decade or so. You should

not have had to live the life you have lived because of this tragedy, whereas I had no choice. You had a choice and you chose to support me and care for me during the horrendous ten years. All of the care you gave me was unpaid care saving the Department of Health tens of thousands of pounds and now you and I have another massive obstacle to get over having been diagnosed with terminal liver cancer.

I am truly sorry to have to put you through this, Christine. You deserve better. But if I can get through this I know it will be because of your strength and support. We both know I may not see the end of this Inquiry but let me say this: I will do everything in my power to beat this condition and I know when I feel like giving up you will be there to push me forward and, as we have spoke about, I don't want you to be subject to a begging bowl lifestyle having to deal with the English Infected Blood Support Scheme and their demeaning demands. So, Chris, keep your chin up and put your best foot forward and I'll try and do the same. But please try and forgive me if I falter. Thank you.

SIR BRIAN LANGSTAFF: Pete, I'm deeply sorry that chances are that you may not see the end of this Inquiry. Can I just thank you for what I think is enormous courage

in telling us that you have not yet, and it's obvious, had time to come to terms with your recent appointment and the diagnosis as it currently stands and to do that in part in front of us and those who are listening online. I can only admire you for that and thank you.

A. Thank you, Sir Brian.

SIR BRIAN LANGSTAFF: We need a break, Ms Richards, and it will be 12.05.

MS RICHARDS: Yes, sir.

(11.35 am)

(A short break)

(12.09 pm)

SIR BRIAN LANGSTAFF: Ms Richards, we now have four witnesses from the same family and I gather they want to be known by their first names: Jennifer, Eleanor, Sarah and Ann.

MS RICHARDS: That's right, sir.

SIR BRIAN LANGSTAFF: Could you please come forward.

ANN DORRICOTT, SARAH DORRICOTT, ELEANOR DORRICOTT, and JENNIFER DORRICOTT, sworn

Questioned by MS RICHARDS

MS RICHARDS: You are here to talk about Mike Dorricott, Michael to you, Jennifer?

JENNIFER: Yes.

MS RICHARDS: Michael was your son. Ann, Mike was your husband, Eleanor and Sarah, Mike was your Dad. We are just going to have a photo of him up on the screen, just to start with.

It's 1196020.

That's Mike. Can you tell us about the medals.

ANN: Yes. He was selected to play golf for transplant golf games and he went to South Africa. He was passionate about golf, that was his biggest passion, and he was really proud and he won.

MS RICHARDS: Thank you. We'll take the photo down now and we are going to put it up towards the end again when Sarah will be reading some material that Mike wrote.

Jennifer, I am going to start with you, if I may, and ask you a little bit about Michael's childhood?

JENNIFER: Yes.

MS RICHARDS: When Michael was about three he fell off a slide and bumped his head; is that right?

JENNIFER: Yes, that's correct.

MS RICHARDS: What happened?

JENNIFER: He bumped his head and there was a swelling came on the back and after a little while it was bleeding and when it didn't heal up as well as we

thought it should have, we took him to the doctor's and because we knew that haemophilia was in the family he sent us to the Halifax General Hospital to have him tested.

I took him to the hospital and they gave him some sedative to make him a bit sleepy and eventually they managed to take some blood from him and when we saw the specialist when the result was done, he told us they couldn't find haemophilia and so we were very pleased.

But after a while his head still didn't heal up as it should have done so we went back to the doctor again and he sent him to Huddersfield Royal Infirmary where he was tested again and they did find haemophilia, but we were told it was mild.

MS RICHARDS: So mild that throughout Michael's childhood in your care he played football and you didn't wrap him in cotton wool.

JENNIFER: No.

MS RICHARDS: He was a very active boy.

JENNIFER: He was a very active boy. In fact, we once get to take him to see a doctor, a surgeon I think it was, and as we walked through the door the gentleman said to us, "I know one thing about your son. He is not a lazy boy because lazy boys don't have this", and it

was a thing called Osgood-Schlatter disease, it's with lumps on his knees because he had very big muscles in his thighs and he was, you know, very active and football, cricket at that time and then golf.

MS RICHARDS: You said in your statement, Jennifer, that only once during his childhood at the age of seven or eight did you have to take him to hospital and on that occasion he was given cryoprecipitate.

JENNIFER: Yes.

MS RICHARDS: In December 1982 when Michael was 15, he required some dental treatment in relation to impacted wisdom teeth.

JENNIFER: Yes.

MS RICHARDS: The plan was for him to be given cryoprecipitate but you understand he was, in fact, given Factor VIII. What can you recall about that?

JENNIFER: I can't remember very much actually about when he went for his teeth out. I couldn't tell you offhand or I couldn't have done, how many teeth he did have out but I've since found out it was two teeth. They didn't tell me anything. I just assumed they would give him the treatment that he'd had before and that was it. He was going to have the teeth out so that they were, you know, get rid of them.

MS RICHARDS: You put it this way in your statement,

Jennifer:

"There was no discussion; there was no dialogue; there was no consent."

JENNIFER: No, there was none of that. They just gave him what they gave him and it just happened to be Factor VIII.

MS RICHARDS: Mike obtained his medical records and you've exhibited those to your statement. We'll just have a look at a couple of them to show what was happening during this period.

Paul, could we have 1196002.

We can see this is a letter from November 1982. It's about the dental treatment that Jennifer has just been describing and the concluding paragraph explains that:

"The doctor proposes to admit him to Huddersfield Royal Infirmary on 14 December for extraction of these four teeth under general anaesthesia the following day and will arrange this with *[redacted]*, Consultant Haematologist, in order that appropriate cryoprecipitate can be administered."

So Mike's understanding, Ann, when he looked at his records was that the plan had been for him to receive cryoprecipitate.

ANN: That's correct.

MS RICHARDS: Then if we have up on screen, please, Paul, 1196003, we can see that, in fact, this is dated 15 December, so the day after, we see there the reference top of the page 3000 units Factor VIII given and if we have the next page of that please, Paul, top of the page there we can again see it says Factor VIII before 2,820 units injection, Factor VIII after 2,820 units injection and then the factor measurements there.

