Friday, 3 May 2019

(10.02 am)

SIR BRIAN LANGSTAFF: Now, Ms Richards, I understand the first witness today would like to be known as Matt.

MS RICHARDS: That's right, sir.

SIR BRIAN LANGSTAFF: Would Matt like to come forward, please.

MATTHEW JOHNSON, affirmed

Questioned by MS RICHARDS

MS RICHARDS: Matt, you suffer from a condition known as haemophilia B; is that right?

A. Correct, yes.

Q. Can you tell us what that is?

A. It's a bleeding disorder where my blood doesn't clot properly.

Q. It involves a deficiency of a different factor product from haemophilia A. Your deficiency is Factor IX?

A. Correct.

Q. It is a condition, I think, that used to be known as Christmas disease?

A. Yes, correct.

Q. And it's, in your case, it's severe?

A. Correct, yes.

Q. That means you have a very tiny percentage, indeed of the clotting Factor IX in your blood?

A. Correct.

Q. Now when approximately was the haemophilia B diagnosed?

A. When I was around a year old. I fell out the cot, put my two teeth through my front lip.

Q. Your parents took you to hospital?

A. Yes.

Q. That's went it was diagnosed?

A. After about three or four days of testing, but yeah.

Q. As I understand it there was no previous family history of haemophilia?

A. No, no.

Q. You were referred, and you were a very young child at this time, but you were referred to the Oxford Haemophilia Centre under the care of Dr Rizza and Dr Matthews?

A. Correct, yes.

Q. For many years your parents regularly took you to the Oxford Haemophilia Centre for check ups and for treatment?

A. It was pretty much on a weekly basis for the first three or four years of my life and then ongoing check-ups every three to six months.

Q. Now, you started to be treated with a factor product and, as I understand it from your statement, you'd be treated when you had a bleed but also there came a point in time fairly quickly when you were given treatment prophylactically on a regular basis?

A. Correct.

Q. What is your understanding from your records or from your conversations with your Mum and Dad about how that came about?

A. Discussion with Dr Rizza, Dr Matthews to prevent bleeding to have prophylaxis to stop you from becoming poorly in later life or have joint issues.

Q. We can see from the handful of records that you have been able to obtain from the Oxford Haemophilia Centre, if we have up on screen please, Paul, 1057003.

This is a letter from August 1986, so a little while further on. If we pick it up in the first paragraph, it refers to you going on holiday to France with your family:

"He is on home treatment with NHS Factor IX concentrate given prophylactically in a dose of approximately 600 units once a week."

My understanding from your statement, Matt is that when it started it was about 20 units a week but obviously at some point it seems to have increased?

A. Yes, it did increase, yes.

Q. That treatment was often given to you at home. Was it administered by your parents?

A. Yes, my Mum used to do it. My Dad was awful. He used to miss the vein.

Q. What is your understanding based upon the conversations you have had with your Mum and Dad about this I know many times over the years, what is your understanding of what your parents were told of the Oxford Haemophilia Centre when they were asked to give their consent to you receiving these factors treatments?

A. My parents made it clear to me from a very young age that they were told that, obviously, with any medication there's always a risk but they were told that this product was ground-breaking, it was clean and it was as good as good can be.

You have this to prevent having issues in later life such as arthritis and what not, but they were told categorically, "As far as we're concerned, there is no risk".

Q. There was some discussion at some point early on about something to do with the risk of hepatitis but they were given a particular assurance by Dr Rizza about the nature of that risk and how severe it would be.

Can you recall from what your parents had told you what was said to them?

A. This was about when I was eight or nine there was a risk of non-A non-B but it was just it was nothing to worry about, it was nothing more than a cold, pretty much like hepatitis A, but nothing to worry about. It's just like a bad cold. You'll get over it and carry on.

Q. Now, you don't know, obviously you were very young at the time, exactly what products or what time period led to you being infected?

A. No.

Q. But if we just look at the records. Can we have 1057004, please, Paul.

These are records that you've obtained from the Oxford Haemophilia Centre; is that right?

A. Correct.

Q. We can see here time periods from 1981 and we don't need to look any further than this period, I think, that we've got on the screen now, 1981 through to 1983. We can see in the box type of material, you were being given something called 9D and then I won't ask you to look at all the detail of it, Matt, but a point in time comes in about 1986 you start to be given something called 9A and then later on again the product name changes?

A. Yes, correct.

Q. You have said in your statement that you think you were probably exposed to contaminated concentrates at some point between 1981 and 1984. What's the basis for you thinking that that's the likely time-frame in which you were exposed?

A. Because the treatment improved from 1985/1986 but I'm not -- I don't know, I don't know. It can't be proved either way the exact date but I believe because of the heat treatment that came out in '86 that it was probably before that, so '84/85.

Q. You have also set out very clearly in your statement your view that you may have been what's been referred to in some material as a PUP, a previously untreated patient?

A. Yes.

Q. What's the basis for that belief, Matt?

A. I was very, very young. If my parents were told the risk then they wouldn't have given me the factor that's caused so much damage, that there was no need for me to have factor. My parents weren't told about the risks of it but, yeah, I've seen records which show that various people in the profession knew the risk from 1979. They knew the risks were there, they were live, but I was still given this product.

My parents would never have given me if they knew the risks involved and my parents weren't told that I had it until many years later, so yeah.

Q. I think you put together the fact you were treated at Oxford, at this particular haemophilia centre by the these particular consultants, that you were young --

A. Yes.

Q. -- so the chances of you having been exposed to anything else were very small?

A. Yes.

Q. And that you received in this critical period in the early 1980s a very large amount of Factor IX concentrates?

A. Yes.

Q. And your belief that you've set out in your statement is you might have been used as a guinea pig to test the effectiveness of the developing processes of heat treatment.

A. Exactly that.

Q. It's my understanding, Matt, that it's important to you to try and find out if that is the case or not.

A. Yes, of course. I'd like the people or person, if that is the case, to be held accountable for what they've put me and more importantly my family through.

Q. You have not pulled the punches in your statement, Matt. You have said you think your parents were lied to.

A. I can tell you now, hand on my heart, my parents would not have given me that medication if they knew the risks. They enquired about taking me to Wales to get a different sort of treatment. Later on my Dad looked about paying for it himself personally, so there is no way my parents would have given me that medication if they knew the risks.

Q. There came a point in time in which your parents were told that you had been infected with hepatitis C.

A. Yes.

Q. If we could have on screen, please, Paul, 1057005.

We can see this is a letter from the Oxford Haemophilia Centre dated 18 June 1990 to a haematology consultant, a Dr Miller, in Milton Keynes and we'll see from the last sentence of that, if you could just highlight that, please, Paul, "we found him ...":

"We found him hep c Ab positive from a sample taken last September."

So we've got this letter June 1990, reference to a sample being taken in September 1989. Your statement says that it was in January 1992 that your parents were first informed that you had hepatitis C.

A. Correct.

Q. Were you ever given or were they ever given any explanation as to why there was a significant delay between the testing and the knowledge that doctors had about your infection and your parents being told of your condition?

A. No.

Q. Do you know whether your parents were even asked to consent to you being tested for hepatitis C?

A. I don't know. I don't believe so.

Q. In the documents you've seen -- I know you have asked Oxford Haemophilia Centre to give you what they have --

A. Yes.

Q. -- and what we've got, which isn't very much, is all you've been given, as I understand it?

A. Correct.

Q. Is there anything in the material that you've been given which suggests that they were ever asked to give that consent?

A. No. I would just like to add it took four requests to get this information and I only got that information which is missing documents when Ben, my legal chap, intervened.

Q. Between September '89 when it looks as though the sample was taken for testing and January 1992, 27 January 1992 is the date your statement gives when

your parents were finally told you had been infected with hepatitis C, would there have been a number of opportunities in that period when your parents were taking you to the haemophilia centre to see the doctors for check-ups and so on for them to have been told of your diagnosis?

A. Undoubtedly, I was there every other week with bleeds, et cetera, or even not bleeds for check-ups, so I probably would imagine in that year-and-a-half, two-year period I went there probably 15 times minimum.

Q. How does that delay in your parents being told about the infection make you feel?

A. Angry, upset, more so for my parents. They have a massive sense of guilt on them.

Q. You have said in your statement that that delay in your parents being told causes you an enormous amount of anger and you've made two observations. One is potentially you weren't being treated properly for the hepatitis?

A. Yeah.

Q. But also there was a potential risk of others being infected by you?

A. Well, yeah. My Mum used to do my injections. What would have happened if she would have pricked herself

at that young age. Obviously, it was quite fortunate my Dad didn't do it because he probably would have pricked himself but, yes, that risk was always there and it was always I had the sense of shame and what if I was to infect my Mum or sisters or someone in the house.

Q. Do you know whether your parents were given any advice or information in 1992 about the hepatitis C and its seriousness and what should be done about it?

A. No, they were told it was essentially just like the flu, a bad cold, "but you'll get over it, nothing to worry about", and that was it.

Q. Your statement suggests that in January 1992 when your parents were finally told about the hepatitis C that there was some discussion about you moving on to a higher purity concentrates?

A. Yes.

Q. But you think that didn't happen until about 1994?

A. Correct.

Q. So again there was a delay in that change in the products?

A. Correct.

Q. You yourself from about early 1998, by which time you were a young adult, you asked about the possibility of being moved on to recombinant treatments you said in

your statement.

A. Yes.

Q. You were told what?

A. No. I was too old. I missed the age bracket by a couple of months. I think the reason that I wasn't put on it was because I had the infection of hep c and there was no point putting me on that because the damage was done and, obviously, it's a cost implication involved, isn't it? I understand the treatment was slightly more expensive and, therefore, it was no.

Q. You were being treated still at Oxford?

A. Yes.

Q. In England?

A. Correct.

Q. You've made an observation in your statement about the different position for patients, as far as you were aware at the time, in Scotland and Wales. What was that difference?

A. That the Welsh people would get it at any age, so my parents enquired about moving to Wales to get me that better treatment but Oxford said, "If you do that, we'll stop it because that isn't the way it's done".

Q. Now, there came a point in time at which a letter was sent to you -- I'm going to ask for that to go up on screen. It's 1057006.

It's a letter dated 20 September 2004 and it provided information about possible risks of vCJD. Do you recall receiving that letter?

A. No, no, I don't. I'm blessed to have an amazing family and my parents hid that from me because they knew that with what I'd been through with haemophilia and other infections they thought that might push me over the edge, so I did not receive that.

When I went to the Oxford Haemophilia Centre for my next check-up I was informed by a doctor that I had this, that -- I had been told that I am at risk and obviously it wasn't ideal.

Q. If we just keep this letter up on screen but we go to the second page, please, Paul, we'll see under what has happened there's a reference to product recalls after donors had been found to have vCJD and then it says this:

"We're writing to you to give you further information about these and about further batches that had been made using plasma from donors who later developed vCJD ..."

Then over the page, please, "Who is affected?" Top of the next page, Paul, could you just highlight that.

This identified the need for special public health precautions to be taken for many people who had received clotting factors. We can see that from the bold print. Then if you could just go down the page please, Paul, to, "What special precautions should I take", the letter told you this:

"You should not donate blood. You should not donate organs or tissues. You should tell whoever is treating you before you undergo medical, surgical or dental treatment ... it would be best if you tell your family about this ..."

When you finally saw this letter what did you feel on receiving this information?

A. I was really angry because it could have been prevented if I got given the factor earlier on. This was all completely preventable, obviously, because I've seen people in the past that have died of hepatitis C and died of HIV. I thought this would be the next wave coming through, people would then be wiped out from that, and it was just a massive, massive mental hit on me.

Q. If we could just go to the next page, please, Paul, if you could just highlight the section under "Can I find out if I've been treated with an implicated batch", second paragraph, Paul,"If you would like to find

out", just highlight that.

So this letter said:

"If you would like to find out whether you have received any of the implicated batches or you wish to discuss this further with us please indicate this on the reply sheet."

You decided you did want to find out --

A. Yes.

Q. -- whether you were just generally at risk as someone who had received clotting factors or whether there was a more specific and focused risk in your case?

A. Yes. Against my parents' wishes, because obviously I had been through enough in their opinion, they said, "Look, don't worry yourself with it. What will be will be", but, yes, I chose to find out. In hindsight, probably the wrong thing to do.

Q. If we look at, please, document 1057007, Paul.

This was the request you sent. You wanted a risk assessment to ascertain what risk you were at from CJD. You wanted to know how many batches you had had and whether or not the risk in increases due to the number of batches you had had.

Then if we can go to the next document, please, that's the one, if we could just see the whole text of it.

So this is the response you received, Matt and it told you this in the first paragraph:

"I know that you are already aware from discussions in the past that you have received batches of Factor IX concentrate including material donated from a donor who subsequently developed variant CJD."