So Mike's understanding when he looked back at his records, Ann, was that whilst the plan had been to give him cryoprecipitate, he had in fact been given Factor VIII.

ANN: He did, yes.

MS RICHARDS: It was Mike's view and, Jennifer and Ann, you both expressed it in your statements Mike believed that he had been treated as a PUP.

JENNIFER: Yes.

ANN: Yes, correct.

MS RICHARDS: We can see his view scribbled on some documents, 1196017 please, Paul.

We see this is a document from the Tainted Blood website. If we just go down to the handwritten bit, please, we see there there's a reference to previously untreated patients, PUPs, that usually meant either children or infrequently treated mild to moderate haemophiliacs and then the handwritten entry:

"Was I one of these?"

Is that Mike's handwriting?

ANN: It is, yes.

JENNIFER: Yes, it looks like it.

MS RICHARDS: If we go on to the next page please, Paul -- in fact it's the page after, sorry. That's it, keep going. Thank you.

We can see this is a letter again from the Tainted Blood website and there's a reference to previously untreated patients which has been underlined by someone in the letter, and then we've got at the top:

"My first Factor VIII December '82. I was a PUP."

Again, is that Mike's handwriting?

ANN: It is, yes.

MS RICHARDS: That was Mike's conclusion, he had been given Factor VIII unnecessarily and contrary to the plan that he had understood --

ANN: Yes, that's right.

MS RICHARDS: -- which was Cryoprecipitate.

Ann, you have explained in your statement that Mike had liver function tests around the time of his operation and they were normal.

ANN: Yes.

MS RICHARDS: But follow-up or liver function tests the following year and after that showed abnormal ranges in terms of the liver enzymes.

ANN: Yes.

MS RICHARDS: Jennifer, do you recall any discussion with you about the significance of any liver tests following the operation?

JENNIFER: No. Nobody said anything to me.

MS RICHARDS: You've got Mike's UKHCDO records, Ann, and we will have them up on screen again, please.

1196009 please, Paul.

If we look at the entries here, if we look at the centres 047 is Huddersfield, and we can see that at 047 there's a reference to Mike receiving the cryoprecipitate in 1978 and then 1982, '83, '84 and '85 at Huddersfield he receives Factor VIII. There's four entries for BPL Factor VIII and then Armour Factorate is the last of those entries.

Whilst we are looking at that, do you recall, Jennifer, any occasions after the dental treatment where Michael received Factor VIII?

JENNIFER: No, I don't recall any, no, because I'm just wondering if he'd left home by that time.

MS RICHARDS: You do make a reference in your statement to a discussion when Mike was going to go on holiday and there was a possibility of him taking some Factor VII with him.

JENNIFER: Yes.

MS RICHARDS: And you are not sure that he even needed to use it.

JENNIFER: No, he didn't. I saw the doctor that day, *[redacted]* and he gave me the Factor VIII and said that Michael had to take it with him just in case he needed it because they knew it was heat-treated. Those were his word. It was heat-treated.

MS RICHARDS: Then if we look at the entries above that, centre 140 this is when Michael went to university, Jennifer, in Newcastle.

JENNIFER: Yes.

MS RICHARDS: Is that right, he went to Newcastle University?

JENNIFER: Yes.

MS RICHARDS: We see after that there he received cryoprecipitate or DDAVP but when he returned to Huddersfield, centre 047 again, we see him being given BPL Factor VIII.

JENNIFER: Yes. I'm amazed.

MS RICHARDS: Did Mike ever recall being given any advice or warnings himself about any risks associated with Factor VIII?

ANN: No.

MS RICHARDS: Ann, you met Mike in 1988?

ANN: Yes.

MS RICHARDS: In 1990 Sarah was born.

ANN: Yes.

MS RICHARDS: What can you tell us about Mike at this time?

ANN: He was a very ambitious man, kind, caring, was a good father, good husband. Sorry, I'll just look at my notes.

MS RICHARDS: That's all right.

ANN: He was hard working, he was highly intelligent. He was a family man. He was a straight talking Yorkshire man. You know, you knew where you stood with him.

MS RICHARDS: Eleanor was born in 1996.

ANN: Yes.

MS RICHARDS: It was in 1996 that Mike was diagnosed with hepatitis C.

ANN: Yes.

MS RICHARDS: How did that come about?

ANN: Well, Sarah was having her tonsils out in '95 and I think her platelets were low at the time and Mike got chatting with one of the nurses and he mentioned

that he was a haemophiliac and she just says, oh, I think maybe you should, you know, get tested because he hadn't been to a Haemophilia Centre for quite some time, so that's what he did.

MS RICHARDS: So there had been any follow up to the abnormal liver tests that you recorded in your witness statement?

ANN: None.

MS RICHARDS: It was almost accidental that he was prompted, as it were, that he was prompted as it were, to go to have a check-up.

ANN: Yes.

MS RICHARDS: If we have up on screen please, Paul, 1196012, we can see this is a letter from June 1996 from Addenbrooke's Hospital. If we look at the first paragraph, the last four lines, it refers to Mike having come into the clinic and then it says this:

"While he was in clinic we took the opportunity to take some blood in order to check his inhibitor status and his viral status. We explained to him that as he has had blood products in the past prior to 1985 he may well have been exposed to hepatitis C."

That was the first Mike knew of this risk; is that right?

ANN: Yes.

MS RICHARDS: He had to have a liver biopsy.

ANN: He did.

JENNIFER: That showed that he had chronic hepatitis C and cirrhosis.

ANN: He did, yes.

MS RICHARDS: What was the impact on you and Mike of the receipt of that diagnosis?

ANN: Well, we were shocked. We were shocked about the hepatitis C. We didn't really know very much about hepatitis C at the time but when he had the liver biopsy and it came back cirrhosis, you know, we were devastated, yes.

MS RICHARDS: Mike had been leading a busy and normal life.

ANN: Yes.

MS RICHARDS: Had he been experiencing any symptoms at that stage?

ANN: Well, he was always tired and he'd come home from work and go to bed. He was just tired and then he just realised later that having been diagnosed with hepatitis C that that was one of the conditions and he went, "Ah, I realise now why I've been so tired".

MS RICHARDS: He carried on working. He was working for Weetabix I think at the time.

ANN: Yes.

MS RICHARDS: And then in 1997 he changed jobs and you relocated to Surrey.

ANN: Yes.

MS RICHARDS: As part of his job he travelled a lot, travelled all over Europe.

ANN: He did, yes. He loved his job.

MS RICHARDS: I think at the time of Mike's diagnosis with hepatitis C you also underwent testing?

ANN: I did get tested, yes.

MS RICHARDS: You described the wait for that result which was negative as a terrible wait.

ANN: Definitely, yes.

MS RICHARDS: In January of 1999 Mike had his first course of treatment for hepatitis C. That was interferon and ribavirin.

ANN: Yes.

MS RICHARDS: He persisted with it for 27 weeks but then it wasn't successful.

ANN: No, it failed.

MS RICHARDS: Can you recall in relation to that first course of treatment what the side effects were?

ANN: I just remember he had flu-like symptoms and that's all I can remember at the time.

MS RICHARDS: He was put on the liver transplant list in the middle of 2000.

ANN: Yes.

MS RICHARDS: There were a number of false alarms, of calls. What can you recall about that time, waiting for that call?

ANN: There was three false alarms. Just the waiting was bad enough but having three false alarms, you know, you'd get to the hospital and then they'd decide they wouldn't use the liver because it wasn't healthy enough and then the call that he did get was okay and they went ahead with the transplant.

MS RICHARDS: That was October 2000 when Mike had his liver transplant, his first liver transplant.

ANN: Yes.

MS RICHARDS: You said seeing Mike in intensive care was devastating.

ANN: It was, yes.

MS RICHARDS: He didn't want the girls to see him like that.

JENNIFER: No.

MS RICHARDS: Jennifer, you visited Mike with your husband daily in hospital during this time.

JENNIFER: Yes.

MS RICHARDS: How was he?

JENNIFER: He was -- well, very ill at first but eventually they moved him out of intensive care and he

gradually, slowly, over three weeks made a recovery so he could go back home. You know, he seemed to chatter normally and he seemed to be his normal self at that time.

MS RICHARDS: He recovered sufficiently to return to work.

ANN: He did, yes.

MS RICHARDS: He had various surgical procedures, surgery for a blocked bile duct the following years, he contracted MRSA at one stage.

ANN: He did, yes.

MS RICHARDS: He had lots of appointments over the years that followed.

ANN: Yes.

MS RICHARDS: But he continued working for that period of time.

ANN: He did, yes.

MS RICHARDS: Then in 2007 Mike had a routine scan and what did that show?

ANN: It showed tumours and they said he would need another liver transplant and he was lucky enough to get another liver transplant.

MS RICHARDS: What was the impact of that diagnosis of cancer on Mike and on you?

ANN: We were devastated. Every time he went to the hospital for scans we were -- it's always in your

mind, you know, is it -- is the cancer going to be there? So, yes, we were devastated. Yes.

MS RICHARDS: He was put on the waiting list for a second liver transplant.

ANN: Yes.

MS RICHARDS: That was carried out the following year in 2008.

ANN: Yes.

MS RICHARDS: Again, Mike suffered a number of infections. He contracted sepsis at one stage.

ANN: Yes.

MS RICHARDS: But he recovered, but it was after that second transplant that the hepatitis C came back.

ANN: Yes.

MS RICHARDS: He had to undergo a second course of treatment for the hepatitis C.

ANN: Yes.

MS RICHARDS: That was again interferon and ribavirin.

ANN: Yes.

MS RICHARDS: What was the effect of this second course of treatment on him?

ANN: Well, this treatment, the second course of treatment was really bad, really bad. He had the flu symptoms, he had aching joints. At one point I remember him saying he just feels like he's been hit by a bus. He

was not himself. It was -- he was very aggressive, which was a really, really hard time for us. We didn't know what to do, and I was away from my family. I felt really alone at the time. It was like he had a rage in his eyes. It was as if he was possessed, and I was scared of him.

MS RICHARDS: You said in your statement that he became, on this course of treatment, a different man, volatile, aggressive, mood swings, a Jekyll and Hyde character.

ANN: Yes, a Jekyll and Hyde character.

MS RICHARDS: Completely unlike him.

JENNIFER: Yes.

MS RICHARDS: Sarah and Eleanor, what can you recall about this period when your Dad was undergoing this second course of treatment.

SARAH: I just remember being like walking on egg shells in the house and, I mean, I was a teenager at the time and I was pushing boundaries, so trying to find where the line was, and I'd often challenge him and that made things worse. There was a few times where Mum had to come between me and my Dad where he'd been quite violent.

We knew it was the drugs. We knew it was just the treatment. It wasn't him. He was a different person. It wasn't him. He was a lovely, lovely man and this treatment really altered his mind. It was just very, very difficult years and it took its toll on all of us and especially him.

MS RICHARDS: I am going to ask both of you in a while to talk more generally about how the years were but in relation to the relationship that you had with your Dad at this particular point in time, one of your responses was to self-harm.

You have explained in your statement how after your Dad concluded his treatment you were able to re-establish your close and loving relationship with him.

SARAH: Yes. In later years Dad and I became really, really close and I'm so grateful for it. I rang him every day and we'd talk about anything and everything and we put all of it behind us and I'm really grateful that we both had that closure on such a really difficult time.

MS RICHARDS: That treatment, when it finally finished, did clear the hepatitis C but Mike continued to have routine scans every three to six months and he retired on health grounds in 2008 --

ANN: He did, yes.