Then if we look at the second paragraph you were told that you have been exposed to two batches of the material. You'd received a total of 20,600 units of one particular batch in the period February to April 1995 and 10,200 units in the period May 1997 to July 1997, and you were told that the general rule is that the risk of contracting any infection through blood products is related to the total amount of potentially contaminated product.

A. Mmm.

Q. What did you understand from the information you were receiving?

A. I was extra lucky: I got two hits. So from that, obviously, it caused serious concern and alarm. I spoke to the Haemophilia Centre. They tried to say the risk was minimal but I'd heard that before with hep c. I'd heard that before with people with my illness, with HIV, and then I thought automatically I'm going to die.

When I was growing up I didn't ever have an issue with passing away from liver or liver illness but this came along and I'd seen people who literally lost all their functions. It was like catching Alzheimer's but dying in six months but I couldn't have that for me and I couldn't have that for my parents, but I was convinced in my mind, rightly or wrongly, this was going to kill me because I had seen people pass over from HIV, there was hep c, and now this one came along and I was like, "I'm going to die".

Q. Have you ever received any more information than what we see set out in letter --

A. Nothing.

Q. -- about the nature or extent of the risk you personally may be exposed to?

A. Nothing. I had to chase it. The Haemophilia Society posted on their website about two years ago there was two cases of sporadic CJD in haemophiliacs, and that was posted about two years ago and that sent me ...

Q. Take your time?

A. That sent me over the edge because at that point I had a little boy who was my life and I didn't want him to see his Dad waste away, so it was quite tough.

Q. Do you want some water, Matt?

A. Sorry.

Q. That's all right. There is no need whatsoever to apologise.

SIR BRIAN LANGSTAFF: If at any time you want a break just say, would you.

A. Thank you. I'm all right.

MS RICHARDS: Since 2004 when you received this information, you've lived with the fear and you continue to live with the fear that you may develop vCJD.

A. Yes, every day you fall off balance or you forget something you think it's starting, you think it's starting and it's horrible. I am antidepressant dependent. I can't come off them. It's had a massive impact on my life but more so for my parents. It's not been easy.

Q. You very powerfully said in your statement, Matt, that one of the things that makes you most angry and most upset is the impact on your wider family. You've got a sister?

A. Two sisters.

Q. Your parents, you've said for them there's a feeling of guilt because they allowed you to have the concentrates, given the assurances that they had been given?

A. Correct, correct. Like I said before, I have an amazing set of parents. I couldn't wish for better parents. I'm blessed. But what I've seen it do to them it makes me feel guilty because it's me that's causing it. Although its not my fault I still feel guilt.

My parents have been beset by their only emotional problems, their own mental problems, and it's been -- as it's me affected I think it's been not as bad for me but as a parent now to two amazing boys I can't even imagine to begin what they must have gone through. For me, it's tough and if I die, I die but it's what happens if I die, the impact on them because of the guilt they have, because that could have been prevented. I could have been given the recombinant factor, which could have prevented all of that, but I wasn't because of cost. So it's quite tough.

But, like I say, the CJD thing was very difficult for me and when the Haemophilia Society posted that on their website perhaps it wasn't the most thought out thing to do, I would imagine.

Q. Just going back to the hepatitis C infection --

A. Yes.

Q. -- I'm going to ask you in a moment about the treatment you had and the effect of that treatment?

A. Yes.

Q. -- but before you had treatment for the hepatitis C, how did the knowledge that you had hepatitis C affect the rest of your childhood and your young adulthood?

A. It's very hard because when I was young, it was -- I was told it's not a big deal, its non-A non-B. Its just like a cold or a flu. You'll be fine. You'll get on with it but then when you start to go back and more and more people were dying from it, obviously, it started to set all of alarm bells and I thought why me? It's like why me and since then I've lost people that are close to our family who have been infected and I'm like, "Why is it me that's still alive?"

I feel sometimes in my head, why is it -- why am I deserving to still be here when so many others have gone before me and it's a horrible thought.

Q. Did it affect your schooling?

A. I was tired. My attention span is that of a gnat. I can't sit still. It's -- yeah, can't concentrate. It did affect it massively.

Q. What about as a teenager and young adult, your behaviour, your emotions, how was that impacted.

A. Yes, my emotions have been impacted massively by this but what caused the most damage was the treatment. I've always been a very affectionate caring person.

I had the treatment and that completely changed me. There was a spell for many years I'd go out, I'd get arrested. My Dad had to come to the hospital and I was handcuffed to the bed after fighting, getting myself into trouble, completely out of character.

But the treatment, I can't describe it. It's awful. It really is horrific. It was for a year and it was the worst thing that I've ever been through and it's like I'm taking these tablets, giving myself these injections, why? I haven't done this to myself. I haven't caused this. I haven't caused this. This could have been all prevented and the sense of anger.

It doesn't linger so much now because I'm constantly -- I'm always on tablets, so that puts a lid on my anger and emotion but if I don't take my tablets for three or four days I'm horrific to be around. I'm awful. It's literally like I have got bipolar. I can be the most amazing person and I can be the most horrible person and that's not like me and I was never like that before.

Q. That treatment, there's the treatment for hepatitis C that you began in autumn 2005.

A. Correct.

Q. What treatment were put on?

A. Ribavirin interferon.

Q. In terms of the physical effect of it, how can you describe that?

A. Dog-tired, angry, couldn't concentrate, can't sit still. It was just horrific. Constantly like your mind's in a cloud. You can't concentrate. You can't think straight. You can't focus things probably. It wasn't the best. But, again, I'm lucky because I've cleared it. I'm lucky it's no longer here. I'm lucky I have gone through that.

There are many, many people that aren't as fortunate and those people who have lost loved ones, I can't imagine what they have been through.

Q. But whilst you were having that treatment, you became very depressed. Your temperament altered in the way you described. You decided there was no point bothering --

A. Correct.

Q. -- with things because you thought you were going to die?

A. Yes.

Q. -- and you had suicidal thought thoughts?

A. Big time, yeah, and I even have those thoughts today. I just still have this immense feeling of guilt over me. I have this irrational anger that burns inside me and I don't -- I've driven to the train station on two

occasions to kill myself, in fact, because I just thought I can't carry on. But then I don't because I think about my parents and think about my son, and now my two sons, and I can't do it but, yeah, it hasn't been easy.

Q. So the hepatitis C virus was cleared by the treatment?

A. Yes.

Q. So now the levels of hepatitis C are undetectable is the way in which you have put it in your statement?

A. It's untraceable; so it's gone.

Q. In terms of physical consequences for your liver, what's the position in relation to that?

A. Got scarring and cirrhosis; so my liver's damaged because of it.

Q. And you have tests routinely --

A. Correct, yes.

Q. -- to keep that under review?

A. Yes. So when I had it, recently one of my liver function tests went very high and obviously I get concerned thinking, "Oh, is this the start of liver cancer? Is this the start of the end for me?" and that's what you think about.

If I go to the haemophilia centre -- now I've moved to the Royal Free in London, if I do go there and the blood tests are abnormal, I think I'm going to

die. I know it's irrational and I'm probably not and I can have a liver transplant, I can clear this, I can get over it but that's the irrational thought that's there.

Q. What's the impact of everything you've described, the infection with hepatitis C, the treatment, the effect the treatment had on you, and then this fear that overshadows everything in relation to the vCJD, what's the impact of that been on your ability to work and maintain your career and to look after your family?

A. So I'm -- again, my Dad has installed a work ethic in me. He's always worked and I've always tried to work. But I've found a job where I can work from home so I can have a nap in the day. I sleep loads. I'm in bed every day by half seven -- every day. If I could, I'd be in bed the whole day but unfortunately I have to work, I have to provide for my boys and for my partner.

So it hasn't been easy. It has been really, really hard and I would be so much better off if I hadn't been through what I've been through. I wouldn't be -- obviously I wouldn't be sat here, but I would be so much better off mentally, emotionally, physically. But it is what it is, isn't it?

Q. You have had to -- in terms of work opportunities, you've had to, for the reasons you've given, turned down promotions, turned down opportunities to travel?

A. Yes. I get very, very tired. If I -- because my ankles have been fused and they're arthritic and I got -- I can't lift my elbow because that's gone as well. But, yeah, in terms of going out to meet clients, I'll have a one-hour meeting then I fall asleep on the train coming back, not something you do with someone who's 38. It is hard. You are dog-tried all the time.

Q. One of the things you say in your statement is one of your many fears is, if something happens to you, is that you are not in a position to leave your partner and your children financially well cared for?

A. I won't be working by the time I'm 40 I don't feel. The tiredness, the fatigue, the depression is getting worse, so my concern is what happens when that happens. I don't want Naomi to provide for me. I'm the man. That's what a man should do. My Dad has instilled that. He has always gone out and worked. I should provide for the people I love and those people that I have made, my two sons.

Q. What have the effects been in terms of when you are trying to access other treatment, for example, dental treatment what's happened then?

A. Yeah, so I went to my dentist some time ago and he wouldn't treat me because I was exposed to new variant CJD. The instruments were too expensive so he said he couldn't treat me. I then probably spent the best part of two or three years to find a dentist who would find me and they wouldn't, so I went to another dentist and I didn't tell him because I had an abscess in my mouth and it was really, really sore, I mean painfully sore so I didn't tell him. Probably not the best thing, but I had to get the abscess sorted.

Q. What about when you just go for some of the routine treatment that as a life-long haemophiliac you will inevitably have to go to, what happens in terms of the way in which you are treated?

A. So obviously I'm blessed to have cleared the virus and I cleared that at a young age, but there's massive stickers, danger of infection, risk of infection, I presume about the CJD and it's not good to see when people ask what's this about.

It's almost like I feel like sometimes that I have been a drug user and that's the perception of me because I've got this. Obviously when going back to the early '80s it was much worse with what was perceived the gay plague but it's still bad for me now. Like I've got amazing family, I've got amazing

friends and I'm very, very lucky but obviously back 20/30 years ago people weren't so forgiving.

Q. Whenever you do have any kind of procedure you are at the end of the list.

A. Oh yeah, yes.

Q. You are made to feel very aware that you are at the end of the list?

A. Yes.

Q. Have you ever been offered any form of counselling to deal with the issues that you have identified in terms of the exposure to infection and risk of vCJD?

A. No, no, none, absolutely none. I've had to -- my Dad when I was younger was desperate to put me on it because I was slowly killing myself so he would pay for it for me but I didn't like it, I didn't like talking about it, I didn't like bringing it up.

The reason I'm here today is I want to talk for those people that can't be here. There is someone close to the family who has passed away through an illness and he can't be here so I'm talking partly on his behalf, but partly because this all could have been prevented. My life has been completely dismantled, completely taken apart for something that could have been stopped and it's just -- yeah.

Q. You get an amount of regular payment from you, got

some monies originally from the Caxton Foundation and now form the EIBSS?

A. Yes.

Q. What has been your experience of making applications for financial assistance?

A. Caxton Foundation, I can't -- I don't even remember applying for it. That money went in a matter of months. I thought I was going to die, so I just spanked it. I was 20. I thought, do you know what, I'm not going to be here, so let's have fun. So that's what I did.

Then the other ones, the regular payments, it's you have to go through so many forms. Even though everything is on my records, I am fatigued, I am tired, I can't walk, I do get out of breath, you still have to apply. They have my notes and you apply, send off the forms, you get more information back, it goes on and on and on, and also as well it's just hard applying. I don't feel like I should apply to the Government who, in my opinion, the NHS are the ones that gave me this and I'm asking them to help me for what they've given me. It doesn't make sense.

Q. Matt, those are the questions I had for you. I am going to ask Mr Stein in a moment if there is any other matter he would like me to raise but is there anything else you'd like to say about your evidence?

A. The evidence is true. It's all been really, really painful. I love my family so much and thank you for everything that they've done for me. I know it hasn't been easy for you two, and I just hope that some good can come of this. I hope that justice can be done. I hope the people who are accountable, because in my opinion there is, are held to account and this is never repeated. This is never repeated.

I don't want the people in this room, their families to go through what I've been through. I don't want any other haemophiliac to have to die or to go through the pain I have been through, or anyone else for that matter.

We are a very, very rich nation. People should not be put behind profit from pharmaceutical companies. It should be about preserving people and life and I just feel that the people, the poor people that I was speaking to last night at the hotel and the poor people in this room that have lost loved ones, it breaks my heart.

I'm lucky I'm here, I've cleared hep c, I'm okay. Obviously, I'm damaged. I'm irreparably damaged but there are people that have lost people that they love and as a parent now I can only feel

nothing but pain and sorrow for them, but yeah.

Q. Matt, I am just going to turn my back and ask Mr Stein if he has anything else he'd like to raise. *(Pause)*

There's nothing further that Mr Stein asks me to ask you.

Sir?

SIR BRIAN LANGSTAFF: Matt, it has taken immense courage for you to be there and lay bare some of your innermost emotions. You have told us of a number of reasons why you've done that. Is there one that you choose? Which is the main one, do you think, that brings you here to tell us what you have?