MS RICHARDS: -- at the time of the second transplant.

At some point he received a letter about the risk of vCJD. What can you recall about that, Ann.

ANN: I just remember getting the letter, Mike getting the letter and showing it to me. I've searched for the letter, I can't find it. He just thought it's like another nail in the coffin, you know. We were shocked again.

MS RICHARDS: You've recalled in your statement an incident where a doctor shouted something across a crowded room.

ANN: Yes, I wasn't there at the time and he'd gone for bloods and he was in a crowded room waiting to have bloods taken and a doctor came in and said out loud, "Are you aware that you're at risk of variant CJD", and Mike was shocked, you know. He didn't know what to say.

Afterwards he was really, really angry but I know he was upset. He was very, very upset and the doctor -- Mike complained and somebody had spoken to the doctor and he came and apologised at his bed.

MS RICHARDS: In 2011 Mike had operations to resolve multiple stomach issues and swelling that he was experiencing as a result of all the operations he had had.

ANN: Yes.

MS RICHARDS: We have an email Mike wrote from around that time to explain how he was feeling physically.

Paul, it is 1196016, please.

It's a letter Mike wrote to his doctor in June 2011 and he says this:

"I do not know how I would cope if I had to go back to work. My head feels like it is full of cotton wool and I am having difficulty concentrating on even the most simple of tasks. When I do have to do things, even the most simple of tasks takes me ages to do. What I used to do as a matter of course whilst having a senior role travelling around the world dealing with time zone changes and the general abuse that I put my body through now leaves me struggling. I'm sorry if I'm not explaining this properly but I guess that is symptomatic of the way I am feeling right now. This is something that's been going on for at least a year now and I cannot say that this feeling is getting any better or any worse. I don't know if this feeling is due to the interferon, the immunosuppression, the steroids or what. It cannot be the state of my liver as I believe that the LFTs are as good as they have ever been. To be honest with you I don't really care what is causing it as I can deal with it as long as I don't have any pressure put on

me. It gets worse when I must do something and then the most trivial of tasks just seem to become the biggest deal in the world. In addition to this, I am constantly tired and my legs are causing me more concern. They are so swollen that I am now having difficulty in finding trousers that will go over my calves."

That's a brief summary but in Mike's words of how physically and mentally he was feeling at this time.

ANN: Yes.

MS RICHARDS: You decided you were going to downsize and relocate to Cumbria.

ANN: Yes.

MS RICHARDS: You completed on the purchase of a house that you and Mike were going to live in.

ANN: Yeah.

MS RICHARDS: Then in February 2014, Mike had a routine scan again, and what was the outcome this time?

ANN: Well, he was cancer-free for five-and-a-half years, so we thought everything was fine. That's why we decided to downsize and move to Cumbria. And I relocated to Cumbria first while Mike stayed with Eleanor while she finished college, and I was at work at the time and Mike phoned me and said, "I've just had my scan and it's not good", and he just said the cancer's come back and there's nothing they can do and it's terminal.

MS RICHARDS: And he was given to understand he might have about 12 months to live.

ANN: Yes, he was given 12 months to live, yes.

MS RICHARDS: Eleanor, I think you recall being at home when your Dad was on the phone receiving the diagnosis. What can you remember?

ELEANOR: All I remember was sitting on the top of the stairs and hearing the phone call that he was having with his doctor and I can't really remember much about it but -- because I kind of blacked most of it out, but all I can just remember is sitting at the top of the stairs and crying and then going downstairs and just talking to Dad about it, him being really upset.

MS RICHARDS: Mike underwent a number of treatments. He had internal radiation therapy and chemotherapy.

ANN: Yes, he had to ...

MS RICHARDS: His health went downhill.

ANN: It did.

MS RICHARDS: There was an occasion when Eleanor had to call you because Mike was acting very strangely. He was confused. He didn't know where he was.

ANN: Yes.

MS RICHARDS: He was admitted to Lancaster Hospital on one occasion because of a serious infection and you had a particular difficulty with a paramedic. What was that?

ANN: We'd got to hospital and we were waiting in the corridor, waiting for Mike to be seen, and Mike was in and out, drifting in and out of consciousness, and the paramedic was stood with me and the other paramedic was checking him in, and we just got chatting and the paramedic said to me, "Do you realise how much it costs for an ambulance to come out", and I said, "No, no idea", and so she told me, which I can't remember now, and also she said maybe next time you should go through your GP.

MS RICHARDS: Mike was seriously unwell at this stage.

ANN: He was. He'd just had chemotherapy and they said to look out for high temperatures. I was obsessed with taking his temperature. He wasn't aware of what was happening. They gave me a list of things to look out for, you know, and I did the right thing, you know.

MS RICHARDS: In March 2015 Mike succumbed to another infection and this time I think Mike's sister, Jane, drove you to hospital, a different hospital, you didn't want to go back to the Lancaster Hospital.

ANN: No, he didn't, no.

MS RICHARDS: By this time Mike's organs were failing.

ANN: Yes.

MS RICHARDS: He died on 3 April 2015. He was 47.

ANN: Yes.

MS RICHARDS: One of Mike's dying wishes was that his death certificate should accurately reflect what he believed was the true cause of his death and so there was an inquest.

ANN: Yes.

MS RICHARDS: What can you recall about that?

ANN: Obviously, because he knew he was going to die he said to me, "Please make sure that you get on the death certificate exactly how I died". He was very adamant about that, and when he did pass away the doctor that was on duty at the time wouldn't put down a cause of death, so it went to an inquest.

MS RICHARDS: If we have up on screen 1196004, please, Paul, we can see a letter from *[redacted]*, Consultant Hepatologist, to the coroner and if we go down please, the second paragraph explains that:

"There were no risk factors for hepatitis C other than the fact that he had been transfused with Factor VIII for his underlying haemophilia. Almost all the patients that we screened in that early period in the 1990s were positive for hepatitis C."