A. I don't want people to go through what I've been through. I don't want parents to have to relive the horrors my parents have had to -- that have had -- that have had to go through over the years.

I know the guilt that they feel and the pain that they feel and the horror that they see me go through. I don't want any parent to go through that. I don't want any son to go through that or any sibling to go through that.

SIR BRIAN LANGSTAFF: Thank you very much. Thank you very much indeed.

I think we will take a break. Shall we say 20 minutes.

MS RICHARDS: Yes, sir. Thank you.

(10.42 am)

(A short break)

(11.05 am)

SIR BRIAN LANGSTAFF: Our next witness wishes, I understand, to be known as Jackie.

MS RICHARDS: That's right, sir.

SIR BRIAN LANGSTAFF: Jackie.

JACQUELINE BRITTON, sworn

Questioned by MS RICHARDS

SIR BRIAN LANGSTAFF: Jackie, your voice is quite soft. You need to be a bit closer to the microphone I think that should probably do it.

A. Thank you.

MS RICHARDS: Jackie, I am just going to give you a copy of your statement to have with you?

A. Thank you.

Q. I don't think you'll need to look at it but it's there in case you want to check anything or refresh your memory.

Jackie, I'm going to ask you, first of all, about 1983. You were in hospital having given birth to your first daughter?

A. Yes.

Q. Saint Mary's Hospital Portsmouth, and then a few days

later having been discharged home you were rushed back into hospital. What happened?

A. My daughter was eight days old and I had an old GP that was about to retire coming in. I was living with my Mum because my husband had come back from the Falklands and we were stationed in Dover, but because he was away I stayed with my Mum because it was the end of the pregnancy, and my blood pressure had been high all of the days that I had been at home, and he had had a go at me about being a young Mum and letting my Mum do everything for me because I had these raging headaches. I had taken to bed. So I thought all young mums must feel like this.

So I got up and I put my daughter -- it was the first time I'd put her in her pram and I took her for a walk on the Friday and we were due to register her the next morning, and got home, had a bath, stood up, and it was like a horror film. My husband just ran and got my Mum and I'd started haemorrhaging. Doctor came out, called an ambulance and they took me back into Saint Mary's Hospital.

Q. So you were rushed back to hospital as an emergency?

A. Yes.

Q. The doctors undertook a procedure known as a D & C?

A. Yes.

Q. You were in theatre for a while?

A. Yes.

Q. Presumably under anaesthetic?

A. Totally, yes.

Q. When you came round from the anaesthetic after the surgery were you told that you had had a transfusion?

A. I was on my own, groggy from the anaesthetic, and naively I looked up and said to the doctor that had come in, "I'm fine now. Everything's okay", and he said no and he said, "You had four units of blood. The only reason I stopped was that I thought I was going to perforate your uterus and I'm expecting you to haemorrhage again. When that happens, we will have to give you a full hysterectomy". And I was 21, and he told me that with no-one else in the room.

Q. So that was how you discovered you had had a transfusion. I think you're not critical of the fact that before the transfusion you weren't given information because it was an emergency?

A. That's right.

Q. But you stayed in hospital for about a week after that?

A. That's right.

Q. Were you ever in that period of time given any information about any risks associated with having had

a transfusion?

A. None whatsoever. I was happy that I didn't have to go back to theatre. I didn't haemorrhage again, so I was discharged and I went on with my life thinking everything was fine.

Q. Now, you then had, a number of years later -- in the mean time you had had your second daughter?

A. That's right.

Q. A number of years later, in 1993, you had further surgery, serious surgery, at Saint Mary's Hospital in Portsmouth. You didn't need a transfusion.

A. No.

Q. But you were at pains, I think, to give the doctors some information before your surgery was undertaken. What did you tell them?

A. Totally. On the pre-op checks I'd haemorrhaged with my second daughter as well but I didn't need a transfusion, so I was at pains to tell them that I'd haemorrhaged twice and that, you know, would they definitely have blood on stand-by. I had had a four unit transfusion in 1983. My Mum had had a hysterectomy and had internal bleeding. It just seemed there was like a history with the family, so I was at pains to make them aware of that.

Q. Did the doctors, having been given that information by

you, that you had had a transfusion in the 1980s, did they give you any information during that hospital stay about any risks that you might have been exposed to during that earlier transfusion or give you any advice about what you might want to look out for?

A. None whatsoever.

Q. You had over the following years a couple of further operative procedures at the same hospital. Again, did you pass on any information in advance of those procedures to the doctors?

A. Each and every time I told them, I warned them because I had two young children then to worry about and so I always was concerned of the bleeding, and I always was at pains to tell them that I'd haemorrhaged twice, I had had a transfusion, and would they have cross-match on stand-by.

Q. On either of those occasions did the doctors pick up on the significance of you having had a transfusion and give you any advice or information?

A. None whatsoever.

Q. Now, you began to or you had been experiencing I think for a number of years certain physical symptoms.

Can you describe to us what they were?

A. I was always very tired. I was told that I was suffering from IBS. I always had pains in my stomach,

lots of issues, so I was diagnosed with IBS.

Just before I was diagnosed with the hep c, again things were getting worse. So I went back to my GP and because of the nausea, the weight loss, the pains in my stomach, they did do scans and they just happened to find that I had cysts on my ovaries and so they assumed that's what was causing the problems, and I had another operation, and they were removed and, again, I told them that I had had the transfusion, that I'd had -- and this is in about 2009 -- I had had a transfusion and did they have blood on stand-by just in case.

Q. Again, on that occasion in 2009 did anyone say to you --

A. No.

Q. -- anything about the risks that you might have been exposed to?

A. No.

Q. Even though you were complaining by then, bringing to doctors' attention the symptoms you had been experiencing?

A. That's right. At one stage, even with -- I mentioned the brain fog, that I'd be lost for words, I'd be walking out the door and then thinking I'd have to go back I don't know how many times, did I lock the door, did I switch something off? I'd be talking to somebody and then I'd have to say to them, "What was I just saying", and so because I had had a hysterectomy at 30, it was assumed that it may be hormonal and so I was put on HRT as well. But it's only since that I was diagnosed that I look back now and I think how much of that was down -- like my gall bladder -- how much of that was down to the underlying hep c.

Q. So you would go to your GP, and you make this very clear in your statement, Jackie, you reported the brain fog, the symptoms you were experiencing, you were told, well, it's hormonal due to your hysterectomy.

Then in 2009 you were told and, indeed, it was picked up that you had ovarian cysts but it was assumed by the medical professionals caring for you that that was the sole cause of the problem?

A. That's right, that I would pick up afterwards and I never, ever did.

Can I just say at this point I feel that I could kick myself because I remember watching Anita Roddick on GMTV with my Mum and saying to her. I knew that I had the transfusion in the at risk period but it's like I've had so many operations, I've had so many NHS

staff with their hands inside my stomach, if I go and ask for a test, my doctor's going to think I'm neurotic. That's going to be written large on my notes and so I didn't. I assumed I was fine.

Q. So having had the operation in relation to the ovarian cysts in 2009 the symptoms that you described continued. They didn't go away with that surgery?

A. Continued.

Q. You went back to your GP in June 2011, and you said you had a newly qualified GP who saw you on that occasion.

A. That's right, yes. He was just attached to the practice for a short amount of time so when he went in, it was a long consultation. You know, he wanted to know everything. I assumed going there that, you know, I was coming up to 50, I was overweight, he would say stress, but he was lovely and he did -- because I was also suffering from heart problems at the time, there was pains, so he organised a nuclear scan of my heart and he organised lots of blood tests.

Q. The blood tests showed deficiencies in the functioning of your liver and, therefore, more blood tests were undertaken?

A. That's right.

Q. Then there came a point I think where the GP phoned

you --

A. At home.

Q. -- late at night at home, and what did he tell you?

A. That there was a major problem with my liver, that they'd tested for hep c and it had come back positive and that could they use the same batch, I wouldn't have to give any more blood, but could they use the same batch for an HIV test, which obviously I said yes, and that I needed to book my daughter, my youngest daughter and my husband in as an emergency to get their bloods tested for ...

Q. In relation to your family members who were tested, that was clear?

A. Thank God. I couldn't have lived with myself. I couldn't have coped if my daughter, because she had a two year old, my granddaughter, and if I'd passed it on to her, my two year old granddaughter would have had to be tested.

Q. It must have been a terrible shock receiving this phone call late at night. I don't think you are critical of your GP, however, because you were so glad to be told --

A. That's right.

Q. -- finally, what it was that was wrong.

That was June 2011. Your GP made, as

I understand it from your statement, the right urgent referrals.

A. That's right.

Q. But the hospital couldn't see you until when?

A. They booked me in for August 18. My GP, because I was feeling so unwell, he sent off a fax asking if they could bring the appointment forward and they couldn't. I had a letter back to say no. So I went through the phone book and I paid to see a consultant within the week and it was the same consultant that I would have seen if I'd been sent to a Southampton hospital. It was the same consultant. He worked for the NHS and private.

Q. But when you got the hospital point for August, so a number of weeks or months off from when you had first been told you had HCV, did you receive any information about hepatitis C from the hospital to inform you what it was about?

A. None whatsoever and my doctors apologised that they weren't totally up on liver problems. So obviously you go to the net, because you find out that you have been infected so many years, from what I read, my -- you know, I might have weeks to live, the way I was feeling especially.

Q. So you researched the internet yourself?

A. Yes.

Q. What you read filled you with --

A. Dread.

Q. -- dread, and you've said in your statement you are very strongly of the view that there should be booklets of information available for GPs to be able to give patients or hospitals to be able to give patients in your situation.

A. Totally. You don't drop a bombshell on somebody and then let them go home with nothing. My daughter was diagnosed as a diabetic in hospital and before we came out of hospital we had a DVD to watch, we had booklets to read. You are given this devastating news and there's nothing. You go home and in the early hours of the morning you are planning your funeral. You are wondering what's going to happen.

Q. So you paid privately for peace of mind to see the consultant?

A. I did.

Q. What information was the consultant able to give you?

A. He was lovely. He organised blood tests so that he did the genotype, so I knew what genotype I was. Straight away, he said that in his experience treatment and just having the hep c causes depression in most people so he advised that I started

antidepressants straight away and he organised that with my GP.

Q. You had a liver biopsy?

A. As I say, I was very concerned so I had nothing on my credit card and then all of a sudden I had paid for a £2,000-odd liver biopsy because I needed to know.

Q. That told you that you had fibrosis, the bridging stage before cirrhosis, at that stage?

A. That's right.

Q. I think it was this private consultant who also told you about The Skipton Fund?

A. Yes.

Q. You then had the NHS appointment that you had been waiting for on 18 August 2011?

A. Yes.

Q. What did that consultant tell you about how you had probably contracted HCV?

A. Well, I was put off straight away when he sort of looked at me and said, "Why on earth have you gone and had a liver biopsy and, you know, gone and paid to see someone, you know. I'm here", and I said because mentally I couldn't live that amount of time with not knowing how badly I was, so that put me off of him straight away.

As I say, that just set the tone for the meeting

that we had at that first meeting.

Q. Your statement says that it was, however, that consultant who told you that you'd probably contracted the hepatitis C from the blood transfusion back in the '80s?

A. Yes. As I say, my GP as well had said that and obviously I laughed at the time but I looked at -- I led a boring life. I got married at 18. I was with the same man for 38 years so, you know, they couldn't put it down to my lifestyle. I wasn't brave enough to get tattoos. All there was that stood out loud and proud was the four units of dirty blood.

Q. So from having been infected in 1983, it took until 2011 for that infection to be diagnosed?

A. Yes.

Q. Notwithstanding the fact that in the intervening years you had gone to doctors numerous times with the classic symptoms that you've described?

A. That's right.

Q. What impact was there on you of learning at that point that you had been infected for so many years?

A. I was really, really angry. The fact is the blood saved my life at that point. That's fine. If they didn't realise there was issues with the blood I can accept that. If they didn't know that there was

issues until after the transfusion date, I can accept that.

What I can't accept is they had numerous, numerous occasions to find me and give me treatment so that I wouldn't now be cirrhotic and, as soon as I found out, I went to my MP and I said to him, you know, "I'm the tip of the iceberg. I'm not the last person in England to have an infected transfusion and be finding out about it".

If there is a simple question on a pre-op form, everybody that has an operation has to go to a pre-op clinic, a simple question that says, "Have you ever had a transfusion?" If the answer is yes and the dates are in the at-risk period, you are offered testing and he blubbered something about data protection and I said, "By that question not being asked I wasn't able to make an informed choice. You need to give people -- it's a simple question. You need to give people the opportunity to say yes or no, they want the testing. With that, they then can get the treatment. You're dying in ignorance if you don't know you're infected", and after the data protection thing, you know, I looked up and said, "You don't want to find us because it's going to cost the Government money. That's the be all and end all", and I don't think I've been escorted out of an office with my Dad so quickly.

Q. You had a great fear that you might have infected not just your family but others whom you had come into contact with, medical and nursing professionals who had operated on you over the years?

A. I told him, you know, "Your NHS staff have had their hands in my stomach. I've been open from top to bottom and I could have infected how many more people", and you know ...

Q. You had worked in childcare --

A. I was a nursery nurse.

Q. -- dealing with cuts and scrapes of children who had fallen over?

A. Yes, totally.

Q. What can you tell us then about the treatment you received? So August 2011 you have seen the NHS consultant and you I think fought to begin treatment as soon as possible --

A. That's right.

Q. -- having been undiagnosed for so long.

What was the first course of treatment you underwent?

A. The first course was interferon and Ribavirin for three months but unfortunately I was a non responder.

Q. What was that treatment like?

A. I injected myself every Wednesday, took tablets a couple of hours after, paracetamol, and then went to beds and the flu symptoms kicked in big style. The Ribavirin also, towards the end, they had to cut my dose because I would walk along the corridor and it was like an old lady, my breathing, and it was because of the anaemia, my platelets had dropped and that was due to the Ribavirin, so they had to adjust the dosage of that.

Q. So that treatment came to a premature end and then in 2012 you ended up paying to have a fibroscan of your liver. Why did that happen?

A. Again, I was researching. I was still feeling so poorly. My hospital at the time, it was new technology, they didn't have a fibroscan, so I paid to go to London and I was examined and the fibroscan was done by Professor Thursz, who I didn't realise was an eminent professor. I was very lucky that I just happen to find him.

Q. What did that fibroscan show?

A. Well, he talked to me before the fibroscan and he said from what I was telling him he would almost certainly think I was already cirrhotic and that probably I was cirrhotic the year before when I had the biopsy but he

explained that the liver is quite large and the biopsy is minuscule and they might miss cirrhotic tissue by millimetres and you would have the pre-cirrhotic result that I had.

So he'd almost laid the groundwork that he thought I was cirrhotic. I had -- he did the test and he said that he would make a report and he sent it to me and the fibroscan scores I think at the time, if you were 12 to 14 they -- or over 12, they considered you had cirrhosis. Mine came back as 39.9.

Q. You then embarked upon a second course of treatment. You were given a pretty poor prognosis I think at the outset in terms of the likelihood of it succeeding; is that right?

A. Yes. What had happened is Professor Thursz looked up to me and said from everything you are telling me you haven't really got time to play around with with treatment. So my hospital, the next lot of treatment that was coming online, which I again fought for funding for, was to Telaprevir, Ribavirin and interferon and I was due to the Telaprevir for three months, 12 weeks, and stay on the interferon and the Ribavirin for a year, and I was expecting an 80 per cent chance of clearing, and when I actually got to the hospital and my nurse started going through

things she said, well, actually, because you're a non-responder and because you are 1A your clearance rate is probably about 30 per cent, but there was nothing else on the market and I thought I haven't got time to play with, 30 per cent, I've got to go for it so, as I say, because of the knowledge I had at that time I went for it, side effects regardless. I didn't have a choice.

Q. The 1A is the genotype of hepatitis C that you had?

A. Yes.

Q. What were the side effects from the second course of treatment?

A. The second lot of treatment was they knew that there were issues, skin issues, but the drugs company they did give you a 24-hour hotline to nurses. Your doctors, if you were poorly at all through anything, your doctors had to phone them to okay what drugs because there were so many interactions with drugs, so you couldn't just take anything off of the shelf.

You had to -- it was you had a timer on the bottle of pills, you had to have them on the timer and you had to have them with 30 grams of fat. So again it was like 5 in the morning you had to have a pint of full fat milk and spoonfuls of peanut butter so that it would work, so it wasn't nice and I did have problems with that. I was hospitalised. It caused -- I was sent to see a colorectal nurse because it caused issues but it was side effects.

Q. You had itching all over, you had bleeding and abdominal pain.

A. Yes.

Q. As you said, you had to go to hospital and you said in your statement the side effects were so bad you remember waking up everyday and thinking when is this going to end?

A. That's right. The Ribavirin again was causing problems but I was determined that they didn't drop my dose because that might have been the cause that it didn't work the last time. You know, you pick at straws.

I was on that, as I say, the Telaprevir, I finished three months of that and I carried on until 27 weeks. It was Christmas time and Boxing Day my Mum said I was quiet and I just -- all the feelings of the illness was coming back, so there happened to be, the Liver Trust had organised vans that go round and offer fibroscans. So I queued up in January in a car park in a shopping centre and I was quite surprised that my nurses were all there, they had all come down from the hospital.

They hadn't informed me that this was happening, you know, I just found a little bit in the evening news and I said to them, you know, I haven't had any blood results and she said, "Oh, I'll chase it up", and she went off and made a phone call and it was a porta -- like a porta-cabin thing and she said, "Can you come in", and then ushered me into a little cubicle, and I said, "Before you tell me, it's stopped working, hasn't it?" I was 27 weeks into the year that I should have stayed on and she said, "I'm so sorry". I said, "I knew. I felt it. I felt so ill again", and she said, "You might as well stop taking them now. That's it".

Q. And there were no other treatments available at that time?

A. At that time there wasn't and my hospital, they didn't do liver transplants, so they said to me if for any reason in the meantime that I needed a liver transplant they would automatically send me to the Royal Free in London. So I thought, you know, you're at death's door and they're going to send you off to people you don't know, so I then again researched and I'd heard good things about King's and Kosh Agarwal and I paid to go and see him.

Q. So you went to see Dr Agarwal about a possible new drug trial?

A. Yes, King's were very high on doing trials for drugs.

Q. What happened? What discussions did you have with him?

A. He said he could have started me on a trial the same week but, unfortunately, because I'd been on the previous treatment and failed that that negated it. He couldn't do anything for me and he said if I'd been under him he wouldn't have even put me on that medication, the risk -- you know, the clearance was so poor he wouldn't have even put me on that but obviously I didn't know that at the time. I made an uninformed choice.

Q. He told you you were going to have to wait until there was a new treatment and a new trial for another combination of drugs?

A. That's right and that took until 2015.

Q. In the meantime you transferred to become his patient as an NHS patient?

A. I did, yes.

Q. So you were able to start a third course of treatment in December 2015?

A. I had to fight for it first. Yes, it wasn't handed on a plate. I met my good friend Sally Vickers at a radio station. We were both fighting because, although NICE had cleared it, NHS England had decided that the funding wasn't been there and they'd put like a six-month stop on it. So we were expecting treatment in the April and I think it was about the October, having gone to MPs, having gone in the media and the papers, fighting as ill people for things that we should have been given to us because the NHS had infected us.

Q. What was the combination of drugs that you tried this time?

A. That was Harvoni and Ribavirin, my old friend again.

Q. That course of treatment ultimately cleared the virus?

A. It did.

Q. And that was end of 2015 that it cleared?

A. It was, yes.

Q. Did you have similar side effects during that course?

A. Again, the Ribavirin caused problems but, again, I was determined they didn't drop my dose and it was 12 months and, although there were side effects, it was a walk in the park compared to the last two treatments.

Q. Now, although the virus has cleared, you continue to experience the symptoms of hepatitis C, don't you?

A. I did and I actually went back to my doctor and said -- my GP -- because I wasn't due to go back to

King's, and I said I think the hep c's come back. I'm getting all of the same, the brain fog, the tiredness, the fatigue. You'd stand up to cook something or wash up and it was like you'd run a marathon, and you were being sick because the energy it took to stand up. You know, your legs buckled and you were vomiting because the energy it took.

So she did blood tests and it came back that -- she phoned me and said, "I need you here this afternoon, you've got pernicious anaemia" and they started injecting me that afternoon.

Q. You were also told that you had fibromyalgia?

A. I was. She arranged for me to go to a rheumatologist in my local hospital, and I went there and the rheumatologist did tests and examined me and diagnosed fibromyalgia. And she said, "If you hadn't have had the diagnosis of hep c already, we would have tested you for it because the link is so close". You know, you normally -- if you find fibromyalgia, there's a strong possibility hep c is there.

Q. The ongoing symptoms which you describe in your statement, still the fatigue, still the brain fog, still nausea, and itching, and you get -- you have through the fibromyalgia, you are constantly in pain, aches and pains?

A. Aches, pains. Totally, yes. The pernicious anaemia, the normal thing is that every three months you go for a vitamin B12 injection. They give me the injections and I inject monthly at home.

Q. What about the effect on you mentally?

A. It's been devastating. I tried -- it's only recently that I've let my daughter know a lot of what I've thought.

When I was first diagnosed, I sought out a grant from their hep c -- no, not the hep C, the Liver Trust. They were offering a £900 grant for counselling and I got it. I was lucky enough to get it and my counsellor that I found was fantastic. But £900 doesn't last when you've got a chronic condition. It's not something that's going to be fixed and when you have treatment and you're going up, you know, you're thinking "this is working" and then the treatment fails, you crash.

So I started off seeing her weekly and then we went to fortnightly to try and string out the £900. Then we went to monthly, and I did pay. When the money run out, I did pay a couple of times for myself but it's not something you can keep up.

But I found it really, really useful because she was my sounding board, the poor woman. I could tell

her my deepest, darkest thoughts and I wasn't burdening my family. I didn't want to put any more guilt on them.

Q. In the early hours sometimes, particularly in the early years, you would be writing poetry out. What was the purpose of writing the poetry out?

A. It was what I wanted at my funeral.

Q. Your feelings over the years, I think, have developed into a lot of outrange and anger at what's happened and you've talked -- you've mentioned already a lady who you met and became friends with?

A. Sally, yes.

Q. How did you meet?

A. We met at a radio station, both fighting for funding for treatment. Sally lived in Portsmouth; so we were close. So we went through -- although she wasn't on exactly the same treatment as me, we went through treatment around the same time. We both cleared, which was amazing. We both had cirrhosis already, so we were still ill people.

Then Sally had three-monthly scans because she had a bleeding disorder too. She wasn't a haemophiliac but she had a specialised bleeding disorder and one of the scans they found a nodule and so they had to investigate. So I went through that

with her.

Then I'd cleared Christmas 2015, and Christmas 2016 I went for my scan and I knew that they were taking an awful lot longer taking the scan and so I said, "What have you found?" The poor radiologist said, "Yeah, I've found something. I think they will need to do further investigations".

Luckily with me, with King's you have the scan in the morning, you see clinic in the afternoon. So my previous hospital, you fought for your six-monthly scans, which could take eight months, and then it was a wait to see your consultant. So the best practice which everybody should be entitled to was to have your scan in the morning, especially if they find something, and see a doctor in the afternoon.

So a CAT scan was organised before Christmas of that year. Luckily, it was fine. So, as I say, me and Sally went through the same things and then Sally had another three-month scan: fine. Second three-month scan: terminal and she was dead within two weeks. My daughter happened to be at the hospital when she was in and we both went to see her. And I heard her before we got on to the ward. I thought, "Please don't let that be Sally". She was such a bubbly, full-of-life person and there was a shell, a yellow shell, in the bed struggling for breath. Her husband GRO-C had popped home and her niece was there, and I said, "Has she been like this all morning?" and she said, "No, she'd been out, sat out, and we just put her back and she'd been talking to GRO-C". And I said, "When he's due back?" and she said, "Well, any time". I said, "Go outside and warn him. Don't let him walk into this. Warn him".

He came in and obviously the change in her was so dramatic. He had wanted to take her home and I said, "Alan, please, don't try and take her home. If anything, take her to a hospice because at least then she would have the pain-killing drugs on tap. You wouldn't have to wait for nurses or whatever to come in".

We went off to my daughter's clinic and I had a phone call from GRO-C I said, "I'm just about to pop up GRO-Cs going home. I'm just about to pop up again, so you can get some lunch" and he said, "She's gone. She went about ten minutes after you saw her".

That really hit me because I was stood there with my daughter thinking is my daughter going to be stood there alone watching me in the bed? It happened so quickly, and it's murder by any other name because it shouldn't be allowed to have happened and it's still happening. There are still people undiagnosed that nobody is bothering to find because of the cost it will involve and a £12 test needs to be offered to everybody so that they don't die in ignorance. Without testing, without knowing you're dying, you can't access treatment.

Q. Can I ask you just a little bit more about the impact that your diagnosis and illness has had on you and on social life, work life, family life.

A. I was medically retired. I was off sick, obviously, when I got the diagnosis and then after a year they put into place that I saw occupational therapists and I never, ever returned to work. Obviously, it was hep c and I was cirrhotic. I wasn't well enough anyway.

I've had a long-standing friend who has stood by me but she was used to me -- we couldn't make plans anymore. We couldn't say we'll do this on this day because you never know from one day to the next, from one hour to the next, how you're going to be feeling, if you've got the energy.