Then in the final paragraph, *[redacted]* says this:

"There is no doubt in my mind that he acquired his hepatitis C virus infection as a consequence of transfusion of infected Factor VIII."

Then if we have please up on the screen 1196014. This is the death certificate following the conclusion of the inquest and if we go down to the cause of death in section 9:

"Cause of death: 1 (a) liver failure; (b) hepatocellular carcinoma; (c) hepatitis C virus infection; 2 haemophilia and the treatment thereof. Conclusion, narrative: death was the consequence of transfusion with infected Factor VIII blood products."

ANN: Yes.

MS RICHARDS: So the outcome of the inquest reflected what Mike knew and believed to be the case.

ANN: Yes.

MS RICHARDS: I want to ask each of you just a little to the extent that you feel able to, to talk about the impact of Mike's death.

Jennifer, you have said in your statement it was totally and utterly devastating.

JENNIFER: It is, yes.

MS RICHARDS: That the loss of a child is not one that you ever come to terms with.

JENNIFER: No, I'll never get over this.

MS RICHARDS: The wider family, Mike's sister, Jane, with whom he was very close and other family members have all been profoundly distressed by losing Mike.

JENNIFER: They have, yes, and continue to be so.

MS RICHARDS: Ann, what was the impact on family life of Mike's illness and treatment?

ANN: Well, we tried to lead a normal life. You know when he was well enough we'd go camping and caravanning and we'd have some good holidays abroad. We tried to lead a normal life for the girls but it was just out of our control. It was out of our control completely and we tried to make the best of things. But it did have an impact on all of us, definitely.

MS RICHARDS: Were you or Mike ever offered any counselling or psychological support?

ANN: No -- well, Mike was offered counselling when he got the diagnosis of terminal illness, yeah. He didn't take it.

MS RICHARDS: But at no other stage?

ANN: Nothing.

MS RICHARDS: You were both offered antidepressants. Neither of you wanted them. Mike didn't want feelings to be taken away.

ANN: No, he didn't want to suppress his feelings. He wasn't the sort of man to take antidepressants. He was a strong man.

MS RICHARDS: You describe in your statement your devastation at the loss of Mike. You loved him and you miss him every day.

ANN: Yes.

MS RICHARDS: Sarah and Eleanor, I will ask Eleanor first, what can you tell us about the impact of your Dad's illness on you growing up and how it affected you.

ELEANOR: Well, when we were growing up Mum and Dad gave us everything that we needed and obviously tried to act like a normal family despite everything that was happening. You know, Dad worked really hard to live in an nice area in Surrey and we went to good schools and we went on nice holidays like Mum said and stuff like that, and obviously that was nice but obviously there was that underlying aspect of, you know, he's had two liver transplants, he was on borrowed time, he knew at some point something was going to happen and go downhill at some point.

Can I just have a minute?

MS RICHARDS: Of course you can.

You have talked -- would you like a break?

SIR BRIAN LANGSTAFF: Let's take a ten-minute break.

MS RICHARDS: Thank you.

(12.45 pm)

(A short break)

(12.55 pm)

MS RICHARDS: Eleanor, we have agreed I am going read a couple of passages from your witness statement where you explained how matters have affected you. You say this:

"I did not know the extent of my father's illness and I did not know that he would not be with us for most of my life. He died when I was only 18 years old. Sarah and I should not have to lose our father at such a young age. We should not have to explain to our children why they have not got a grandfather. We should not have to walk down the aisle without him. My mother should not have to be a widow at 48 years old. This could have been avoided. This should not have happened. We have to live our lives with no father to support us.

"Watching my father slowly deteriorate and watching him die whilst holding his hand has severely affected my mental health. Since he passed away I have suffered from severe anxiety, stress, depression and suicidal thoughts. I had never suffered from panic attacks before my father died and

after he passed I had one a week on average. When I started university in 2015 this increased to about two or three a week and I felt suicidal. I had never felt like this before and it was getting to the point where I could not leave the house. In January 2017 during my second year I dropped out of university due to the severity of my anxiety. I am seeking therapy to help my mental health and I now have CBT and bereavement therapy. However, these events will forever be with me. I believe had my father not have died this would not be the case."

Is there anything else you would like to add to that, Eleanor?

ELEANOR: No.

MS RICHARDS: Thank you.

Sarah, you wanted to talk about how growing up with your Dad's illness and his death had affected you.

SARAH: I think when you grow up as a child and your life is so full of hospital visits and medication and death always potentially being on your doorstep, you have a different outlook on life. After my Dad's second transplant, he very much lived for the moment. And then after the second as well he just wanted to make the most of every single second. So he was very impulsive and spontaneous and if he wanted to do something he went and did it or he learned how to do it, and we very much lived by that lifestyle and it was lovely, you know, being able to have such good memories with him and making the most of it, but when you live with death on your doorstep constantly throughout your childhood and your teenage years it leaves a mark. I have quite bad anxiety now and I get very stressed quite easily and I have control issues which I've said in my statement has got quite a lot to do with the bad interferon years with my Dad, and there was a lot of control in that house and because my Dad's health was out of his control we had to find control in other ways and it took its toll on us.

I find myself almost replicating that in my own parenting and I have to stop myself sometimes to not be so controlling and just kind of -- it's the fear of the unknown, the fear of death, it's being paranoid, it's very stressful. When I was pregnant, I found out I was pregnant two weeks after my Dad's funeral, which was quite a shock for all of us, and I don't regret my decision to continue the pregnancy whatsoever. My little boy is amazing but had I not been grieving, I think my decision to continue the pregnancy might have been different as the circumstances as to

conception was un-ideal.

But we wanted to -- I wanted to bring this little joy, a bundle of love into our lives and he did exactly that and he looks just like my Dad as well sometimes. In the right light, he looks just like him. But when I was pregnant with him, obviously pregnancy hormones do wicked things to your brain but adding grief into the mix as well, it's not a nice experience.