So the impact is massive. I looked after my granddaughter. Her Mum went back to work when she was 12 weeks old and as a little girl I had her from 12 weeks and she was two when I was diagnosed. In the afternoon, I would put the stair-gate across the top of the stairs and she had a nursery in my house and I would either lay on the single bed in the nursery with her playing, she was playing shops, or I would put a DVD on and I'd lay on my bed. She would toddle off, get her nurse's uniform, and then come back and her little bag and say, "I'll make you better, nanny". She's grown up knowing that I haven't done the things that my 80-year old parents have playing with her, playing badminton and doing things in the garden and it's not right.

Q. You are a carer for one of your daughters?

A. Yes.

Q. I am not going to ask you to say anything about your daughter's particular needs, but you spend a very substantial part of your week caring for her?

A. I do.

Q. And one of your great fears is what might happen in the event of your death --

A. That's it.

Q. -- to your daughter.

A. *[Answer redacted]*

Q. Can I ask you about any experiences you have had in terms of seeking financial assistance from The Skipton Fund or from its replacement the EIBSS?

A. I think I was lucky when I was diagnosed because the Skipton was straightforward. They paid out when I was initially diagnosed and then the year after although I had issues with my consultant filling in the paperwork and my sick pay was coming to an end so I was desperate for him to fill out the paperwork because obviously I had a mortgage, so I had to keep chasing the nurses to chase him, but once they'd got the forms it was straightforward and so I did have the second payment, lump sum, and I used that to pay off my mortgage so that that was one thing I didn't have to worry about.

As I say, at that stage I'd put money on my credit card for my biopsy and they did pay that off for me.

Because I'm a proactive-type person, that's the way I deal with things, I got on the Caxton Partnership meetings to try and change things from the inside, and one of the things that they stopped doing was paying retrospectively. So if I'd gone to them as a person with a credit card later on, they wouldn't have paid that off and to, you know, I explained my situation and sometimes -- it doesn't have to be a liver biopsy. It could be a washing machine or -- if you need it you need it, you can't wait weeks and if you put it on your credit card, you know, if it's something that you needed, to me the retrospective -- taking the retrospective payments away was not good for the beneficiaries. So I did bring that up and I did have a voice in those meetings and I can remember saying that, you know, "We're beneficiaries, you're there supposedly supporting us", and they went on about their budgets and I said, you know, "Sorry, if somebody needs something and it's due to their hep c or whatever, you need to increase your budget, you know. Are you telling me because the DHSS pay your wages that you're not going to bite the hand that feeds you? It's about us not about you and your big fat wages". Yeah, that didn't go down very well in a meeting.

As I say, once I was on there they had to ask me back. I did not expect to be asked back, but yeah.

Q. You've spent since your diagnosis and particularly I think since you cleared the virus, you've spent a lot of your time, a lot of your energies campaigning to raise awareness of hepatitis C, to raise awareness of the fact --

A. Of people like me.

Q. -- that many people like you who for years had the symptoms but it was never diagnosed and therefore not

treated?

A. That's it.

Q. You've still got to go for your regular scans?

A. I've got one next week, next Friday.

Q. You now have them three-monthly?

A. Every three months.

Q. Jackie, those were the questions that I had to ask you but are there any matters you would like to add we haven't covered?

A. Yes, I've just written a little bit if I'm allowed to read it, thank you.

First of all, I would just like to say thank you for the privilege of allowing me to speak today, although it's an ordeal, so many lives cut short, voices silenced, families devastated, my voice is just one of thousands diagnosed and yet to be diagnosed that exist in the same nightmare.

My hopes for this Inquiry is that at its conclusion it will be a fitting epitaph to our dead, no longer ignored, a written memorial to their bravery, tenacity, standing in demos terminally ill; and to our living, the chance to live what lives they have left without the need for campaigning, fighting for treatment, begging for financial assistance.

This Government along with all of those gone

before need to accept liability for the harm done and that continues to be done on their watch. The buck stops with those in power. They have the control and should now move swiftly to right the wrongs, provide a duty of care to those allowed to be infected and in the passing three decades have ignored in the hopes that we will die quietly.

I for one am not dying quietly and I am not alone. The powers that be created this murderous scandal. It is to them that we seek justice and an honest apology that lasts more than 30 seconds and is not just lip service.

Thank you.

MS RICHARDS: Jackie, I'm just going to turn my back on you and ask Mr Lock who, as you know, represents you if there's anything else he thinks needs to be asked?

A. Thank you.

MS RICHARDS: No, there's nothing else, thank you.

A. Thank you.

SIR BRIAN LANGSTAFF: Just before you go, you've made a number of very practical suggestions.

Can I just go through the ones I've noted and see if I have missed anything.

A. Yes.

SIR BRIAN LANGSTAFF: The first you mentioned was that

you, as you put it, you don't drop a bombshell on someone and leave them to go home with nothing. You were suggesting that anyone who was diagnosed with hepatitis C should, for the first time that they were diagnosed, go home with printed information which they could understand which would help them to sort things out in their mind. That was the first.

A. Yes, I was part -- I took part in a computer thing in America, there was people all over the world to come together to try and form a booklet that people that were newly diagnosed, they were handed this, and it was like a pathway of what they should expect and what should happen, almost like best practice, and I did that, as I say, I would like to be proactive and I don't know if it came to fruition and I know that obviously things that happen in America don't always translate here but I thought it was a really good idea that, you know, you're given this.

But if you don't know the right questions to ask, you don't ask them and, as I say, that would be a good opportunity to have a booklet to help people through the journey.

SIR BRIAN LANGSTAFF: The second thing I noted was that in any pre-operative assessment when there's a form there should be a simple question, tick or not, "do you want to be tested for hepatitis C".

A. That's right.

SIR BRIAN LANGSTAFF: The third was the best practice for those who are suffering from potential liver disease is to have a scan in the morning and see the consultant in the afternoon.

A. That's right.

SIR BRIAN LANGSTAFF: As happened with you.

A. Yes, it happens every time at King's.

SIR BRIAN LANGSTAFF: You suggest that there should be a test offered to everyone so that, in similar words to the Government's AIDS campaign, not quite the same, people don't die in ignorance, the campaign says of ignorance but you don't want them to die in ignorance.

A. That's right.

SIR BRIAN LANGSTAFF: Was there anything I've missed that you would recommend as a positive practical measure?

A. Well, like I say, it's finding the people, offering them the choice, you know. Some people may not want to find out and live a nightmare but without the knowledge, you can't make informed choices.

If I'd had the knowledge, I would have chosen to be tested, I would have chosen to have got earlier treatment and in all the time that I was undiagnosed I was putting my family at risk unknowingly, I was

putting other people at risk.

As soon as I was diagnosed, I set in measures. Without a car -- if I went in a car journey there were gloves in the car and I've told people if I was in an accident I would rather bleed out than anybody come near me unprotected because I would not want anybody to go through the hell that we've gone through as a family and we are an ordinary family and it's happened to many other thousands of ordinary families and it shouldn't be allowed to continue to happen.

SIR BRIAN LANGSTAFF: Thank you very much.

A. Thank you.

SIR BRIAN LANGSTAFF: Ms Richards.

MS RICHARDS: Sir, we have one further witness today but our suggestion would be that we take our lunch break now a little early and then resume with the last witness after that.

SIR BRIAN LANGSTAFF: That also seems like a very practical suggestion. Let us do that and be back shall we -- it's now just about 12.00, so shall we aim to be back at 1.15.

(11.58 am)

(Luncheon Adjournment)

(1.17 pm)

SIR BRIAN LANGSTAFF: Ms Fraser Butlin, I think the next

witness would like to be known as Joan.

MS FRASER BUTLIN: She does, yes.

SIR BRIAN LANGSTAFF: Could Joan come forward, please.

JOAN EDGINGTON, affirmed

Questioned by MS FRASER BUTLIN

MS FRASER BUTLIN: Thank you, Joan. Joan, you, trained originally to be a secondary school teacher, didn't you?

A. I did, yes.

Q. Then in about 1987 you became a youth worker and then a centre manager?

A. Yes.

Q. And in 1989 you started a mountain leadership course?

A. I did.

Q. And became part of the Outward Bound team?

A. Yes. My original degree was a geography degree. I joined the Somerset youth team and landed up with a gruff phone call from somebody saying, "I assume you can read maps. Do you like the outdoors", and that's how that bit started.

Q. Can you describe for us your level of fitness at that point in your life?

A. As the only female member of the team, I'd been recruited because we get girls interested in joining the Outward Bound but they needed a female member,

I was able to, and did, maintain the same effort, work ethic and hours as any of the men. That includes climbing, kit, carrying kit, and working 24/7 with young people because that's what you do when you're outdoors.

Q. When you were outdoors what kind of activities were you leading?

A. It was a mix but the whole point really was for young people sometimes for the first time to get a chance to experience the outdoors. So we worked at their level. Sometimes for them it was the first time they had walked the countryside, some were on their way to becoming quite advanced climbers. Once or twice we included water aspects, you know river swimming and things, so you name it we tried it.

Q. Then all of that changed in December 1990.

A. Yes.

Q. When you were admitted to hospital with ulcerative colitis.

A. 1991.

Q. I understand that in January 1991 you underwent surgery?

A. Yes.

Q. Because the steroids weren't able to get on top of the colitis?

A. Yes, we'd come back from a field trip that summer in the Dolomites and from one camp site we'd all landed up with a tummy infection and just, basically, it didn't settle over the winter and my GP at the time did wonder if it was ulcerative colitis but I had had no history of any medical problems up until then.

Q. So you underwent a colectomy, removal of your colon?

A. Yes. The steroids didn't settle the bleeding. We had Christmas as a holiday and I was meant to rest. The bleeding got to the point where basically an ambulance had to turn up after Christmas and take me into hospital. I was on a medical ward and I forget the dates to be honest but a long time and they upped the steroids and were waiting for things to settle.

In the end it became apparent, I think it was after a good month, that it wasn't going to work and I was transferred to the surgical ward under Mr Collins, who was excellent, but by then my colon was so damaged it had to be totally removed.

Q. During that surgery, you received substantial quantities of whole blood?

A. Yes.

Q. Prior to the surgery, were you made aware of any risks involved in receiving a blood transfusion?

A. No.

Q. Was there any discussion after the surgery of any possible risks of infection?

A. No.

Q. You say in your witness statement that you:

"... now understand that by the time I had my blood transfusion there was a screening test for blood but it wasn't being used. There was a risk of infection and I wasn't informed. I believe that the risks of the blood transfusion should have been discussed with me at the point that major surgery was being considered. My understanding is that there were safe products that could have been used during surgery instead of giving me a blood transfusion but these would have cost the NHS more money."

A. Yes, absolutely.

Q. Is that still your understanding?

A. Yes. Actually, I just for the first time saw my medical notes about a week ago and I realise I also had transfusions before surgery because I was so weak. They had to build me up so I actually had transfusions on several occasions.

Q. You were then unable to work for about two years after that surgery.

A. Yes.

Q. You had some difficulties with the child support agency and you were campaigning against them in relation to some payments that you didn't want your husband, your ex-husband, to make to --

A. Yes.

Q. By 1994 though you had managed to return to full-time work; is that right?

A. Yes.

Q. Before I was ill I had been -- I'm not quite sure -- contributing to the Somerset Youth Service on lots of levels. I was part of a forum. I was part of training team, and when word got out within our network that I was regaining strength and fitness, because I was -- there's an interim bit. In the recovery from the surgery -- I left the hospital so weak and underweight because I had been in for three months, basically bed rest. I'd lost muscle tone and my style is to just roll your sleeves up, sort it out.

I went to homeopathy. I was building up muscle tone. I was getting fit, and really felt I was on a road to recovery. There were issues about stamina that I couldn't quite pin down, didn't quite know, and then I just thought, well, that's because my body's been through quite a trauma. It will come back.

But then in all of this and being seen out walking and everything else and friends said she's up and running again and it was actually the county officer that approached me and said would I work again.

Q. You managed that for a little bit of time but then your health deteriorated again.

A. It was a full-on job, managing a large youth centre that had had quite a few problems. So some of my working days started at 9 and finished at 12 -- not often but that was the process that if you were supporting an evening session when the youth club was open by the time I had driven home it was really late.

So you're operating on lots of levels. There was the physical demand, there was the sort of intellectual planning, meeting with committees, meeting with politicians, looking for funding.

Q. What were your symptoms at that point just before 1995?

A. I think in many ways it will sound daft but I felt quite lucky with retrospect that I had gone to a homeopath because I was paying more attention than most people would because I had been extremely fit and used to working through keep fit programmes, I think I was more aware than most people would be, and I became aware that if I pushed it, if I got tired, flu-like symptoms would be generated with no sense of having caught a cold. The sort of wanting to rest up at the weekend, normally if I had a nice weekend off I'd bounce back and be ready for Monday and that old familiar pattern just wasn't happening.

Q. You've described it as:

"... having general flu-like symptoms, aches and pains and fatigue. There is tired and then there is ill tired. Sleep wouldn't cure it. My lymph glands in my neck and armpits would flare up if I pushed myself too hard. My body seemed to overreact to coughs and colds and my glands would swell for no apparent reason when I was tired. I had been very resilient before the blood transfusion."

A. Exactly, yes.

Q. Then in June 1995 you received a letter from the South-west Blood Transfusion Service as part of a look-back exercise.

A. Yes.

Q. Paul, could we have document 0065002, please.

In this letter, if you just go down to the -- thank you -- in this letter you were told that the transfusion you had received may have been carrying the hepatitis C virus.

What did you do when you received that letter?

A. I'm assuming and I can't find that there was a contact number. I have a memory of having a number to phone to make an appointment.

SIR BRIAN LANGSTAFF: I think you may find it is there if you look at the letter, the paragraph second before last, which has got the letters "GRO-C" over it.

A. I see, thank you.

SIR BRIAN LANGSTAFF: "Please contact myself on ..." and for legal reasons that number has just been taken out.

A. Thank you.

SIR BRIAN LANGSTAFF: So your memory is absolutely right.

A. Thank you. Yes, so I made a phone call which seemed to be, in my memory, just a general number and you were making a general appointment; so no big deal. But I had to wait, again in my memory, well over a week for that appointment.

MS FRASER BUTLIN: Yes. You say in your statement I think actually it's two weeks.

A. Thank you.

Q. But it felt like a very long couple of weeks that you were waiting.

A. Yes, yes. There's so many layers to this when we're talking because I'm trying to remember what it was then and what I've learnt since. What it was then felt like a vacuum. There wasn't much information around. I didn't even know what this thing was.

I wasn't sure what the process now was, other than that I was making an appointment to go and see somebody. I didn't even know if that was for a blood test. I was just making an appointment.

Q. How did you feel during those two weeks? It was a vacuum but what was going through your mind?

A. The physical thing is just holding your breath. The mental process is all the what ifs. You know, I thought I was getting well, what's this? So I think for that very first bit until I had an appointment I'm literally just physically and mentally holding my breath.

Q. You have said that you know you had to be alerted to the possibility of being infected by a letter or a phone call?

A. Yes.

Q. But you think it would have been better if you could have had an appointment much more quickly, perhaps within 24 hours, than having to wait for two weeks.

A. Exactly, because not only did you wait for that initial appointment, which then did mean I met actually with a clinician in a white coat, though I can't tell you who it was, and a blood test, a sample was taken, but then you also have to wait for the results, so I believe it was about a month went by before it was actually confirmed that I did have hep c.

Q. You've said that you attended that appointment two weeks later and what was the attitude of the person taking your blood?

A. My memory is that it was just an appointment. Very pleasant, very polite. My assumption was that nothing's confirmed yet, this is just a process that, you know, a retrospective, not quite sure what that means.

I didn't then realise that if they've bothered to contact you it basically means you are infected, so I thought I was still yet to be confirmed.

Q. Then you went back for the results a week or a few weeks later and you were told you had hepatitis C. Can you tell us how you were told.

A. Invited into a room, sat down the other side of a desk. Again, a doctor saying, you know, terribly sorry to have to confirm it is hep c, and I've realised whilst listening over this last week, there's an interesting issue about the word "counsel". I've got my notes back now and I truly believe that the clinician that saw me felt he had counselled me about it. I would use the word "counsel" as in "informed". He informed me about toothbrushes and razors and said it might mean that I will need a liver biopsy and that ... that was it.

Q. When you left that appointment, having been told you had hepatitis C, did you understand what the next steps were going to be for you?

A. No. And I can absolutely say that because I remember sitting in the car park for a good half hour just not really trusting myself to drive and the only phrase going round my head was what now, what's this, what do I do?

I think -- and again I was pretty careful about keeping papers and things and I think I did leave with a leaflet in my hand and if I did, then that was where I heard about the British Liver Foundation, so I do believe they did do that, but the overpowering feeling was just "what now? What now?"

I should add to that at the time I was a single parent and very conscious I had two teenage daughters and all that goes with that, the mortgage, the job, the bills to be paid.

Q. We will certainly come to that shortly.

A. Thank you.

Q. You also then went to see your GP.

A. Yes.

Q. What was their response? What understanding did they have of hepatitis C?

A. Nothing really is the short answer. The longer answer is met with kindness and concern and, again, if I'm really honest, that chapter's quite a blur. But I was left with the impression that we were on cutting-edge medical discovery, that whatever this thing was, there wasn't a lot of information to hand and once I got through the initial shock of it all, my normal paternal of survival kicked in and I was just trying to find out, you know, who, what, when do I need to talk to, thank goodness for the internet, although that has some drawbacks, and that started a whole journey.

Q. But in terms of your GP you said he was a kind and supportive GP but he was the first to admit that for him this was new ground.

A. Yes.

Q. Then, as you say, you did a lot of research yourself into the condition helped along by your GP --

A. Yes.

Q. -- pointing you towards relevant websites?

A. Yes.

Q. You were never referred to a hepatologist but were seen by the gastroenterologist who was seeing you, in any event, in relation to the colectomy at this stage?

A. Yes. I actually realised that -- it's funny how you forget these things, until I saw the notes, I was between two hospitals, in the end Taunton where I was originally operated on, Taunton where I eventually had the treatment, and Yeovil my local hospital.

Within Taunton the consultant I was referred to turned out to be the same gentleman whose ward I had been on for a long time failing before I had surgery, so that was tricky.

Q. When you attended those appointments you took a lot of questions with you, didn't you?

A. I did.

Q. How was that received?

A. Not very well. I genuinely think I approached it in my usual style which is quite open. Both my GP and my Dad, who at that time was a great support, had counselled me to keep writing down questions as they popped into my head whilst waiting for the appointment. That turned out to be quite a list and I had tried to resolve some of the questions myself but I went in to, hopefully, discuss my concerns.

Q. What response did you receive when you went in with that list of questions?

A. Again, in absolute fairness to not only this particular gentleman but where the whole system was at the time, I genuinely think they did not have the answers to a lot of the questions I was asking. That was my impression.

I honestly can't remember what was said but I did come away feeling that didn't go very well and then since have found in my notes his wording --

Q. Which we're going to come to in just a moment but before we go there can you just tell us some examples of the questions you were asking.

A. Okay. Some of it was directly, you know, I've obviously been carrying this virus now for a period of time. I'm beginning to get information about its impact. There was I think at the time this phrase "slow burner", so to start off with the conversation, it was trying to be reassuring I believe and saying, yes, you know, people have lived with this for a long time and I was lucky to have been told early and I do believe that's true. But that stuck in my mind.

I was also asking about treatments and I was also asking about the impact on my children, you know, should they be tested and -- well, it was a longer list than that and I can't remember them all.

Q. That's okay. But you didn't particularly receive any answers to any of those questions?

A. No. It was admitted that I could get my children tested, although it most probably wasn't necessary.

Q. Before we come to the letter from one of your treating doctors, I want to look at something first to understand a little bit more of what your situation was at the time?

A. Yes.

Q. Before we even go there, can you describe how you were feeling in the sort of years of '95, '96 through to '98? What symptoms, physical symptoms, were you facing?

A. I work in images so bear with. Some of them are quite simplistic and I've heard other people use them so it's universal.

Partly trying to explain to my daughters, I found the image of a car. I'd got the car polished, it was fit, there was muscle tone but if I put my foot on the accelerator there was not the power there there used to be and that is how I was trying to describe stamina. It's also the flat battery syndrome.

Aches and pains for no reason, noticing joints were an issue. As I said before, my glands swelling, stiff neck, and the other thing, and I just hold on to this and for me it is a very specific thing, as a people-working person one of the greatest skills, one of the greatest gifts you can give somebody is to

remember their name.

If you are working with young, disaffected teenagers who are used to being "Oi you", to be able to go up to them and say, "Hi Chris, how's it going? How's the dog", or whatever it is you remember about them, I was losing that facility and I was putting that down to being tired. I've never really regained that facility in as much as I know that was a real skill and I have worked at putting that back. I have to write it down now if I want to really remember somebody's name.

Q. You were involved in litigation concerning the blood transfusion, subsequently, and some expert reports were written about you. I wonder if we can look at one of those now. It is document 0065010. If we could go down to the third paragraph, which starts at "As far as her present health ..."

It says there:

"Although she found she wasn't able to recover her previous levels of stamina, she finds she gets cyclical symptoms, which essentially the major component of which is lack of energy and mild general malaise. At times these are associated with a range of further flu-like symptoms, failure of body temperature regulation, some joint pain, dry skin. In

addition to this she suffers from low back pain. This is a pain in her lower back and shoulders radiating to he legs on occasion. It is usually present when she wakes first thing in the morning ..."

Then if we go to the next paragraph:

"She is able to do most things physically but she is unable to cope with the fairly strenuous physical exertion she used to do as part and parcel of her life and career prior to these episodes."

Is that what it was like?

A. Yes, yes.

Q. Then if we go over the page to the final paragraph:

"The fact that her liver is not particularly inflamed or scarred at the moment may indicate she has less of a chance of developing chronic liver disease in the future. I think her low back ache are probably not related to hepatitis C. However, it is well known that a large proportion of patients with chronic hepatitis C virus infection do suffer from quite profound general malaise and lack of energy. The cyclical nature of these symptoms in Mrs Taylor and the fact that she is otherwise a very sensible lady who clearly does try to push herself to the best of her ability would lead me to suspect that these symptoms are related to her continuing viral

infection."

That view wasn't accepted, as you have alluded to, by others who were treating you, was it?

A. It's really difficult to shuffle the time zones but it did feel that if you were talking to a specialist versus a nonspecialist there was quite a gap in the understanding. I think that's fair to say.

Q. You said it wasn't just a gap in understanding, it was also a gap in attitude.

A. Yes, yes.

Q. Can we look at 0065008, please, and the third paragraph "She expressed herself ...":

"She expressed herself rather put out that I do not attach such importance to her non-specific symptoms as to have reported them to some central authority responsible for hepatitis C. I have explained to her that her symptoms are very non-specific and of low discriminant value, probably occurring in up to 30 per cent of most patients with most diseases attending my clinics."

That's what was written to your GP at the time unbeknownst to you?

A. Absolutely.

Q. But I think you have said that was representative of the attitude that you were facing at this time?

A. And it's interesting to see the response to my list. That top one:

"She was emotionally a bit more stable, although still very intense."

That means I came in with a list of questions.

Q. How did it make you feel when you attended those appointments and were faced with that attitude?

A. If I hadn't had a really kind, caring GP I would have really struggled because at the time the information on the net wasn't that brilliant either and it was very easy to get drawn into chat groups that were being extremely negative. Yeah, thank goodness for my GP.

Q. Having obtained your records recently, you've also found another letter. Could we have up 0065009, please. This is letter is dated 3 July 19 --

A. Do you mind can I -- I hang on to thoughts rather fragilely and I was going to save it to the end but, Sir Brian -- it's going now because it's important. Let me look at my notes.

Part of the thing that I have continued to struggle with is the so-called non-specific symptoms. I totally understand that a medical professional person cannot take action until there is clinical evidence. What I'm beginning to understand is if

nobody is recording all our non-specific post treatment, post infection symptoms, there never will be any clinical evidence.

So there's a whole bunch of us out there going to specialists, going to different departments, trying to describe our symptoms over and over again, only to have, quite rightly, these physicians saying, well, it isn't whatever their specialty is, I can't help you. So I personally over the last few years have been to rheumatology, I do not have lupus. Thank you. I didn't think I did.

I was -- yes, rheumatology. I was under haematology because my platelets spiked very high after a kidney infection. I was within a fortnight of taking chemo for a leukaemia-related illness and then my platelets dropped of their own accord. It was just my body overreacting to three lots of antibiotics due to the kidney infection.

If there was somebody somewhere, please, recording and cataloguing the evidence we now have of possibly -- I will say that, possibly -- permanent post interferon or post treatment and post infection, that would be such a help.

Q. Just to pick that up with you, Joan --

A. Sorry to drop it in there but I was scared of losing

it.

SIR BRIAN LANGSTAFF: Just give me one moment. Yes, thank you very much.

MS FRASER BUTLIN: Just to pick that up, it's a little bit more than that, though, that you have had, isn't it? In 2010 you had a possible transient ischaemic attack, mini-stroke.

A. Yes.

Q. 2013, you had a kidney infection requiring three courses of antibiotics. That's when you had the very high white cell count and abnormal bone marrow biopsy?

A. Yes.

Q. And the doctors thought you may have some form of leukaemia?

A. Yes.

Q. And December 2017 you had what seemed to be like flu but you were then left with very severe fatigue thereafter.

A. Yes.

Q. Since then you've been unable to work --

A. Yes.

Q. -- because it's been so severe.

A. Yes.

Q. You don't know whether they are related to hepatitis C but you wonder, as you said, whether there is a link

either with the hepatitis C or with the treatment you've received.