So obviously haemophilia runs through our family bloodline so it was very, very paramount that I could potentially have a haemophilia boy, although my Dad's haemophilia was only very mild, the haemophilia that my son could potentially have would also be mild, as far as I'm aware, but when I was pregnant with my son, I went into overdrive and paranoid.

I was phoning haematologists. I was having appointments with anyone I could get my hands on. I had meetings at the haemophilia clinic with what treatments are like nowadays, because I was so scared of the fact that I thought that if my own son had haemophilia and that he had to be treated, that the same thing would happen again and again and again and I just, I couldn't live with that fear that my son could potentially have -- I know it sounds silly but

it's the way your mind works and I was very, very paranoid.

But luckily he's not a haemophiliac and, yes, so -- it's very, very hard bringing up what would have been my Dad's first grandchild and he's three and a half now so he's, you know, he knows people and he's always pointing to pictures of my Dad, you know, and asking, you know, who's that? Who's that? And it's very, very hard and he would have loved him so much and I knew that he wanted a grandchild and ... yes.

MS RICHARDS: Is there anything else you want to say?

SARAH: No, that's it.

MS RICHARDS: Ann, I wanted to ask you about Mike's campaigning work. He was closely involved with campaigning activities --

ANN: Yes.

MS RICHARDS: -- in the years before his death and one of the issues he was most passionate about was the issue of proper financial support or compensation.

What can you tell us about what Mike did.

ANN: Lobbying MPs, various letters to MPs. At the time when we lived in Farnham in Surrey our MP was Jeremy Hunt who was also Health Secretary at the time and he used to write to Jeremy Hunt, emails, met up with him a few times. He respected Jeremy Hunt. They were on

first -- you know, they called each other by their Christian names. He had a good relationship with him, yes.

MS RICHARDS: There was a meeting that Mike was invited to, you attended as well, around February 2014 to meet with Jeremy Hunt in his capacity as Secretary of State for Health --

ANN: Yes.

MS RICHARDS: -- to discuss what would be a fair and final settlement for victims of contaminated blood is how you have described it.

ANN: Yes.

MS RICHARDS: Mike did a lot of work in trying to come up with a proposal and some figures and some suggestions.

ANN: Yeah, it was very difficult because each circumstance -- everyone's different, so he found it really difficult to come up with a figure but we went to discuss -- we went to his offices to discuss this and in the room were Jeremy Hunt, Jane Ellison, who was undersecretary, and also about 20 other civil servants in the room and the week before we'd just got the result that he was terminal so, as you can imagine, the room was -- when Mike told the room that it was terminal Mike got very upset, very emotional and towards the end of the meeting Jeremy Hunt came to myself and Mike and shook our hands and said to us, "Don't worry about this, we'll sort it". Those were his words.

MS RICHARDS: You said:

"Jeremy shook mine and Mike's hands and guaranteed him, 'I will sort this out'."

ANN: He did.

MS RICHARDS: Then you say in your statement since this:

"Since that meeting he has not fulfilled his promise."

ANN: No.

MS RICHARDS: That is your view and that was Mike's view?

ANN: Yes.

MS RICHARDS: Is there anything else you would like to say about that subject?

ANN: No.

MS RICHARDS: Sarah, you want to read something your Dad wrote and we'll put back up on screen your Dad's photo.

SARAH: It's quite long, so you will have you bear with. He wrote it over the course of three years so chronologically it doesn't quite flow. You know, he didn't have time to obviously finish it.

"This nasty, nasty disease has completely shattered my life. I'm 44 years old and until last

year lived in Farnham Surrey with my wife Ann and two daughters. Up until the end of November 2008, I had quite a senior position within United Biscuits (McVitie's) where I worked in the international part of that business. My team managed roughly half of the world and I was lucky enough to get to travel all over the place. I thoroughly enjoyed my job, had a great time and have made some truly great friendships along the way. Unfortunately, I was pensioned off at the end of 2008 on the grounds of ill health.

"I used to be a mild haemophiliac and only ever needed blood products for traumatic injuries or medical procedures. In 1982 I was treated with a product called Factor VIII. Prior to my treatment my liver function was tested and was normal. 12 months after the treatment my liver function was tested again and was abnormal. The only possible cause was the treatment I was given. It was now taken that for every haemophiliac the first date of treatment with Factor VIII is the date at which they were exposed to hepatitis C, around 25 per cent of British haemophiliacs were also infected with HIV.

"Because I was a mild haemophiliac I was lucky enough to only require treatment as a result of sporting injuries or when I had surgery. Before my

infection with hepatitis C in 1982 I had only ever had one course of cryoprecipitate. My liver function tests in 1982 prior to treatment with Factor VIII were perfect. Why I was changed from cryoprecipitate to Factor VIII in 1982 is beyond me. There was no discussion, no dialogue and no consent.

"The three treatments of Factor VIII that I had prior to heat treatment being established in 1985 were for teeth extraction and minor muscle bleeds caused by playing football. None were for life-threatening situations.

"The Government of the day are fully aware of the risks involved in the new treatment -- the Government of the day were fully aware of the risks involved in the new treatment. In 1980 a report to ministers from an advisory group indicated a 90 to 100 per cent certainty that the new treatment would expose people to non-A non-B hepatitis, later to become known as hepatitis C.

"I found out I was hepatitis C positive in 1996 when I was 28 years old and then only by chance. I had dropped out of haemophilia care as I didn't need it. Within two weeks of seeing a haemophilia consultant I'd found out that I had hepatitis C and I was grade 5 cirrhosis of the liver, where 5 was the

maximum. I didn't even realise and I thought my fatigue was down to working too hard and not getting enough exercise. I was lucky enough to be able to carry on working as thankfully it was not a physical job. The brain seemed to continue to be working even though the liver wasn't.

"Following this, I was treated with combination treatment, interferon and ribavirin, which did nothing except annoy me. I was injecting every other day so continually felt ill. I had the usual flu-like symptoms and felt generally ropey. The combination treatment is awful. It is 27 weeks of feeling like you have the flu and I'm talking proper flu where you feel shattered all of the time, not just a cold. Unfortunately, this treatment didn't work and I was eventually told in early 2000 that I would need a liver transplant. I literally went to pieces.

"I had previously been an active sporty energetic type, despite my haemophilia and was now reduced to being a wreck. I was put on the liver transplant list and subsequently received a replacement liver on 2 October 2000. Thankfully I recovered relatively quickly. I had a great employer at United Biscuits and a great boss who eased me back in and I was able to return to a full and active life with only a few compromises. The transplant meant that I could do things I had written off being able to do. The family all learned to ski together and my daughter and I learned to scuba dive. I started sailing, had a go at paragliding, in fact, I had a new lease of life.

"There were some minor hitches in the next few years which included a bit of re-plumbing, hernia repairs, MRSA and C.diff but nothing I couldn't get over. That was until the summer of 2007 when a routine scan found cancer in the transplanted liver. I was put on the transplant list again as it was suspected that I had developed cancer. I was advised it would take four weeks to get a liver as cancer patients went quite high up the list. Eight hellish months later I had the second transplant in April 2007. Surgery went well but the hepatitis C came back very aggressively and things weren't looking good.

"At the end of 2007, United Biscuits started the process to pension me off. I had the option to challenge this but, given the circumstances and my state of mind, I think it was best for all that I just took it. I couldn't work then and can't do so now as I get too tired. Retiring was the only viable option

that was open to me.

"I was still hepatitis C positive at the time. However, it was running riot as I was heavily immuno-suppressed to stop the rejection of my new liver. The body's defence against the hep C was squashed and so it could do what it wanted. The decision was taken to offer me the combination treatment again. This time it was for 72 weeks and again was awful. The doctors at Addenbrooke's put me on peginterferon and ribavirin which has thankfully controlled the hepatitis C for the time being. I came off the combination therapy in February 2010 after 72 weeks of it. I felt like I had flu and was extremely tired most of the time. I also had an almost constant run of infections and minor complaints which became very, very irritating. There were times when I struggle to get out of bed in the mornings as I just couldn't be bothered.

"Thankfully it was seen to be successful as the hep C went undetectable. As I understand it, I was the fourth person in the UK to have the combination treatment post transplant. One of the first three didn't make it; so, as I mentioned, it wasn't looking good.

"The lumps were confirmed as being cancer after

the transplant. Cancer cells were found in the blood vessels of the liver meaning that they might have got out and circulated around my body and started again.

"There is a huge difference between my salary when I worked and my pension. We have had to change our lives from top to bottom. It now means that I cannot do what I wanted for my family but we are all still here, so I'll count my blessings.

"I also believe I'm in a better position than so many others infected, similarly infected, so I try not to go on about my lot too much. I'm lucky that I did not get HIV. I am lucky that I was able to continue to work until relatively recently. I am lucky that I get a pension from the company which means we can survive -- survive, not live. I am lucky that have we have been able to stay in our family house, although should the need arise we will have to sell up and move somewhere less expensive."

Note: since he wrote this, Mike has had to uproot his family in order to cut down expenses and move closer to Ann's family.

"I am lucky to have a caring and supporting wife and family. I'm lucky to have two great kids who just get on with things without seeming to let our circumstances affect them. I was lucky to have two

transplants. Unfortunately, I've been told that there won't be another should the need arise but will fight that decision as and when.

"Everything was going fine with the second transplant until February 2014 when a routine scan nearly six years after the operation showed that the cancer had returned. Unfortunately, it was seen to be inoperable and treatment options were very limited. A further transplant has been ruled out. I'm now undergoing chemotherapy. However, the chance of success is less than 10 per cent. The original prognosis was that my cancer is terminal and if I make it to this time next year I will be doing well."

Note: since Mike wrote this, the chemotherapy has had to be discontinued as it made him so ill. He is now fighting recurrent infections and hoping to get well enough to try final treatment in tablet form that might hopefully shrink the tumour and buy him a little more time with his family, which he never got well enough to start taking.

"Looking at the impact that this has had on my family and I is hard to explain. I had a senior general management role within United Biscuits, working in the international division. I travelled the world with my job, having a team of managers across the globe. Following my second transplant, I was offered early retirement on the grounds of ill health and I had no option to take it as I was too ill to return back to work. The financial impact of this decision was that my package to pension difference was in the region of £65,000 a year lower. I was 41 when I retired. When you gross this up to include a reasonable rate of salary increase per annum and one promotion over the next 24 years, this would give a loss income of around £2.25 million. This does not include any share options either. To put this into perspective, United Biscuits has just been sold. A manager who worked for me will receive a bonus of around £500,000 as a result of this change in ownership. I would have been expected to receive in excess of this.

"My situation is atypical of haemophiliacs. I understand that and I would not be expecting any Government to put up a support package in place to cover these losses, unless of course previous governments were found to be fully culpable of my infection. I believe they are, by the way. The impact of this scandal had has on my family is measurable. I am now not in a position to be able to provide what I should have been able to do. As you

will understand, a reduction in income as indicated has had huge implications like the payment of university fees, the provision of nicer things in life, the fact that my wife has had to go back to work full time to make the books balance, to the fact that we have had to move from the south-east to a more cost effective part of the country leaving all of our friends behind. I shudder to hear that the house prices in the south-east continue to soar after we have moved out of the area. My eldest daughter is now at university and I am not able to provide any financial support for her, which upsets me tremendously. Realistically, if I make it to the age of 50 I will be lucky.

"You may be aware Jeremy Hunt was my constituent MP until we moved. He is fully aware of my situation, as we have corresponded regularly and met on a number of occasions. I might have mentioned that I have had a meeting with him in February 2014, and Jane Ellison, where they invited me to a meeting to understand what a potential settlement would look like. The impact that this scandal has had on individuals varies. The package offered could be pro rata'd to reflect this, i.e. those most severely affected receive 100 per cent of said package, those less so receive some

proportion. It would be quite easy to put categories into place to cover the differing levels of impact, thus managing the overall cost. It would also be all inclusive.

"The financial impact of the scandal is only one part of how this has affected me and my family. The chances are that I will be dead in the next 12 months. Nothing will ever repay this. I won't be there for my wife and two daughters, I won't get to walk them down the aisle, I won't be there to meet our grandchildren, and my wife will be on her own. We won't be able to enjoy our move to the lovely Yorkshire Dales. I look out of my window now and I see that I am going to be missing this view. The diagnosis of cancer came two weeks after we had completed on our house purchase.

"The only thing that will mitigate the impact to a certain extent is a financial package that will make my wife and family financially secure for the future. No apologies or potential criminal prosecutions for what have taken place will mean anything and it is time that the Government sorts this issue out. We have had years of pain and anguish as a result of the actions taken by previous governments. They knew the risk of moving from relatively safe product cryoprecipitate to the massively riskier Factor VIII.

"The risk involved with me passing hep C to my wife and children has been frightening. People automatically assume that hep C infection is due to intravenous drug usage and living with the stigma of it cannot be underestimated. The current Government have resolved a lot of the outstanding issues: Hillsborough is being resolved, Icesave has been dealt with, Equitable Life has been resolved. This is the last big issue that remains undealt with, despite previous attempts. I have tried to keep this brief but, as you will see, it's not easy.

"If this has been a little incoherent, I do apologise but I am currently sat here hooked up to a pump delivering my chemotherapy. This is the impact that this wholly avoidable infection has had on my life. Whatever the reasons are for changing me from cryoprecipitate to Factor VIII when I was 15 years old has had the impact of ruining my life. I have gone from being a fit, active man to someone who can just about manage day-to-day. I have gone from a senior role flying around the world and thoroughly enjoying life to being a retiree at the age of 42. I have gone from having a relatively good income to scraping about to make ends meet. I have gone from being able to provide for the needs of my family to not being able to do so at all. This nasty, nasty disease has completely shattered my life."

MS RICHARDS: Thank you, Sarah. Is there anything else any of you want to say?

ANN: I just wanted to say we're so grateful for the two transplants that Mike had, and the donor families. I also wanted to thank Sir Brian and also Collins, who have been wonderful. That's all I wanted to say.

MS RICHARDS: Eleanor, Sarah, Jennifer? That's all the questions, sir.

SIR BRIAN LANGSTAFF: Thank you very much indeed, each and all of you, for giving us what your story is and for allowing Mike's voice from beyond the grave to be heard. Thank you.

As you know, we finish now for the day and we finish our sessions here in Leeds. The Inquiry will move on in honour of its promise to be a UK-wide Inquiry. It seems that each day brings another moving day that there are aspects which are barely bearable in a number of the accounts which we've heard, deeply moving, all unique, all with a common base.

For those who are listening remotely, as well as you who are here, can I just say this: Sue when she gave evidence told us that she didn't think she was worthy of giving evidence earlier in this week because

of the stories which everyone else had to tell and hers was just her own account. You will have agreed, I'm sure, that it was important to hear it. It is important to hear those who have not yet spoken and there will be many. I can't promise -- I never have promised -- that everyone who makes a witness statement will be asked to give oral evidence but some might be and it is important to me, it is important to us, it is important to the public knowledge of what has happened, that the Inquiry should take its evidence to be as reflective as it can be of the various different experiences which people have had with infected blood and infected blood products.

In particular, there are many who we think have not yet come forward in the numbers that we might have expected if one took a demographic approach, those in particular who suffer from thalassaemia and sickle cell disease who would have had transfusions necessarily, and disease being no respecter of rank or persons or race or origin, one would have expected to see perhaps more from that community or those communities. It may be that what has restricted people such as those with such diseases coming forward has been the feeling that they can't really add to the emotion, the moving accounts which we have been

hearing here in Leeds in particular but elsewhere.

That's not true. I'm not inviting people to come and tell me of their misery but of their experience, which will include misery. It will be important for them if they can bring themselves to come forward and offer what they have to say to do so. I can thank you for being here and for offering your accounts, all of which have had different aspects to them to massively increase the knowledge of me, of the Inquiry team -- I know I speak for them all -- and many of which have been, as I say, hardly bearable because they have been so moving. Today is a perfect example of that.

It bears repeating that we do not have the luxury of time. That's obvious. So the sooner that those who feel that they might possibly have something to offer from their own experience -- it will be unique because each person's is unique -- do so and every statement will be read whether or not the witness is called for oral evidence. Those of you here or those of you outside this room who think, "Well, I missed the boat, the Inquiry's come to Leeds and they haven't asked me to give a statement" should know this: I promised at the outset of this Inquiry that it would put people first and last. This is only

the first part. The last obviously has to come.

We shall hear at that stage from a number more. It won't be everyone who has made a statement, I cannot say that and I will not make you any false promises, but it will include -- we will consider for those sessions anyone who has given a statement whether already or yet to come. So no-one should please feel inhibited at offering what insight they have, and it may be critical insight even if the individual themselves does not think so.

That's my rallying call to others. My thank yous go to you. It's been a privilege for me to meet so many of you and to be able to listen to what you have had to say to me here, what you have had to say to me around this Inquiry room which I have found rewarding. So thank you very much indeed.

That's it in Leeds. The Inquiry will move on. We have a week's break -- we need a break -- but a week's break before we start again in Edinburgh where we have two weeks. Those of you who are at all interested in northern supremacy may reflect on the fact that we have had a week in Belfast and we will move on from Edinburgh after a further week's break to have a week in Cardiff. We have had two in Leeds. It is not long. We haven't been able to accommodate as many as we would have wished but, as I have said we don't have the luxury of time and if anyone wanted to reflect on that, today is all one needs to go to.

So thank you all. Thank you to counsel and the legal teams and goodbye for now.

(1.29 pm)

(Hearing adjourned until Tuesday, 2 July 2019)

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