A. Yes. Sorry to interrupt the flow.

Q. Not at all. It's such an important piece, Joan, I want to just read part of your statement and ask you to confirm it or comment further on it. You've said:

"Whether these symptoms and others were as a result of the interferon or the hepatitis C I do not know. I just know that I have not been well since the blood transfusion and I used to be a very fit and determined person. I knew that the treatment had side effects but the possibility of long-term or possibly permanent side effects were never discussed with me. I know that there was enough research in the US for them to have doubts about the treatment and I am not aware of any information being withheld from me but if you don't know the questions to ask, it's difficult to say."

You now reflect whether you would have pushed so hard for the treatment if you had known about the effect of it in a longer term sense; is that right?

A. Yes, and thank you for that prompt.

Nothing happens in isolation and if I just give you a thumbnail sketch, I knew I was infected, I was aware it was impacting on me in unknown ways. I was a single parent. My Mum died when I was 22/23. I had two girls approaching that age and I was just absolutely determined to be well.

So with the help of my very supportive GP, we were looking for treatments. I even started looking at what it would cost to do that privately because I was aware that all the treatment seemed to be linked to trials and then it was just pot luck if a trial was being run in your area and you qualified for the treatment.

Through my GP, he heard of a trial that originally was a three-drug treatment and I just missed the boat. That was closed.

Then Taunton were given the chance of running the interferon Ribavirin treatment and originally I had had a biopsy that had shown I'd been impacted by hep c but if I wanted to qualify for this chance on this treatment, I would need another biopsy, which is not a pleasant process.

We went through that and found that my scoring was just below the benchmark to qualify for the treatment. So, again, was I going to get treated? To this day, I'm not sure why but I did get on the trial. I think it's partly because I was pushing so hard and keen but mainly because somebody dropped out because

they were too ill.

Now, my logic, and my GP had agreed, was if you can have the treatment early enough it's going to be more successful, if only because your body is able to cope with the treatment. A lot of the trials, people had to be really ill to qualify for and these treatments are tough or they were, but for whatever reason I got on the trial and I felt very fortunate.

Q. Before you got on the trial you say:

"I began to get angry with the mindset that it was somehow okay to get hepatitis C because it would not kill you. That was coming from people who didn't have hepatitis C."

A. Yes. I really think -- at one point I do remember meeting this particular brick wall again and being made to feel almost neurotic that I was trying to push for treatment. I did have it explained to me that there was only a 50/50 chance, that it is tough, that there were side effects and even today they use the term long-term side effect but the implication that that is only within the treatment and then a recovery period. I have yet to find mention of permanent side effects.

Q. You got on to that trial and it was 52 weeks of interferon and Ribavirin that you underwent.

How did you feel physically during that treatment?

A. In a way coming here this week and listening and it is also something that's part of this whole fabulous process is the validation. It was tough. I started off again relatively well bearing in mind my heart goes out to half the people I've heard just because they were so poorly by the time they were facing these treatments. They had been living with liver problems.

I truly mean it when I say I was lucky. If it had to happen, I was lucky that my liver was still healthy because I managed the first four -- yeah, the first four weeks I was thinking, "I can do this".

I'd enrolled on a part-time art course, save my sanity, always wanted to do art. You get into a routine where you inject yourself once a week and you've got tablets to take. The interferon, the injection would give you flu-like symptoms which other people have confirmed and I worked out a system where I knew that I would be feeling rough for at least three days. I did home-made soup, fresh bread, had that in the fridge so limited effort in eating. I was -- there's a whole chunk, isn't there. There's layers and layers to this.

I was by then living on my own by choice. Both

my girls, thank goodness, were off in their independent life, uni ... I deliberately didn't want them to know because I did know this was going to be tough and, in a way, I apologise now because they're catching up.

Yeah --

Q. They were out of the house?

A. Exactly.

Q. You would fill in fridge with soup and bread?

A. Yes, yes, totally doable I felt.

Q. At what time would you give yourself the injection, Joan?

A. One of the elements of all of this that caused me distress was the lack of control. So I played a bit of a game where I could go right up to midnight before I injected myself. That was my choice. I had the choice when on that day I would inject myself and it's silly to say it now but for some reason that seemed important.

Q. Your statement says:

"I used to wait until one minute before midnight to inject myself."

A. Yes, yes, and then you go to bed and that's also a way or short circuiting the not feeling so well because hopefully you're asleep.

Q. You love to read, don't you --

A. Yes.

Q. -- Joan, but during the treatment there were times when you couldn't even do that.

A. I started this trial with a group of people, some of whom just had to do the six months and I do remember getting to six months and realising I had a whole other six months to go and that was bleak. By then my body was really struggling.

I think technically my platelets and everything else that they looked at were fine. My body was obviously under stress but there was no clinical reason to stop, so I was determined to keep going. But by then the symptoms had intensified.

My eyes -- I wouldn't need another prescription but the ability to focus, fine focus and read, would come and go. So I couldn't get lost in novels which when I was really poorly was something that was something I liked to do.

Q. So you've described setting up a chair in front of the window where you could simply sit and look out at nature.

A. Yeah, and that was another thing. Part of the contraindications is you've got to be very careful about sunlight and I keep myself sane by walking and

being out in nature. So if I went out during bright sunlight it was hat, long sleeves, sunscreen, or -- and I thought this was quite smart -- I'd go out really early in the morning or in the evening but there were times when I needed to be outdoors but couldn't really walk. So then the next best thing was to sit by the window.

Q. You also had substantial hair loss and numb toes and fingers and you still have some residual partial numbness?

A. Yes, and the hair hasn't grown back on the nape of my neck. It's a minor thing but when people then say there's no evidence of permanent damage, actually there is. Perhaps we're just not looking in the right places.

Q. Emotionally, it's been very difficult as well and more recently you were seen by your GP and a counsellor and they diagnosed you with PTSD. Do you feel able to say any more about that?

A. I do and this is what I mean about life -- things don't happen in isolation, do they? Goodness knows how this set of combination of events could ever have come together but [redacted], he was on holiday in Somerset, became critically ill with pancreatitis and landed up in the hospital that not only I was operated

on but that I had my treatment in.

The impact of the stress of worrying about him, I think, was part of the trigger but I did walk down a corridor -- most -- quite a lot of the hospital is now changed so I approached the hospital and it felt like a new place but every now and then you turn the corner and you're in the same old corridor and I'd never experienced this before but it isn't even an intellectual process, it's a sheer body impact of -- it manifests as shaking and sweating, a sense of dread and you don't quite know where the danger is coming from.

I thought, perhaps I was -- well, I didn't know what I thought. I had to go sit in the loo for a while. That happened on one occasion when I walked down a corridor and then I realised it had been my route to the chemo ward, which is where my treatment had been run.

Then another night I was with [redacted], who was actually sleeping quite peacefully. But he has learning difficulties, so we had to -- or we took rota change so that if he woke up, he wouldn't start pulling out his tubes. That was fine. We were dealing with that. But then the crash button alarm went for somebody else and just that noise ... I had

another visit to the toilet to shake.

Q. You have had some counselling. You've had three blocks of counselling over the years but, on each occasion, there's been a very long wait between the referral and actually getting to see the counsellor.

A. Yes, yes.

Q. I just want to go back to when you were undergoing the treatment. You claimed Incapacity Benefit while you were undergoing the treatment and, for the year after, when you were recovering and you were required to go for a medical assessment during that time.

Can you tell us what happened during that first assessment.

A. The first assessment, I believe, was after the six-month benchmark. So I know I'm struggling. A friend very kindly drove me to the appointment and it was a tremendous effort just to get there, and I got ready for the battle, went in and was actually seen by a GP, and I don't know if everybody is anymore, and the first thing he said as I sat down is "I'm terribly sorry, had I seen your file before you would not have been called in", and I'd been ready for a fight and there he was being nice so I burst into tears.

Q. What did he advise you do?

A. He advised that I talk to whoever was in charge of my treatment and get them to write a letter.

Q. Which they did?

A. They did.

Q. But you were still called for a second assessment?

A. Yes.

Q. The DWP insisted on assessing you during the year you were supposed to be recovering and you found the whole benefits system horrendous?

A. Yes. I ... I have professionally supported people claiming benefits and been their supportive other and seem them struggle. I'd never expected to be in that position myself. At best, even if you are treated with common courtesy and politeness, it is a difficult place to find yourself in but I did on one occasion have quite a difficult conversation with a woman who basically said, "Well, it's not chemo, what's the problem?"

Q. You've said:

> "I hadn't perceived myself as having a lot of pride but the one thing I did pride myself on was being resilient and I found the whole process of applying for benefits and attending the assessments really demeaning."

A. Yes.

Q. A year after you had finished treatment, you couldn't face another assessment and so you decided to find some part-time work. You went to your GP to ask when you'd receive confirmation of having cleared the virus because you had cleared the virus --

A. Yes.

Q. -- and whether you had to tell employers about it.

What else did you say to the GP at that point?

A. Do you know, I've got sidetracked by some memories so I'm not quite sure what we're referring to there.

Q. That's okay, don't worry. You've said in your statement you also asked "Who's going to employ me now?"

A. Oh, yes, bless him. If I put that all into context, I had -- having had to give up the youth work post and whilst I was waiting for treatment, I'd cobbled together various jobs and I had found one project job that I'd really loved and then I'd had to give that up because of the treatment.

There was a real issue for me about employment because I have people skills, I work for the Government in teaching, youth work, and the criteria about offering up your medical history is just a given.

Prior to this completion of the treatment, I'd already experienced issues about having hep c, feeling that I would have to declare it, and I know because it's a small network within the people-working field that there's at least two jobs that I didn't get because of hep c.

So here I am out the other side of a really horrendous couple of years, talking to my GP and just basically saying, feeling, I had this battle again. At what point -- you see, sorry, I'm interrupting myself but one of the hard things with the treatment, you do not get a certificate and well done madam you are now clear. We slipped into a limbo of we have to wait to see if it might not come back. So it was years before I actually got to the point where I could say I have absolutely cleared hep c.

Q. But you went to your GP to ask that question?

A. I did.

Q. And said, "Who's going to employ me now."

A. And he said he would.

Q. So you went to work for the GP as a receptionist in the surgery?

A. *(The witness nodded)*

Q. You've since had to give that up because the fatigue is simply too much?

A. Yes. This is now a different surgery and I've moved and things have happened but because of that kind man, I had another career in which I was accepted. I've only ever been able to work part-time but I have worked through every single health thing until now and, yeah, it was a job. Believe it or not it was a job I enjoyed because I was the right side of the table to deal with people who were struggling.

Q. As you spoke a moment ago, you alluded to having tried to apply for work involving young people in the 1990s in that hiatus between having been diagnosed and having your treatment and not getting those jobs.

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

A. I found myself in the position where I wasn't too sure about my health. There was quite a lot of project work going on at the time and I applied for one which would have been short-term and was, in fact, basically overqualified for, knew somebody on the panel who afterwards very kindly took me to one side and said, "You were doing really well. It was just the question of your health".

Actually, I took that on the chin because I thought that particular project, maybe that was fair. It would have been really intense. So the next job I remember applying for would have been I think it was two days face-to-face and a day admin reporting for whatever it was, 18 months, and I think it was somebody on the panel actually raised the question of my health and energy, which surprised me but thinking on my feet I said, "Thank you very much for asking that question because I can affirm that I'm doing okay", or words to that effect but, no, I didn't get that job either.

Nobody actually said anything like are you infectious, are you this, are you that, but it was definitely an issue.

Q. But off the record you were told that you'd not got the job because of your hepatitis C?

A. *(The witness nodded)*

Q. As you say, you went to work for your own GP after treatment?

A. Yes.

Q. For your own GP as a receptionist, then on to other similar types of part-time role?

A. Yes.

Q. You have obviously never returned to the Outward Bound youth work --

A. No.

Q. -- because of your ill health and you have said in your statement:

"It took me a long time to let go of the hopes and dreams that I shared with my peer group. You play the cards you've been dealt and make the best of everything, but it's hard not to grieve about what could have been."

A. Yes. Again, if I use some imagery, where I am now on lots of levels I count my blessings regularly but it's within the context and the image in my head for a long time, I don't know if anybody ever saw it, was of somebody trying to cross the Grand Canyon on a tightrope.

As long as I remain balanced (so not overdo it, not overstress, not overcommitted), I can remain upright and have a pretty good life with a lovely view. But it takes effort even just to do that, of concentration, of monitoring, of keeping as steady as I can, and my family will know that's quite tricky because I'm quite a spontaneous person and likely to say yes when I should say no to stuff.

I'm now of a certain age where just becoming older is having an impact. Where in the past a bit of determination, a bit of steady keep fit, watch your diet, everything else, would see me through.

The reason I'm not working now is I had bad flu 2017 and it's taking me this long to get to a point

where I can commit to maybe going away on holiday because what you deal with all the time is just not knowing quite how the day is going to end. It is incredibly easy to overdo it.

If you can manage to just deplete yourself and deplete yourself but stop, then yes rest and I can just about get on with the next day. If for any reason you have to push yourself like going home tonight is going to be tricky because I do not know if it's a long journey, we get delayed. If I go into what we call deficit then that's a week in bed. Am I glad I'm alive? Yes, I am and so many -- so, so many -- aren't.

Q. That impact -- that hasn't just impacted you. It's impacted your daughters as well. You have said in your statement that your eldest daughter thought she had taken it all in her stride but she had left home by then.

A. Yes and I need to say now I can't answer for them and I would encourage them to make a statement because with all honesty I don't know the impact it's had on them.

Q. But from your perspective you have watched them have a mum who's not been well?

A. I tried really, really hard to save them most of the

story. It's hard enough for no reason of your own to be deflected from a career where you really felt you were making a difference. I put makeup on. I can't cry.

It is hard enough to be deflected from a career that you really put effort into choosing, training for and felt you were making a difference, but then to not be able to be the parent and grandparent you had hoped to be is beyond -- I can't give you the words for that.

Q. I want to go back to somewhere that we were talking about a little while ago and pick up something you said before. Earlier when you were talking to us, you said that you wished that somebody had looked more broadly at the long-term permanent impact of the hepatitis C?

A. Yes.

Q. You have since more recently had copies of your medical records and in those records there was a document we can have up, 0065009. It's dated 3 July 1998 and can we highlight the first paragraph to begin with.

This is a letter from a doctor to your -- sorry, let me double-check before I say something.

A. I think this was to the consultant.

Q. That's exactly, it's to your consultant -- apologies. It's to your consultant and it says at the top:

"As relatively little is known about HCV infection, transmission or the clinical course of the resultant disease, a national register of HCV infections is being created ... funded by the Department of Health and will provide a facility for the future monitoring and long-term assessment of HCV infection within the UK."

Then the third paragraph, please, Paul.

"I have enclosed an information sheet explaining the purposes of the registry which you may like to pass to your patient. No patient will be contacted directly. However, this information sheet has been provided for clinicians who feel they would like to notify their patients of their inclusion in the register."

It is explained that the register will include information on all patients who have become infected with hepatitis C on a known date and it will gather information on other people who are definitely not infected.

Were you ever informed that you had been added to the register?

A. No.

Q. Or even as to the existence of the register?

A. No.

Q. If we go over to the third page, third paragraph, it says:

"The National Register will gather information. When The Public Health Laboratory Network identifies a patient who could be included in the register, they will contact the doctor who cares for that patient and invite them to include their patient in the register. Your doctor can then pass information but not your name from your medical records to the register in order to advise us of your state of health. He or she can also keep us updated with your progress."

Were you ever told whether further information about you from your medical records has since been passed on?

A. No. But this piece of paper then made sense of something else that had happened in my life, in that I was approached in about '94 -- no, it must have been after '96, whenever it was -- by the group that were taking that first action that eventually ended in the Skipton Fund and I did join in that process but I at no point had looked to join. Life was too full. I wouldn't -- it had not even crossed my mind to look at sort of litigation or anything. So somehow somewhere my name had been shared and I don't remember even how I was approached, whether it was a telephone call -- I eventually had a letter and liaised locally with Clarke & Son and they were linked with whoever was organising the action.

Q. Your belief is that the lawyers found your name through the HCV register?

A. As far as I know, that's the only register I'm on. So I would assume that is the link.

Q. But you've never been told that you were on the register?

A. No.

Q. And you have never been told that your medical information is being provided to anyone else?

A. No, I'd not seen that paperwork before I saw my notes.

SIR BRIAN LANGSTAFF: Just by way of observation, the information sheet says the register itself is totally anonymous as no names are recorded within it. If that is correct, then it could not have been the source of the information. It must have come from somewhere else.

A. But the other letter shows that the GP holds the code still; so, yes, I honestly don't know. I don't know.

SIR BRIAN LANGSTAFF: Thank you.

A. That's the only register I'm aware of where my information has been shared.

SIR BRIAN LANGSTAFF: Somebody somewhere passed your name to the person who wrote about you, plainly.

A. Yes. To be honest, I had no sense of the significance of that at the time.

SIR BRIAN LANGSTAFF: Just as a matter of interest, I don't know if you are able to tell me but was this before or after the coming into force of the Data Protection Act?

MS FRASER BUTLIN: It's just around about the time the Data Protection Act was coming into force. I'm looking behind me to Mr Lock because we raised that exact point between us yesterday.

MR LOCK: Sir, I think the Data Protection Act was passed in 1998. I am sure it was passed in 1998 because I was there when it was passed, and it came into effect in 2000, so this letter was sent at a time when the directive was in force and, obviously, this is a Government body and, therefore, it's of direct effect but before the implementing UK legislation was implemented.

SIR BRIAN LANGSTAFF: Thank you very much.

MS FRASER BUTLIN: At the very least in your own mind there are questions about how your name came to find its way to somebody else in the litigation field.

A. Yes.

Q. Financially things have been difficult for you and particularly in relation to having to claim benefits and not being able to work to the extent you would have liked.

Have you ever applied for insurance?

A. No, is the short answer.

Q. Why not?

A. Part of the reasoning that I even joined the original litigation was that I became aware how little I knew.

One of the useful bits of information -- and I do mean that -- that came through was -- and this is me, my interpretation of what I read -- was hold fire on requesting any insurance because within the time-frame historically the hep c was being lumped in with the HIV and it was the time of all the negative publicity and I was informed that insurance companies were counting them as one and the same, and if I had a refusal on an application, that would carry forward to any other application.

Q. In terms of financial assistance, you've received a payment from The Skipton Fund?

A. Yes.

Q. But then you weren't aware of the England Infected Blood Support Scheme until the Inquiry was announced.

A. Yes.

Q. How did you come to hear up hear about it?

A. Thank heavens for Facebook and the networking.

I dug out my folder that still had the Skipton information and emailed just wanting to know what the current state of affairs was and within that -- and I didn't think to print it off -- it was basically stated they hadn't passed on my information to this new body because I had never granted them the authority to do so, which is good. But then they didn't contact me to tell me they needed my authority; so nothing got passed.

Q. How did that make you feel?

A. I realise I must be quite punch-drunk with all of this now because I just remember laughing. I mean, how ridiculous is that?

Q. Since then, you have applied to the EIBSS --

A. Yes.

Q. -- and have received some payments but how do you feel about the process of applying for financial assistance?

A. It feels like the benefit system again in that, above and beyond the basic payment, anything else you need to fill out forms, you need GPs to qualify and state how ill you are or not. It comes back to one of my

original points which was this thing of if nobody is recording our chronic fatigue-like symptoms, there is no recognition of them as a condition. If you don't tick the right box on the conditions list, then you don't get benefits, you don't get the next notch up.

Q. You've described the process as:

"... incredibly humiliating and demeaning. My feeling is if they have decided we qualify for some kind of compensation support, they should stop making us jump through the hoops to get it."

A. Yes. You're left in this position where if -- to be left with any modicum of sort of dignity, if I go out of my front door, I hold my head up, I dress well and I try and present well. If you turn up at a benefit office like that, you're immediately disqualified. So what do I do? Do I then go in still upright but then tell them of the bad days? To tell them of the bad days is doable but you're talking to a stranger, you're talking to somebody who has no concept of what I mean when I say I'm having a bad day. To them, that maybe means they stubbed their toe. To me, that means I'm in pain, my joints ache, I'm potentially running a temperature. If I push it, I will get the shakes. If I push that beyond that threshold -- I have issues with body temperature regulation, so I can go cold or

hot. If I push that, then I'm in bed.

Q. You feel that the process to obtain payments or different levels of payments from the EIBSS is the same system and requirements that are on you then?

A. Because they are looking for the same clinical tick-box exercise and, no, I do not have lupus and no, I do not have ME and no, I do not have MS. "I cannot tick your box for you, madam" is what I land up saying but, no, that does not mean I'm fit to work.

Currently, I've worked really hard to get back to a certain level of fitness. The only reason I haven't been able to return to my job is what I cannot do is guarantee to you that every morning for my 9 o'clock shift I can turn up and do five hours.

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

A. Thank you.

Q. I am just going to turn my back and ask Mr Lock if there's anything else.

(Pause)

Just one more thing, Joan, Mr Lock would like me to raise. Do you feel anyone should act as a care co-ordinator given that hepatitis C produces so many different symptoms?

A. It loops back, Sir Brian, to what I was trying to say.

I don't quite know how we resolve this but just by the sheer weight of numbers -- thank goodness for this Inquiry that so many people are able to come forward and tell their stories -- but just in this first week I've heard enough, I've had enough personal validation around these non-specific symptoms that has no label but that I begin to feel is connected with either the impact of having had hep c, even if it's now clearing, and/or the treatment that I had to clear it.

If there is no one body or anybody ever trying to collate that information, it remains anecdotal. If it remains anecdotal and not clinical, it can be disregarded by the benefit people and everybody else.

MS FRASER BUTLIN: Can I just take a moment, sir, to check one other matter. *(Pause)*

There's a second matter that I think I did ask you but we can't instantly find it on the transcript; so if I have, I apologise.

Now you know about the data being passed to the National Register, how do you feel about the NHS having data about you?

A. That's a good question. There are so many layers to everybody's story. Fundamentally, I do not want to damage the NHS. I am no longer angry.

What I would like is to know that things are

done with integrity, that the core of it is caring for the patient. So to say "no, there should be no registers", no; but please ask us, please let us know why and what's going to happen to it. Because that was another thing, actually, that it's just reminded me. I joined the medical trial because I wanted to be well but then had a naive expectation that I would get some idea of feedback. How did it go? What was the outcome? What were the results? I was quite surprised to get the impression that even the people processing me through this didn't really quite know where the information was going. Maybe the consultant did but the person that you see on your day-to-day clinical how are you, whatever, and I did ask several times just out of interest, no other reason, you know, did it help? What were the results? Never found out.

MS FRASER BUTLIN: Thank you.

SIR BRIAN LANGSTAFF: Joan, can I just say this: a number of times during your evidence you've been reminded of something. It's obvious that you have a lot in mind which you haven't perhaps yet told us or remembered. If when you go home tonight or over the next couple of weeks if you follow the Inquiry, or even if you don't, something occurs to you which you would have wanted to say --

A. Oh thank you so much.

SIR BRIAN LANGSTAFF: -- please don't think that the time has passed. Let your solicitors know. Mr Lock and his team will forward that on to the Inquiry. It will be in writing, because that's the way we take material, but there is always space for you to add --

A. Thank you.

SIR BRIAN LANGSTAFF: -- because it struck me that you might have things that you wanted to add and they slipped your mind as you've been telling us.

A. Thank you, because ... the one word I didn't use, partly because everybody else has: brain fog. It's amazing what the trigger will do that will then anchor me back to something and I had not seen my notes until recently and that in itself then gives me more information that I can recall.

I did personally an exercise of a time-line on a spreadsheet because part of the survival of the treatment and the process was to block it. So for a long time there was me and I'm okay, I'm surviving, and there was my poor old body having a heck of a time. It's only when I do this spreadsheet and think, my goodness, at that point in the treatment I was also dealing with X, Y and Z. So I'll carry on with my spreadsheet and I sincerely thank you for

that.

I'd also like to thank your team. Goodness knows how you sit through all these stories. Bless you.

SIR BRIAN LANGSTAFF: It's us that should be thanking you for telling yours. So let me do that now: thank you very much for what you have said and what you may yet say.

A. Yes, thank you.

SIR BRIAN LANGSTAFF: Ms Fraser Butlin, that concludes the evidence for today and indeed for this week.

MS FRASER BUTLIN: It does, sir, and then on Tuesday we will have three further witnesses.

SIR BRIAN LANGSTAFF: Now, can you tell us who they are.

MS FRASER BUTLIN: We have Lauren Palmer, Fiona Rennie and Michelle Tolley on Tuesday.

SIR BRIAN LANGSTAFF: We will start then at 10.30 on Tuesday. I've already told you that we will start at 10.30 next week. There's a slight change to that. Let me explain: it's going to be 10.30 on Tuesday; 10.30 on Wednesday; it will be 10.00 on Thursday, that's for reasons of witness convenience; and it will be 10.00 on Friday. That's because I know that some of you may well be staying over and it makes it easier for you to get home in time for the weekend.

So 10.30 Tuesday/Wednesday, 10.00 on Thursday/Friday. Thank you very much. I look forward to seeing as many of you as would like to be here on Tuesday.

(2.40 pm)

(Adjourned until 10.30 am on Tuesday, 7 May 2019)

I N D E X

F:

F: