

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?

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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

3

**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 when 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

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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?

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- 1 A. This was about when I was eight or nine there was  
2 a risk of non-A non-B but it was just it was nothing  
3 to worry about, it was nothing more than a cold,  
4 pretty much like hepatitis A, but nothing to worry  
5 about. It's just like a bad cold. You'll get over it  
6 and carry on.
- 7 Q. Now, you don't know, obviously you were very young at  
8 the time, exactly what products or what time period  
9 led to you being infected?
- 10 A. No.
- 11 Q. But if we just look at the records. Can we have  
12 1057004, please, Paul.
- 13 These are records that you've obtained from the  
14 Oxford Haemophilia Centre; is that right?
- 15 A. Correct.
- 16 Q. We can see here time periods from 1981 and we don't  
17 need to look any further than this period, I think,  
18 that we've got on the screen now, 1981 through to  
19 1983. We can see in the box type of material, you  
20 were being given something called 9D and then I won't  
21 ask you to look at all the detail of it, Matt, but  
22 a point in time comes in about 1986 you start to be  
23 given something called 9A and then later on again the  
24 product name changes?
- 25 A. Yes, correct.

5

- 1 knew the risks involved and my parents weren't told  
2 that I had it until many years later, so yeah.
- 3 Q. I think you put together the fact you were treated at  
4 Oxford, at this particular haemophilia centre by the  
5 these particular consultants, that you were young --
- 6 A. Yes.
- 7 Q. -- so the chances of you having been exposed to  
8 anything else were very small?
- 9 A. Yes.
- 10 Q. And that you received in this critical period in the  
11 early 1980s a very large amount of Factor IX  
12 concentrates?
- 13 A. Yes.
- 14 Q. And your belief that you've set out in your statement  
15 is you might have been used as a guinea pig to test  
16 the effectiveness of the developing processes of heat  
17 treatment.
- 18 A. Exactly that.
- 19 Q. It's my understanding, Matt, that it's important to  
20 you to try and find out if that is the case or not.
- 21 A. Yes, of course. I'd like the people or person, if  
22 that is the case, to be held accountable for what  
23 they've put me and more importantly my family through.
- 24 Q. You have not pulled the punches in your statement,  
25 Matt. You have said you think your parents were lied

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- 1 Q. You have said in your statement that you think you  
2 were probably exposed to contaminated concentrates at  
3 some point between 1981 and 1984. What's the basis  
4 for you thinking that that's the likely time-frame in  
5 which you were exposed?
- 6 A. Because the treatment improved from 1985/1986 but I'm  
7 not -- I don't know, I don't know. It can't be proved  
8 either way the exact date but I believe because of the  
9 heat treatment that came out in '86 that it was  
10 probably before that, so '84/85.
- 11 Q. You have also set out very clearly in your statement  
12 your view that you may have been what's been referred  
13 to in some material as a PUP, a previously untreated  
14 patient?
- 15 A. Yes.
- 16 Q. What's the basis for that belief, Matt?
- 17 A. I was very, very young. If my parents were told the  
18 risk then they wouldn't have given me the factor  
19 that's caused so much damage, that there was no need  
20 for me to have factor. My parents weren't told about  
21 the risks of it but, yeah, I've seen records which  
22 show that various people in the profession knew the  
23 risk from 1979. They knew the risks were there, they  
24 were live, but I was still given this product.
- 25 My parents would never have given me if they

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- 1 to.
- 2 A. I can tell you now, hand on my heart, my parents would  
3 not have given me that medication if they knew the  
4 risks. They enquired about taking me to Wales to get  
5 a different sort of treatment. Later on my Dad looked  
6 about paying for it himself personally, so there is no  
7 way my parents would have given me that medication if  
8 they knew the risks.
- 9 Q. There came a point in time in which your parents were  
10 told that you had been infected with hepatitis C.
- 11 A. Yes.
- 12 Q. If we could have on screen, please, Paul, 1057005.
- 13 We can see this is a letter from the Oxford  
14 Haemophilia Centre dated 18 June 1990 to a haematology  
15 consultant, a Dr Miller, in Milton Keynes and we'll  
16 see from the last sentence of that, if you could just  
17 highlight that, please, Paul, "we found him ...":  
18 "We found him hep c Ab positive from a sample  
19 taken last September."
- 20 So we've got this letter June 1990, reference to  
21 a sample being taken in September 1989. Your  
22 statement says that it was in January 1992 that your  
23 parents were first informed that you had hepatitis C.
- 24 A. Correct.
- 25 Q. Were you ever given or were they ever given any

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1 explanation as to why there was a significant delay  
2 between the testing and the knowledge that doctors had  
3 about your infection and your parents being told of  
4 your condition?

5 A. No.

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

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

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

12 A. Yes.

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

15 A. Correct.

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

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

23 Q. Between September '89 when it looks as though the  
24 sample was taken for testing and January 1992,  
25 27 January 1992 is the date your statement gives when

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

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

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

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

17 A. Yes.

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

19 A. Correct.

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

22 A. Correct.

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

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

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

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

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

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

21 A. Yeah.

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

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

10

1 your statement.

2 A. Yes.

3 Q. You were told what?

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

12 Q. You were being treated still at Oxford?

13 A. Yes.

14 Q. In England?

15 A. Correct.

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

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

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

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1 screen. It's 1057006.  
 2 It's a letter dated 20 September 2004 and it  
 3 provided information about possible risks of vCJD. Do  
 4 you recall receiving that letter?  
 5 **A.** No, no, I don't. I'm blessed to have an amazing  
 6 family and my parents hid that from me because they  
 7 knew that with what I'd been through with haemophilia  
 8 and other infections they thought that might push me  
 9 over the edge, so I did not receive that.  
 10 When I went to the Oxford Haemophilia Centre for  
 11 my next check-up I was informed by a doctor that I had  
 12 this, that -- I had been told that I am at risk and  
 13 obviously it wasn't ideal.  
 14 **Q.** If we just keep this letter up on screen but we go to  
 15 the second page, please, Paul, we'll see under what  
 16 has happened there's a reference to product recalls  
 17 after donors had been found to have vCJD and then it  
 18 says this:  
 19 "We're writing to you to give you further  
 20 information about these and about further batches that  
 21 had been made using plasma from donors who later  
 22 developed vCJD ..."  
 23 Then over the page, please, "Who is affected?"  
 24 Top of the next page, Paul, could you just highlight  
 25 that.

13

1 out", just highlight that.  
 2 So this letter said:  
 3 "If you would like to find out whether you have  
 4 received any of the implicated batches or you wish to  
 5 discuss this further with us please indicate this on  
 6 the reply sheet."  
 7 You decided you did want to find out --  
 8 **A.** Yes.  
 9 **Q.** -- whether you were just generally at risk as someone  
 10 who had received clotting factors or whether there was  
 11 a more specific and focused risk in your case?  
 12 **A.** Yes. Against my parents' wishes, because obviously  
 13 I had been through enough in their opinion, they said,  
 14 "Look, don't worry yourself with it. What will be  
 15 will be", but, yes, I chose to find out. In  
 16 hindsight, probably the wrong thing to do.  
 17 **Q.** If we look at, please, document 1057007, Paul.  
 18 This was the request you sent. You wanted  
 19 a risk assessment to ascertain what risk you were at  
 20 from CJD. You wanted to know how many batches you had  
 21 had and whether or not the risk increases due to  
 22 the number of batches you had had.  
 23 Then if we can go to the next document, please,  
 24 that's the one, if we could just see the whole text of  
 25 it.

15

1 This identified the need for special public  
 2 health precautions to be taken for many people who had  
 3 received clotting factors. We can see that from the  
 4 bold print. Then if you could just go down the page  
 5 please, Paul, to, "What special precautions should  
 6 I take", the letter told you this:  
 7 "You should not donate blood. You should not  
 8 donate organs or tissues. You should tell whoever is  
 9 treating you before you undergo medical, surgical or  
 10 dental treatment ... it would be best if you tell your  
 11 family about this ..."  
 12 When you finally saw this letter what did you  
 13 feel on receiving this information?  
 14 **A.** I was really angry because it could have been  
 15 prevented if I got given the factor earlier on. This  
 16 was all completely preventable, obviously, because  
 17 I've seen people in the past that have died of  
 18 hepatitis C and died of HIV. I thought this would be  
 19 the next wave coming through, people would then be  
 20 wiped out from that, and it was just a massive,  
 21 massive mental hit on me.  
 22 **Q.** If we could just go to the next page, please, Paul, if  
 23 you could just highlight the section under "Can I find  
 24 out if I've been treated with an implicated batch",  
 25 second paragraph, Paul, "If you would like to find

14

1 So this is the response you received, Matt and  
 2 it told you this in the first paragraph:  
 3 "I know that you are already aware from  
 4 discussions in the past that you have received batches  
 5 of Factor IX concentrate including material donated  
 6 from a donor who subsequently developed variant CJD."  
 7 Then if we look at the second paragraph you were  
 8 told that you have been exposed to two batches of the  
 9 material. You'd received a total of 20,600 units of  
 10 one particular batch in the period February to  
 11 April 1995 and 10,200 units in the period May 1997 to  
 12 July 1997, and you were told that the general rule is  
 13 that the risk of contracting any infection through  
 14 blood products is related to the total amount of  
 15 potentially contaminated product.  
 16 **A.** Mmm.  
 17 **Q.** What did you understand from the information you were  
 18 receiving?  
 19 **A.** I was extra lucky: I got two hits. So from that,  
 20 obviously, it caused serious concern and alarm.  
 21 I spoke to the Haemophilia Centre. They tried to say  
 22 the risk was minimal but I'd heard that before with  
 23 hep c. I'd heard that before with people with my  
 24 illness, with HIV, and then I thought automatically  
 25 I'm going to die.

16



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

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

14 A. Nothing.

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

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

21 Q. Take your time?

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

25 Q. Do you want some water, Matt?

17

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

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

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

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

23 A. Yes.

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

19

1 A. Sorry.

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

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

6 A. Thank you. I'm all right.

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

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

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

21 A. Two sisters.

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

18

1 A. Yes.

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

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

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

17 Q. Did it affect your schooling?

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

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

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

20

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

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

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

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

23 A. Correct.

24 Q. What treatment were put on?

25 A. Ribavirin interferon.

21

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

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

7 A. Yes.

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

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

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

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

15 Q. And you have tests routinely --

16 A. Correct, yes.

17 Q. -- to keep that under review?

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

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

23

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

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

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

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

17 A. Correct.

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

20 A. Yes.

21 Q. -- and you had suicidal thought thoughts?

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

22

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

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

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

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

25 Q. You have had to -- in terms of work opportunities,

24

1 you've had to, for the reasons you've given, turned  
 2 down promotions, turned down opportunities to travel?  
 3 **A.** Yes. I get very, very tired. If I -- because my  
 4 ankles have been fused and they're arthritic and  
 5 I got -- I can't lift my elbow because that's gone as  
 6 well. But, yeah, in terms of going out to meet  
 7 clients, I'll have a one-hour meeting then I fall  
 8 asleep on the train coming back, not something you do  
 9 with someone who's 38. It is hard. You are dog-tired  
 10 all the time.  
 11 **Q.** One of the things you say in your statement is one of  
 12 your many fears is, if something happens to you, is  
 13 that you are not in a position to leave your partner  
 14 and your children financially well cared for?  
 15 **A.** I won't be working by the time I'm 40 I don't feel.  
 16 The tiredness, the fatigue, the depression is getting  
 17 worse, so my concern is what happens when that  
 18 happens. I don't want Naomi to provide for me. I'm  
 19 the man. That's what a man should do. My Dad has  
 20 instilled that. He has always gone out and worked. I  
 21 should provide for the people I love and those people  
 22 that I have made, my two sons.  
 23 **Q.** What have the effects been in terms of when you are  
 24 trying to access other treatment, for example, dental  
 25 treatment what's happened then?

25

1 friends and I'm very, very lucky but obviously back  
 2 20/30 years ago people weren't so forgiving.  
 3 **Q.** Whenever you do have any kind of procedure you are at  
 4 the end of the list.  
 5 **A.** Oh yeah, yes.  
 6 **Q.** You are made to feel very aware that you are at the  
 7 end of the list?  
 8 **A.** Yes.  
 9 **Q.** Have you ever been offered any form of counselling to  
 10 deal with the issues that you have identified in terms  
 11 of the exposure to infection and risk of vCJD?  
 12 **A.** No, no, none, absolutely none. I've had to -- my Dad  
 13 when I was younger was desperate to put me on it  
 14 because I was slowly killing myself so he would pay  
 15 for it for me but I didn't like it, I didn't like  
 16 talking about it, I didn't like bringing it up.  
 17 The reason I'm here today is I want to talk for  
 18 those people that can't be here. There is someone  
 19 close to the family who has passed away through an  
 20 illness and he can't be here so I'm talking partly on  
 21 his behalf, but partly because this all could have  
 22 been prevented. My life has been completely  
 23 dismantled, completely taken apart for something that  
 24 could have been stopped and it's just -- yeah.  
 25 **Q.** You get an amount of regular payment from you, got

27

1 **A.** Yeah, so I went to my dentist some time ago and he  
 2 wouldn't treat me because I was exposed to new variant  
 3 CJD. The instruments were too expensive so he said he  
 4 couldn't treat me. I then probably spent the best  
 5 part of two or three years to find a dentist who would  
 6 find me and they wouldn't, so I went to another  
 7 dentist and I didn't tell him because I had an abscess  
 8 in my mouth and it was really, really sore, I mean  
 9 painfully sore so I didn't tell him. Probably not the  
 10 best thing, but I had to get the abscess sorted.  
 11 **Q.** What about when you just go for some of the routine  
 12 treatment that as a life-long haemophiliac you will  
 13 inevitably have to go to, what happens in terms of the  
 14 way in which you are treated?  
 15 **A.** So obviously I'm blessed to have cleared the virus and  
 16 I cleared that at a young age, but there's massive  
 17 stickers, danger of infection, risk of infection,  
 18 I presume about the CJD and it's not good to see when  
 19 people ask what's this about.  
 20 It's almost like I feel like sometimes that  
 21 I have been a drug user and that's the perception of  
 22 me because I've got this. Obviously when going back  
 23 to the early '80s it was much worse with what was  
 24 perceived the gay plague but it's still bad for me  
 25 now. Like I've got amazing family, I've got amazing

26

1 some monies originally from the Caxton Foundation and  
 2 now form the EIBSS?  
 3 **A.** Yes.  
 4 **Q.** What has been your experience of making applications  
 5 for financial assistance?  
 6 **A.** Caxton Foundation, I can't -- I don't even remember  
 7 applying for it. That money went in a matter of  
 8 months. I thought I was going to die, so I just  
 9 spanked it. I was 20. I thought, do you know what,  
 10 I'm not going to be here, so let's have fun. So  
 11 that's what I did.  
 12 Then the other ones, the regular payments, it's  
 13 you have to go through so many forms. Even though  
 14 everything is on my records, I am fatigued, I am  
 15 tired, I can't walk, I do get out of breath, you still  
 16 have to apply. They have my notes and you apply, send  
 17 off the forms, you get more information back, it goes  
 18 on and on and on, and also as well it's just hard  
 19 applying. I don't feel like I should apply to the  
 20 Government who, in my opinion, the NHS are the ones  
 21 that gave me this and I'm asking them to help me for  
 22 what they've given me. It doesn't make sense.  
 23 **Q.** Matt, those are the questions I had for you. I am  
 24 going to ask Mr Stein in a moment if there is any  
 25 other matter he would like me to raise but is there

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1 anything else you'd like to say about your evidence?  
 2 **A.** The evidence is true. It's all been really, really  
 3 painful. I love my family so much and thank you for  
 4 everything that they've done for me. I know it hasn't  
 5 been easy for you two, and I just hope that some good  
 6 can come of this. I hope that justice can be done.  
 7 I hope the people who are accountable, because in my  
 8 opinion there is, are held to account and this is  
 9 never repeated. This is never repeated.  
 10 I don't want the people in this room, their  
 11 families to go through what I've been through.  
 12 I don't want any other haemophiliac to have to die or  
 13 to go through the pain I have been through, or anyone  
 14 else for that matter.  
 15 We are a very, very rich nation. People should  
 16 not be put behind profit from pharmaceutical  
 17 companies. It should be about preserving people and  
 18 life and I just feel that the people, the poor people  
 19 that I was speaking to last night at the hotel and the  
 20 poor people in this room that have lost loved ones, it  
 21 breaks my heart.  
 22 I'm lucky I'm here, I've cleared hep c, I'm  
 23 okay. Obviously, I'm damaged. I'm irreparably  
 24 damaged but there are people that have lost people  
 25 that they love and as a parent now I can only feel

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1 **MS RICHARDS:** Yes, sir. Thank you.  
 2 (10.42 am)  
 3 (A short break)  
 4 (11.05 am)  
 5 **SIR BRIAN LANGSTAFF:** Our next witness wishes,  
 6 I understand, to be known as Jackie.  
 7 **MS RICHARDS:** That's right, sir.  
 8 **SIR BRIAN LANGSTAFF:** Jackie.  
 9 **JACQUELINE BRITTON, sworn**  
 10 **Questioned by MS RICHARDS**  
 11 **SIR BRIAN LANGSTAFF:** Jackie, your voice is quite soft.  
 12 You need to be a bit closer to the microphone I think  
 13 that should probably do it.  
 14 **A.** Thank you.  
 15 **MS RICHARDS:** Jackie, I am just going to give you a copy  
 16 of your statement to have with you?  
 17 **A.** Thank you.  
 18 **Q.** I don't think you'll need to look at it but it's there  
 19 in case you want to check anything or refresh your  
 20 memory.  
 21 Jackie, I'm going to ask you, first of all,  
 22 about 1983. You were in hospital having given birth  
 23 to your first daughter?  
 24 **A.** Yes.  
 25 **Q.** Saint Mary's Hospital Portsmouth, and then a few days

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1 nothing but pain and sorrow for them, but yeah.  
 2 **Q.** Matt, I am just going to turn my back and ask Mr Stein  
 3 if he has anything else he'd like to raise. (Pause)  
 4 There's nothing further that Mr Stein asks me to  
 5 ask you.  
 6 Sir?  
 7 **SIR BRIAN LANGSTAFF:** Matt, it has taken immense courage  
 8 for you to be there and lay bare some of your  
 9 innermost emotions. You have told us of a number of  
 10 reasons why you've done that. Is there one that you  
 11 choose? Which is the main one, do you think, that  
 12 brings you here to tell us what you have?  
 13 **A.** I don't want people to go through what I've been  
 14 through. I don't want parents to have to relive the  
 15 horrors my parents have had to -- that have had --  
 16 that have had to go through over the years.  
 17 I know the guilt that they feel and the pain  
 18 that they feel and the horror that they see me go  
 19 through. I don't want any parent to go through that.  
 20 I don't want any son to go through that or any sibling  
 21 to go through that.  
 22 **SIR BRIAN LANGSTAFF:** Thank you very much. Thank you very  
 23 much indeed.  
 24 I think we will take a break. Shall we say 20  
 25 minutes.

30

1 later having been discharged home you were rushed back  
 2 into hospital. What happened?  
 3 **A.** My daughter was eight days old and I had an old GP  
 4 that was about to retire coming in. I was living with  
 5 my Mum because my husband had come back from the  
 6 Falklands and we were stationed in Dover, but because  
 7 he was away I stayed with my Mum because it was the  
 8 end of the pregnancy, and my blood pressure had been  
 9 high all of the days that I had been at home, and he  
 10 had had a go at me about being a young Mum and letting  
 11 my Mum do everything for me because I had these raging  
 12 headaches. I had taken to bed. So I thought all  
 13 young mums must feel like this.  
 14 So I got up and I put my daughter -- it was the  
 15 first time I'd put her in her pram and I took her for  
 16 a walk on the Friday and we were due to register her  
 17 the next morning, and got home, had a bath, stood up,  
 18 and it was like a horror film. My husband just ran  
 19 and got my Mum and I'd started haemorrhaging. Doctor  
 20 came out, called an ambulance and they took me back  
 21 into Saint Mary's Hospital.  
 22 **Q.** So you were rushed back to hospital as an emergency?  
 23 **A.** Yes.  
 24 **Q.** The doctors undertook a procedure known as a D & C?  
 25 **A.** Yes.

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1 Q. You were in theatre for a while?  
 2 A. Yes.  
 3 Q. Presumably under anaesthetic?  
 4 A. Totally, yes.  
 5 Q. When you came round from the anaesthetic after the  
 6 surgery were you told that you had had a transfusion?  
 7 A. I was on my own, groggy from the anaesthetic, and  
 8 naively I looked up and said to the doctor that had  
 9 come in, "I'm fine now. Everything's okay", and he  
 10 said no and he said, "You had four units of blood.  
 11 The only reason I stopped was that I thought I was  
 12 going to perforate your uterus and I'm expecting you  
 13 to haemorrhage again. When that happens, we will have  
 14 to give you a full hysterectomy". And I was 21, and  
 15 he told me that with no-one else in the room.  
 16 Q. So that was how you discovered you had had  
 17 a transfusion. I think you're not critical of the  
 18 fact that before the transfusion you weren't given  
 19 information because it was an emergency?  
 20 A. That's right.  
 21 Q. But you stayed in hospital for about a week after  
 22 that?  
 23 A. That's right.  
 24 Q. Were you ever in that period of time given any  
 25 information about any risks associated with having had

33

1 you, that you had had a transfusion in the 1980s, did  
 2 they give you any information during that hospital  
 3 stay about any risks that you might have been exposed  
 4 to during that earlier transfusion or give you any  
 5 advice about what you might want to look out for?  
 6 A. None whatsoever.  
 7 Q. You had over the following years a couple of further  
 8 operative procedures at the same hospital. Again, did  
 9 you pass on any information in advance of those  
 10 procedures to the doctors?  
 11 A. Each and every time I told them, I warned them because  
 12 I had two young children then to worry about and so  
 13 I always was concerned of the bleeding, and I always  
 14 was at pains to tell them that I'd haemorrhaged twice,  
 15 I had had a transfusion, and would they have  
 16 cross-match on stand-by.  
 17 Q. On either of those occasions did the doctors pick up  
 18 on the significance of you having had a transfusion  
 19 and give you any advice or information?  
 20 A. None whatsoever.  
 21 Q. Now, you began to or you had been experiencing I think  
 22 for a number of years certain physical symptoms.  
 23 Can you describe to us what they were?  
 24 A. I was always very tired. I was told that I was  
 25 suffering from IBS. I always had pains in my stomach,

35

1 a transfusion?  
 2 A. None whatsoever. I was happy that I didn't have to go  
 3 back to theatre. I didn't haemorrhage again, so I was  
 4 discharged and I went on with my life thinking  
 5 everything was fine.  
 6 Q. Now, you then had, a number of years later -- in the  
 7 mean time you had had your second daughter?  
 8 A. That's right.  
 9 Q. A number of years later, in 1993, you had further  
 10 surgery, serious surgery, at Saint Mary's Hospital in  
 11 Portsmouth. You didn't need a transfusion.  
 12 A. No.  
 13 Q. But you were at pains, I think, to give the doctors  
 14 some information before your surgery was undertaken.  
 15 What did you tell them?  
 16 A. Totally. On the pre-op checks I'd haemorrhaged with  
 17 my second daughter as well but I didn't need  
 18 a transfusion, so I was at pains to tell them that I'd  
 19 haemorrhaged twice and that, you know, would they  
 20 definitely have blood on stand-by. I had had a four  
 21 unit transfusion in 1983. My Mum had had  
 22 a hysterectomy and had internal bleeding. It just  
 23 seemed there was like a history with the family, so  
 24 I was at pains to make them aware of that.  
 25 Q. Did the doctors, having been given that information by

34

1 lots of issues, so I was diagnosed with IBS.  
 2 Just before I was diagnosed with the hep c,  
 3 again things were getting worse. So I went back to my  
 4 GP and because of the nausea, the weight loss, the  
 5 pains in my stomach, they did do scans and they just  
 6 happened to find that I had cysts on my ovaries and so  
 7 they assumed that's what was causing the problems, and  
 8 I had another operation, and they were removed and,  
 9 again, I told them that I had had the transfusion,  
 10 that I'd had -- and this is in about 2009 -- I had had  
 11 a transfusion and did they have blood on stand-by just  
 12 in case.  
 13 Q. Again, on that occasion in 2009 did anyone say to  
 14 you --  
 15 A. No.  
 16 Q. -- anything about the risks that you might have been  
 17 exposed to?  
 18 A. No.  
 19 Q. Even though you were complaining by then, bringing to  
 20 doctors' attention the symptoms you had been  
 21 experiencing?  
 22 A. That's right. At one stage, even with -- I mentioned  
 23 the brain fog, that I'd be lost for words, I'd be  
 24 walking out the door and then thinking I'd have to go  
 25 back I don't know how many times, did I lock the door,

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1 did I switch something off? I'd be talking to  
2 somebody and then I'd have to say to them, "What was  
3 I just saying", and so because I had had  
4 a hysterectomy at 30, it was assumed that it may be  
5 hormonal and so I was put on HRT as well. But it's  
6 only since that I was diagnosed that I look back now  
7 and I think how much of that was down -- like my gall  
8 bladder -- how much of that was down to the underlying  
9 hep c.

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

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

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

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

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1 you --  
2 **A.** At home.  
3 **Q.** -- late at night at home, and what did he tell you?  
4 **A.** That there was a major problem with my liver, that  
5 they'd tested for hep c and it had come back positive  
6 and that could they use the same batch, I wouldn't  
7 have to give any more blood, but could they use the  
8 same batch for an HIV test, which obviously I said  
9 yes, and that I needed to book my daughter, my  
10 youngest daughter and my husband in as an emergency to  
11 get their bloods tested for ...

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

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

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

23 **A.** That's right.

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

25 That was June 2011. Your GP made, as

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

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

8 **A.** Continued.

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

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

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

24 **A.** That's right.

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

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

3 **A.** That's right.

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

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

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

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

25 **Q.** So you researched the internet yourself?

40

1 A. Yes.  
 2 Q. What you read filled you with --  
 3 A. Dread.  
 4 Q. -- dread, and you've said in your statement you are  
 5 very strongly of the view that there should be  
 6 booklets of information available for GPs to be able  
 7 to give patients or hospitals to be able to give  
 8 patients in your situation.  
 9 A. Totally. You don't drop a bombshell on somebody and  
 10 then let them go home with nothing. My daughter was  
 11 diagnosed as a diabetic in hospital and before we came  
 12 out of hospital we had a DVD to watch, we had booklets  
 13 to read. You are given this devastating news and  
 14 there's nothing. You go home and in the early hours  
 15 of the morning you are planning your funeral. You are  
 16 wondering what's going to happen.  
 17 Q. So you paid privately for peace of mind to see the  
 18 consultant?  
 19 A. I did.  
 20 Q. What information was the consultant able to give you?  
 21 A. He was lovely. He organised blood tests so that he  
 22 did the genotype, so I knew what genotype I was.  
 23 Straight away, he said that in his experience  
 24 treatment and just having the hep c causes depression  
 25 in most people so he advised that I started

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1 that we had at that first meeting.  
 2 Q. Your statement says that it was, however, that  
 3 consultant who told you that you'd probably contracted  
 4 the hepatitis C from the blood transfusion back in the  
 5 '80s?  
 6 A. Yes. As I say, my GP as well had said that and  
 7 obviously I laughed at the time but I looked at --  
 8 I led a boring life. I got married at 18. I was with  
 9 the same man for 38 years so, you know, they couldn't  
 10 put it down to my lifestyle. I wasn't brave enough to  
 11 get tattoos. All there was that stood out loud and  
 12 proud was the four units of dirty blood.  
 13 Q. So from having been infected in 1983, it took until  
 14 2011 for that infection to be diagnosed?  
 15 A. Yes.  
 16 Q. Notwithstanding the fact that in the intervening years  
 17 you had gone to doctors numerous times with the  
 18 classic symptoms that you've described?  
 19 A. That's right.  
 20 Q. What impact was there on you of learning at that point  
 21 that you had been infected for so many years?  
 22 A. I was really, really angry. The fact is the blood  
 23 saved my life at that point. That's fine. If they  
 24 didn't realise there was issues with the blood I can  
 25 accept that. If they didn't know that there was

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1 antidepressants straight away and he organised that  
 2 with my GP.  
 3 Q. You had a liver biopsy?  
 4 A. As I say, I was very concerned so I had nothing on my  
 5 credit card and then all of a sudden I had paid for  
 6 a £2,000-odd liver biopsy because I needed to know.  
 7 Q. That told you that you had fibrosis, the bridging  
 8 stage before cirrhosis, at that stage?  
 9 A. That's right.  
 10 Q. I think it was this private consultant who also told  
 11 you about The Skipton Fund?  
 12 A. Yes.  
 13 Q. You then had the NHS appointment that you had been  
 14 waiting for on 18 August 2011?  
 15 A. Yes.  
 16 Q. What did that consultant tell you about how you had  
 17 probably contracted HCV?  
 18 A. Well, I was put off straight away when he sort of  
 19 looked at me and said, "Why on earth have you gone and  
 20 had a liver biopsy and, you know, gone and paid to see  
 21 someone, you know. I'm here", and I said because  
 22 mentally I couldn't live that amount of time with not  
 23 knowing how badly I was, so that put me off of him  
 24 straight away.  
 25 As I say, that just set the tone for the meeting

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1 issues until after the transfusion date, I can accept  
 2 that.  
 3 What I can't accept is they had numerous,  
 4 numerous occasions to find me and give me treatment so  
 5 that I wouldn't now be cirrhotic and, as soon as  
 6 I found out, I went to my MP and I said to him, you  
 7 know, "I'm the tip of the iceberg. I'm not the last  
 8 person in England to have an infected transfusion and  
 9 be finding out about it".  
 10 If there is a simple question on a pre-op form,  
 11 everybody that has an operation has to go to a pre-op  
 12 clinic, a simple question that says, "Have you ever  
 13 had a transfusion?" If the answer is yes and the  
 14 dates are in the at-risk period, you are offered  
 15 testing and he blubbered something about data  
 16 protection and I said, "By that question not being  
 17 asked I wasn't able to make an informed choice. You  
 18 need to give people -- it's a simple question. You  
 19 need to give people the opportunity to say yes or no,  
 20 they want the testing. With that, they then can get  
 21 the treatment. You're dying in ignorance if you don't  
 22 know you're infected", and after the data protection  
 23 thing, you know, I looked up and said, "You don't want  
 24 to find us because it's going to cost the Government  
 25 money. That's the be all and end all", and I don't

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1 think I've been escorted out of an office with my Dad  
 2 so quickly.  
 3 **Q.** You had a great fear that you might have infected not  
 4 just your family but others whom you had come into  
 5 contact with, medical and nursing professionals who  
 6 had operated on you over the years?  
 7 **A.** I told him, you know, "Your NHS staff have had their  
 8 hands in my stomach. I've been open from top to  
 9 bottom and I could have infected how many more  
 10 people", and you know ...  
 11 **Q.** You had worked in childcare --  
 12 **A.** I was a nursery nurse.  
 13 **Q.** -- dealing with cuts and scrapes of children who had  
 14 fallen over?  
 15 **A.** Yes, totally.  
 16 **Q.** What can you tell us then about the treatment you  
 17 received? So August 2011 you have seen the NHS  
 18 consultant and you I think fought to begin treatment  
 19 as soon as possible --  
 20 **A.** That's right.  
 21 **Q.** -- having been undiagnosed for so long.  
 22 What was the first course of treatment you  
 23 underwent?  
 24 **A.** The first course was interferon and Ribavirin for  
 25 three months but unfortunately I was a non responder.

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1 explained that the liver is quite large and the biopsy  
 2 is minuscule and they might miss cirrhotic tissue by  
 3 millimetres and you would have the pre-cirrhotic  
 4 result that I had.  
 5 So he'd almost laid the groundwork that he  
 6 thought I was cirrhotic. I had -- he did the test and  
 7 he said that he would make a report and he sent it to  
 8 me and the fibroscan scores I think at the time, if  
 9 you were 12 to 14 they -- or over 12, they considered  
 10 you had cirrhosis. Mine came back as 39.9.  
 11 **Q.** You then embarked upon a second course of treatment.  
 12 You were given a pretty poor prognosis I think at the  
 13 outset in terms of the likelihood of it succeeding; is  
 14 that right?  
 15 **A.** Yes. What had happened is Professor Thursz looked up  
 16 to me and said from everything you are telling me you  
 17 haven't really got time to play around with with  
 18 treatment. So my hospital, the next lot of treatment  
 19 that was coming online, which I again fought for  
 20 funding for, was to Telaprevir, Ribavirin and  
 21 interferon and I was due to the Telaprevir for three  
 22 months, 12 weeks, and stay on the interferon and the  
 23 Ribavirin for a year, and I was expecting an  
 24 80 per cent chance of clearing, and when I actually  
 25 got to the hospital and my nurse started going through

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1 **Q.** What was that treatment like?  
 2 **A.** I injected myself every Wednesday, took tablets  
 3 a couple of hours after, paracetamol, and then went to  
 4 beds and the flu symptoms kicked in big style. The  
 5 Ribavirin also, towards the end, they had to cut my  
 6 dose because I would walk along the corridor and it  
 7 was like an old lady, my breathing, and it was because  
 8 of the anaemia, my platelets had dropped and that was  
 9 due to the Ribavirin, so they had to adjust the dosage  
 10 of that.  
 11 **Q.** So that treatment came to a premature end and then in  
 12 2012 you ended up paying to have a fibroscan of your  
 13 liver. Why did that happen?  
 14 **A.** Again, I was researching. I was still feeling so  
 15 poorly. My hospital at the time, it was new  
 16 technology, they didn't have a fibroscan, so I paid to  
 17 go to London and I was examined and the fibroscan was  
 18 done by Professor Thursz, who I didn't realise was an  
 19 eminent professor. I was very lucky that I just  
 20 happen to find him.  
 21 **Q.** What did that fibroscan show?  
 22 **A.** Well, he talked to me before the fibroscan and he said  
 23 from what I was telling him he would almost certainly  
 24 think I was already cirrhotic and that probably I was  
 25 cirrhotic the year before when I had the biopsy but he

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1 things she said, well, actually, because you're  
 2 a non-responder and because you are 1A your clearance  
 3 rate is probably about 30 per cent, but there was  
 4 nothing else on the market and I thought I haven't got  
 5 time to play with, 30 per cent, I've got to go for it  
 6 so, as I say, because of the knowledge I had at that  
 7 time I went for it, side effects regardless. I didn't  
 8 have a choice.  
 9 **Q.** The 1A is the genotype of hepatitis C that you had?  
 10 **A.** Yes.  
 11 **Q.** What were the side effects from the second course of  
 12 treatment?  
 13 **A.** The second lot of treatment was they knew that there  
 14 were issues, skin issues, but the drugs company they  
 15 did give you a 24-hour hotline to nurses. Your  
 16 doctors, if you were poorly at all through anything,  
 17 your doctors had to phone them to okay what drugs  
 18 because there were so many interactions with drugs, so  
 19 you couldn't just take anything off of the shelf.  
 20 You had to -- it was you had a timer on the  
 21 bottle of pills, you had to have them on the timer and  
 22 you had to have them with 30 grams of fat. So again  
 23 it was like 5 in the morning you had to have a pint of  
 24 full fat milk and spoonfuls of peanut butter so that  
 25 it would work, so it wasn't nice and I did have

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1 problems with that. I was hospitalised. It caused --  
 2 I was sent to see a colorectal nurse because it caused  
 3 issues but it was side effects.  
 4 **Q.** You had itching all over, you had bleeding and  
 5 abdominal pain.  
 6 **A.** Yes.  
 7 **Q.** As you said, you had to go to hospital and you said in  
 8 your statement the side effects were so bad you  
 9 remember waking up everyday and thinking when is this  
 10 going to end?  
 11 **A.** That's right. The Ribavirin again was causing  
 12 problems but I was determined that they didn't drop my  
 13 dose because that might have been the cause that it  
 14 didn't work the last time. You know, you pick at  
 15 straws.  
 16 I was on that, as I say, the Telaprevir,  
 17 I finished three months of that and I carried on until  
 18 27 weeks. It was Christmas time and Boxing Day my Mum  
 19 said I was quiet and I just -- all the feelings of the  
 20 illness was coming back, so there happened to be, the  
 21 Liver Trust had organised vans that go round and offer  
 22 fibroscans. So I queued up in January in a car park  
 23 in a shopping centre and I was quite surprised that my  
 24 nurses were all there, they had all come down from the  
 25 hospital.

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1 drug trial?  
 2 **A.** Yes, King's were very high on doing trials for drugs.  
 3 **Q.** What happened? What discussions did you have with  
 4 him?  
 5 **A.** He said he could have started me on a trial the same  
 6 week but, unfortunately, because I'd been on the  
 7 previous treatment and failed that that negated it.  
 8 He couldn't do anything for me and he said if I'd been  
 9 under him he wouldn't have even put me on that  
 10 medication, the risk -- you know, the clearance was so  
 11 poor he wouldn't have even put me on that but  
 12 obviously I didn't know that at the time. I made an  
 13 uninformed choice.  
 14 **Q.** He told you you were going to have to wait until there  
 15 was a new treatment and a new trial for another  
 16 combination of drugs?  
 17 **A.** That's right and that took until 2015.  
 18 **Q.** In the meantime you transferred to become his patient  
 19 as an NHS patient?  
 20 **A.** I did, yes.  
 21 **Q.** So you were able to start a third course of treatment  
 22 in December 2015?  
 23 **A.** I had to fight for it first. Yes, it wasn't handed on  
 24 a plate. I met my good friend Sally Vickers at  
 25 a radio station. We were both fighting because,

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1 They hadn't informed me that this was happening,  
 2 you know, I just found a little bit in the evening  
 3 news and I said to them, you know, I haven't had any  
 4 blood results and she said, "Oh, I'll chase it up",  
 5 and she went off and made a phone call and it was  
 6 a porta -- like a porta-cabin thing and she said, "Can  
 7 you come in", and then ushered me into a little  
 8 cubicle, and I said, "Before you tell me, it's stopped  
 9 working, hasn't it?" I was 27 weeks into the year  
 10 that I should have stayed on and she said, "I'm so  
 11 sorry". I said, "I knew. I felt it. I felt so ill  
 12 again", and she said, "You might as well stop taking  
 13 them now. That's it".  
 14 **Q.** And there were no other treatments available at that  
 15 time?  
 16 **A.** At that time there wasn't and my hospital, they didn't  
 17 do liver transplants, so they said to me if for any  
 18 reason in the meantime that I needed a liver  
 19 transplant they would automatically send me to the  
 20 Royal Free in London. So I thought, you know, you're  
 21 at death's door and they're going to send you off to  
 22 people you don't know, so I then again researched and  
 23 I'd heard good things about King's and Kosh Agarwal  
 24 and I paid to go and see him.  
 25 **Q.** So you went to see Dr Agarwal about a possible new

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1 although NICE had cleared it, NHS England had decided  
 2 that the funding wasn't been there and they'd put like  
 3 a six-month stop on it. So we were expecting  
 4 treatment in the April and I think it was about the  
 5 October, having gone to MPs, having gone in the media  
 6 and the papers, fighting as ill people for things that  
 7 we should have been given to us because the NHS had  
 8 infected us.  
 9 **Q.** What was the combination of drugs that you tried this  
 10 time?  
 11 **A.** That was Harvoni and Ribavirin, my old friend again.  
 12 **Q.** That course of treatment ultimately cleared the virus?  
 13 **A.** It did.  
 14 **Q.** And that was end of 2015 that it cleared?  
 15 **A.** It was, yes.  
 16 **Q.** Did you have similar side effects during that course?  
 17 **A.** Again, the Ribavirin caused problems but, again, I was  
 18 determined they didn't drop my dose and it was  
 19 12 months and, although there were side effects, it  
 20 was a walk in the park compared to the last two  
 21 treatments.  
 22 **Q.** Now, although the virus has cleared, you continue to  
 23 experience the symptoms of hepatitis C, don't you?  
 24 **A.** I did and I actually went back to my doctor and  
 25 said -- my GP -- because I wasn't due to go back to

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

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

12 Q. You were also told that you had fibromyalgia?

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

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

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

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

7 A. It was what I wanted at my funeral.

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

12 A. Sally, yes.

13 Q. How did you meet?

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

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

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

5 Q. What about the effect on you mentally?

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

9 When I was first diagnosed, I sought out a grant  
10 from their hep c -- no, not the hep C, the Liver  
11 Trust. They were offering a £900 grant for  
12 counselling and I got it. I was lucky enough to get  
13 it and my counsellor that I found was fantastic. But  
14 £900 doesn't last when you've got a chronic condition.  
15 It's not something that's going to be fixed and when  
16 you have treatment and you're going up, you know,  
17 you're thinking "this is working" and then the  
18 treatment fails, you crash.

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

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

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1 with her.

2 Then I'd cleared Christmas 2015, and Christmas  
3 2016 I went for my scan and I knew that they were  
4 taking an awful lot longer taking the scan and so  
5 I said, "What have you found?" The poor radiologist  
6 said, "Yeah, I've found something. I think they will  
7 need to do further investigations".

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

16 So a CAT scan was organised before Christmas of  
17 that year. Luckily, it was fine. So, as I say, me  
18 and Sally went through the same things and then Sally  
19 had another three-month scan: fine. Second  
20 three-month scan: terminal and she was dead within two  
21 weeks. My daughter happened to be at the hospital  
22 when she was in and we both went to see her. And  
23 I heard her before we got on to the ward. I thought,  
24 "Please don't let that be Sally". She was such  
25 a bubbly, full-of-life person and there was a shell,

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1 a yellow shell, in the bed struggling for breath. Her  
 2 husband [GRO-C] had popped home and her niece was there,  
 3 and I said, "Has she been like this all morning?" and  
 4 she said, "No, she'd been out, sat out, and we just  
 5 put her back and she'd been talking to [GRO-C]". And  
 6 I said, "When he's due back?" and she said, "Well, any  
 7 time". I said, "Go outside and warn him. Don't let  
 8 him walk into this. Warn him".

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

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

21 That really hit me because I was stood there  
 22 with my daughter thinking is my daughter going to be  
 23 stood there alone watching me in the bed? It happened  
 24 so quickly, and it's murder by any other name because  
 25 it shouldn't be allowed to have happened and it's

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1 afternoon, I would put the stair-gate across the top  
 2 of the stairs and she had a nursery in my house and  
 3 I would either lay on the single bed in the nursery  
 4 with her playing, she was playing shops, or I would  
 5 put a DVD on and I'd lay on my bed. She would toddle  
 6 off, get her nurse's uniform, and then come back and  
 7 her little bag and say, "I'll make you better, nanny".  
 8 She's grown up knowing that I haven't done the things  
 9 that my 80-year old parents have playing with her,  
 10 playing badminton and doing things in the garden and  
 11 it's not right.

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

13 A. Yes.

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

17 A. I do.

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

20 A. That's it.

21 Q. -- to your daughter.

22 A. [Answer redacted]

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

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1 still happening. There are still people undiagnosed  
 2 that nobody is bothering to find because of the cost  
 3 it will involve and a £12 test needs to be offered to  
 4 everybody so that they don't die in ignorance.  
 5 Without testing, without knowing you're dying, you  
 6 can't access treatment.

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

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

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

22 So the impact is massive. I looked after my  
 23 granddaughter. Her Mum went back to work when she was  
 24 12 weeks old and as a little girl I had her from 12  
 25 weeks and she was two when I was diagnosed. In the

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

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

16 Because I'm a proactive-type person, that's the  
 17 way I deal with things, I got on the Caxton  
 18 Partnership meetings to try and change things from the  
 19 inside, and one of the things that they stopped doing  
 20 was paying retrospectively. So if I'd gone to them as  
 21 a person with a credit card later on, they wouldn't  
 22 have paid that off and to, you know, I explained my  
 23 situation and sometimes -- it doesn't have to be  
 24 a liver biopsy. It could be a washing machine or --  
 25 if you need it you need it, you can't wait weeks and

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1 if you put it on your credit card, you know, if it's  
2 something that you needed, to me the retrospective --  
3 taking the retrospective payments away was not good  
4 for the beneficiaries. So I did bring that up and  
5 I did have a voice in those meetings and I can  
6 remember saying that, you know, "We're beneficiaries,  
7 you're there supposedly supporting us", and they went  
8 on about their budgets and I said, you know, "Sorry,  
9 if somebody needs something and it's due to their  
10 hep c or whatever, you need to increase your budget,  
11 you know. Are you telling me because the DHSS pay  
12 your wages that you're not going to bite the hand that  
13 feeds you? It's about us not about you and your big  
14 fat wages". Yeah, that didn't go down very well in  
15 a meeting.

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

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

23 **A.** Of people like me.

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

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

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

13 Thank you.

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

17 **A.** Thank you.

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

19 **A.** Thank you.

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

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

24 **A.** Yes.

25 **SIR BRIAN LANGSTAFF:** The first you mentioned was that

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1 treated?

2 **A.** That's it.

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

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

5 **Q.** You now have them three-monthly?

6 **A.** Every three months.

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

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

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

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

25 This Government along with all of those gone

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

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

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

23 **SIR BRIAN LANGSTAFF:** The second thing I noted was that in  
24 any pre-operative assessment when there's a form there  
25 should be a simple question, tick or not, "do you want

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1 to be tested for hepatitis C".  
 2 **A.** That's right.  
 3 **SIR BRIAN LANGSTAFF:** The third was the best practice for  
 4 those who are suffering from potential liver disease  
 5 is to have a scan in the morning and see the  
 6 consultant in the afternoon.  
 7 **A.** That's right.  
 8 **SIR BRIAN LANGSTAFF:** As happened with you.  
 9 **A.** Yes, it happens every time at King's.  
 10 **SIR BRIAN LANGSTAFF:** You suggest that there should be  
 11 a test offered to everyone so that, in similar words  
 12 to the Government's AIDS campaign, not quite the same,  
 13 people don't die in ignorance, the campaign says of  
 14 ignorance but you don't want them to die in ignorance.  
 15 **A.** That's right.  
 16 **SIR BRIAN LANGSTAFF:** Was there anything I've missed that  
 17 you would recommend as a positive practical measure?  
 18 **A.** Well, like I say, it's finding the people, offering  
 19 them the choice, you know. Some people may not want  
 20 to find out and live a nightmare but without the  
 21 knowledge, you can't make informed choices.  
 22 If I'd had the knowledge, I would have chosen to  
 23 be tested, I would have chosen to have got earlier  
 24 treatment and in all the time that I was undiagnosed  
 25 I was putting my family at risk unknowingly, I was

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1 witness would like to be known as Joan.  
 2 **MS FRASER BUTLIN:** She does, yes.  
 3 **SIR BRIAN LANGSTAFF:** Could Joan come forward, please.  
 4 **JOAN EDGINGTON, affirmed**  
 5 **Questioned by MS FRASER BUTLIN**  
 6 **MS FRASER BUTLIN:** Thank you, Joan. Joan, you, trained  
 7 originally to be a secondary school teacher, didn't  
 8 you?  
 9 **A.** I did, yes.  
 10 **Q.** Then in about 1987 you became a youth worker and then  
 11 a centre manager?  
 12 **A.** Yes.  
 13 **Q.** And in 1989 you started a mountain leadership course?  
 14 **A.** I did.  
 15 **Q.** And became part of the Outward Bound team?  
 16 **A.** Yes. My original degree was a geography degree.  
 17 I joined the Somerset youth team and landed up with  
 18 a gruff phone call from somebody saying, "I assume you  
 19 can read maps. Do you like the outdoors", and that's  
 20 how that bit started.  
 21 **Q.** Can you describe for us your level of fitness at that  
 22 point in your life?  
 23 **A.** As the only female member of the team, I'd been  
 24 recruited because we get girls interested in joining  
 25 the Outward Bound but they needed a female member,

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1 putting other people at risk.  
 2 As soon as I was diagnosed, I set in measures.  
 3 Without a car -- if I went in a car journey there were  
 4 gloves in the car and I've told people if I was in an  
 5 accident I would rather bleed out than anybody come  
 6 near me unprotected because I would not want anybody  
 7 to go through the hell that we've gone through as  
 8 a family and we are an ordinary family and it's  
 9 happened to many other thousands of ordinary families  
 10 and it shouldn't be allowed to continue to happen.  
 11 **SIR BRIAN LANGSTAFF:** Thank you very much.  
 12 **A.** Thank you.  
 13 **SIR BRIAN LANGSTAFF:** Ms Richards.  
 14 **MS RICHARDS:** Sir, we have one further witness today but  
 15 our suggestion would be that we take our lunch break  
 16 now a little early and then resume with the last  
 17 witness after that.  
 18 **SIR BRIAN LANGSTAFF:** That also seems like a very  
 19 practical suggestion. Let us do that and be back  
 20 shall we -- it's now just about 12.00, so shall we aim  
 21 to be back at 1.15.  
 22 **(11.58 am)**  
 23 **(Luncheon Adjournment)**  
 24 **(1.17 pm)**  
 25 **SIR BRIAN LANGSTAFF:** Ms Fraser Butlin, I think the next

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1 I was able to, and did, maintain the same effort, work  
 2 ethic and hours as any of the men. That includes  
 3 climbing, kit, carrying kit, and working 24/7 with  
 4 young people because that's what you do when you're  
 5 outdoors.  
 6 **Q.** When you were outdoors what kind of activities were  
 7 you leading?  
 8 **A.** It was a mix but the whole point really was for young  
 9 people sometimes for the first time to get a chance to  
 10 experience the outdoors. So we worked at their level.  
 11 Sometimes for them it was the first time they had  
 12 walked the countryside, some were on their way to  
 13 becoming quite advanced climbers. Once or twice we  
 14 included water aspects, you know river swimming and  
 15 things, so you name it we tried it.  
 16 **Q.** Then all of that changed in December 1990.  
 17 **A.** Yes.  
 18 **Q.** When you were admitted to hospital with ulcerative  
 19 colitis.  
 20 **A.** 1991.  
 21 **Q.** I understand that in January 1991 you underwent  
 22 surgery?  
 23 **A.** Yes.  
 24 **Q.** Because the steroids weren't able to get on top of the  
 25 colitis?

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- 1 A. Yes, we'd come back from a field trip that summer in  
2 the Dolomites and from one camp site we'd all landed  
3 up with a tummy infection and just, basically, it  
4 didn't settle over the winter and my GP at the time  
5 did wonder if it was ulcerative colitis but I had had  
6 no history of any medical problems up until then.
- 7 Q. So you underwent a colectomy, removal of your colon?
- 8 A. Yes. The steroids didn't settle the bleeding. We had  
9 Christmas as a holiday and I was meant to rest. The  
10 bleeding got to the point where basically an ambulance  
11 had to turn up after Christmas and take me into  
12 hospital. I was on a medical ward and I forget the  
13 dates to be honest but a long time and they upped the  
14 steroids and were waiting for things to settle.
- 15 In the end it became apparent, I think it was  
16 after a good month, that it wasn't going to work and  
17 I was transferred to the surgical ward under  
18 Mr Collins, who was excellent, but by then my colon  
19 was so damaged it had to be totally removed.
- 20 Q. During that surgery, you received substantial  
21 quantities of whole blood?
- 22 A. Yes.
- 23 Q. Prior to the surgery, were you made aware of any risks  
24 involved in receiving a blood transfusion?
- 25 A. No.

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- 1 agency and you were campaigning against them in  
2 relation to some payments that you didn't want your  
3 husband, your ex-husband, to make to --
- 4 A. Yes.
- 5 Q. By 1994 though you had managed to return to full-time  
6 work; is that right?
- 7 A. Yes.
- 8 Q. Before I was ill I had been -- I'm not quite sure --  
9 contributing to the Somerset Youth Service on lots of  
10 levels. I was part of a forum. I was part of  
11 training team, and when word got out within our  
12 network that I was regaining strength and fitness,  
13 because I was -- there's an interim bit. In the  
14 recovery from the surgery -- I left the hospital so  
15 weak and underweight because I had been in for three  
16 months, basically bed rest. I'd lost muscle tone and  
17 my style is to just roll your sleeves up, sort it out.
- 18 I went to homeopathy. I was building up muscle  
19 tone. I was getting fit, and really felt I was on  
20 a road to recovery. There were issues about stamina  
21 that I couldn't quite pin down, didn't quite know, and  
22 then I just thought, well, that's because my body's  
23 been through quite a trauma. It will come back.
- 24 But then in all of this and being seen out  
25 walking and everything else and friends said she's up

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- 1 Q. Was there any discussion after the surgery of any  
2 possible risks of infection?
- 3 A. No.
- 4 Q. You say in your witness statement that you:  
5 "... now understand that by the time I had my  
6 blood transfusion there was a screening test for blood  
7 but it wasn't being used. There was a risk of  
8 infection and I wasn't informed. I believe that the  
9 risks of the blood transfusion should have been  
10 discussed with me at the point that major surgery was  
11 being considered. My understanding is that there were  
12 safe products that could have been used during surgery  
13 instead of giving me a blood transfusion but these  
14 would have cost the NHS more money."
- 15 A. Yes, absolutely.
- 16 Q. Is that still your understanding?
- 17 A. Yes. Actually, I just for the first time saw my  
18 medical notes about a week ago and I realise I also  
19 had transfusions before surgery because I was so weak.  
20 They had to build me up so I actually had transfusions  
21 on several occasions.
- 22 Q. You were then unable to work for about two years after  
23 that surgery.
- 24 A. Yes.
- 25 Q. You had some difficulties with the child support

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- 1 and running again and it was actually the county  
2 officer that approached me and said would I work  
3 again.
- 4 Q. You managed that for a little bit of time but then  
5 your health deteriorated again.
- 6 A. It was a full-on job, managing a large youth centre  
7 that had had quite a few problems. So some of my  
8 working days started at 9 and finished at 12 -- not  
9 often but that was the process that if you were  
10 supporting an evening session when the youth club was  
11 open by the time I had driven home it was really late.
- 12 So you're operating on lots of levels. There  
13 was the physical demand, there was the sort of  
14 intellectual planning, meeting with committees,  
15 meeting with politicians, looking for funding.
- 16 Q. What were your symptoms at that point just before  
17 1995?
- 18 A. I think in many ways it will sound daft but I felt  
19 quite lucky with retrospect that I had gone to  
20 a homeopath because I was paying more attention than  
21 most people would because I had been extremely fit and  
22 used to working through keep fit programmes, I think  
23 I was more aware than most people would be, and  
24 I became aware that if I pushed it, if I got tired,  
25 flu-like symptoms would be generated with no sense of

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1 having caught a cold. The sort of wanting to rest up  
 2 at the weekend, normally if I had a nice weekend off  
 3 I'd bounce back and be ready for Monday and that old  
 4 familiar pattern just wasn't happening.  
 5 **Q.** You've described it as:  
 6 "... having general flu-like symptoms, aches and  
 7 pains and fatigue. There is tired and then there is  
 8 ill tired. Sleep wouldn't cure it. My lymph glands  
 9 in my neck and armpits would flare up if I pushed  
 10 myself too hard. My body seemed to overreact to  
 11 coughs and colds and my glands would swell for no  
 12 apparent reason when I was tired. I had been very  
 13 resilient before the blood transfusion."  
 14 **A.** Exactly, yes.  
 15 **Q.** Then in June 1995 you received a letter from the  
 16 South-west Blood Transfusion Service as part of  
 17 a look-back exercise.  
 18 **A.** Yes.  
 19 **Q.** Paul, could we have document 0065002, please.  
 20 In this letter, if you just go down to the --  
 21 thank you -- in this letter you were told that the  
 22 transfusion you had received may have been carrying  
 23 the hepatitis C virus.  
 24 What did you do when you received that letter?  
 25 **A.** I'm assuming and I can't find that there was a contact

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1 I wasn't sure what the process now was, other  
 2 than that I was making an appointment to go and see  
 3 somebody. I didn't even know if that was for a blood  
 4 test. I was just making an appointment.  
 5 **Q.** How did you feel during those two weeks? It was  
 6 a vacuum but what was going through your mind?  
 7 **A.** The physical thing is just holding your breath. The  
 8 mental process is all the what ifs. You know,  
 9 I thought I was getting well, what's this? So I think  
 10 for that very first bit until I had an appointment I'm  
 11 literally just physically and mentally holding my  
 12 breath.  
 13 **Q.** You have said that you know you had to be alerted to  
 14 the possibility of being infected by a letter or  
 15 a phone call?  
 16 **A.** Yes.  
 17 **Q.** But you think it would have been better if you could  
 18 have had an appointment much more quickly, perhaps  
 19 within 24 hours, than having to wait for two weeks.  
 20 **A.** Exactly, because not only did you wait for that  
 21 initial appointment, which then did mean I met  
 22 actually with a clinician in a white coat, though  
 23 I can't tell you who it was, and a blood test,  
 24 a sample was taken, but then you also have to wait for  
 25 the results, so I believe it was about a month went by

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1 number. I have a memory of having a number to phone  
 2 to make an appointment.  
 3 **SIR BRIAN LANGSTAFF:** I think you may find it is there if  
 4 you look at the letter, the paragraph second before  
 5 last, which has got the letters "GRO-C" over it.  
 6 **A.** I see, thank you.  
 7 **SIR BRIAN LANGSTAFF:** "Please contact myself on ..." and  
 8 for legal reasons that number has just been taken out.  
 9 **A.** Thank you.  
 10 **SIR BRIAN LANGSTAFF:** So your memory is absolutely right.  
 11 **A.** Thank you. Yes, so I made a phone call which seemed  
 12 to be, in my memory, just a general number and you  
 13 were making a general appointment; so no big deal.  
 14 But I had to wait, again in my memory, well over  
 15 a week for that appointment.  
 16 **MS FRASER BUTLIN:** Yes. You say in your statement I think  
 17 actually it's two weeks.  
 18 **A.** Thank you.  
 19 **Q.** But it felt like a very long couple of weeks that you  
 20 were waiting.  
 21 **A.** Yes, yes. There's so many layers to this when we're  
 22 talking because I'm trying to remember what it was  
 23 then and what I've learnt since. What it was then  
 24 felt like a vacuum. There wasn't much information  
 25 around. I didn't even know what this thing was.

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1 before it was actually confirmed that I did have  
 2 hep c.  
 3 **Q.** You've said that you attended that appointment two  
 4 weeks later and what was the attitude of the person  
 5 taking your blood?  
 6 **A.** My memory is that it was just an appointment. Very  
 7 pleasant, very polite. My assumption was that  
 8 nothing's confirmed yet, this is just a process that,  
 9 you know, a retrospective, not quite sure what that  
 10 means.  
 11 I didn't then realise that if they've bothered  
 12 to contact you it basically means you are infected, so  
 13 I thought I was still yet to be confirmed.  
 14 **Q.** Then you went back for the results a week or a few  
 15 weeks later and you were told you had hepatitis C.  
 16 Can you tell us how you were told.  
 17 **A.** Invited into a room, sat down the other side of  
 18 a desk. Again, a doctor saying, you know, terribly  
 19 sorry to have to confirm it is hep c, and I've  
 20 realised whilst listening over this last week, there's  
 21 an interesting issue about the word "counsel". I've  
 22 got my notes back now and I truly believe that the  
 23 clinician that saw me felt he had counselled me about  
 24 it. I would use the word "counsel" as in "informed".  
 25 He informed me about toothbrushes and razors and said

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1 it might mean that I will need a liver biopsy and  
 2 that ... that was it.  
 3 **Q.** When you left that appointment, having been told you  
 4 had hepatitis C, did you understand what the next  
 5 steps were going to be for you?  
 6 **A.** No. And I can absolutely say that because I remember  
 7 sitting in the car park for a good half hour just not  
 8 really trusting myself to drive and the only phrase  
 9 going round my head was what now, what's this, what do  
 10 I do?  
 11 I think -- and again I was pretty careful about  
 12 keeping papers and things and I think I did leave with  
 13 a leaflet in my hand and if I did, then that was where  
 14 I heard about the British Liver Foundation, so I do  
 15 believe they did do that, but the overpowering feeling  
 16 was just "what now? What now?"  
 17 I should add to that at the time I was a single  
 18 parent and very conscious I had two teenage daughters  
 19 and all that goes with that, the mortgage, the job,  
 20 the bills to be paid.  
 21 **Q.** We will certainly come to that shortly.  
 22 **A.** Thank you.  
 23 **Q.** You also then went to see your GP.  
 24 **A.** Yes.  
 25 **Q.** What was their response? What understanding did they

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1 **A.** Yes. I actually realised that -- it's funny how you  
 2 forget these things, until I saw the notes, I was  
 3 between two hospitals, in the end Taunton where I was  
 4 originally operated on, Taunton where I eventually had  
 5 the treatment, and Yeovil my local hospital.  
 6 Within Taunton the consultant I was referred to  
 7 turned out to be the same gentleman whose ward I had  
 8 been on for a long time failing before I had surgery,  
 9 so that was tricky.  
 10 **Q.** When you attended those appointments you took a lot of  
 11 questions with you, didn't you?  
 12 **A.** I did.  
 13 **Q.** How was that received?  
 14 **A.** Not very well. I genuinely think I approached it in  
 15 my usual style which is quite open. Both my GP and my  
 16 Dad, who at that time was a great support, had  
 17 counselled me to keep writing down questions as they  
 18 popped into my head whilst waiting for the  
 19 appointment. That turned out to be quite a list and  
 20 I had tried to resolve some of the questions myself  
 21 but I went in to, hopefully, discuss my concerns.  
 22 **Q.** What response did you receive when you went in with  
 23 that list of questions?  
 24 **A.** Again, in absolute fairness to not only this  
 25 particular gentleman but where the whole system was at

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1 have of hepatitis C?  
 2 **A.** Nothing really is the short answer. The longer answer  
 3 is met with kindness and concern and, again, if I'm  
 4 really honest, that chapter's quite a blur. But I was  
 5 left with the impression that we were on cutting-edge  
 6 medical discovery, that whatever this thing was, there  
 7 wasn't a lot of information to hand and once I got  
 8 through the initial shock of it all, my normal  
 9 paternal of survival kicked in and I was just trying  
 10 to find out, you know, who, what, when do I need to  
 11 talk to, thank goodness for the internet, although  
 12 that has some drawbacks, and that started a whole  
 13 journey.  
 14 **Q.** But in terms of your GP you said he was a kind and  
 15 supportive GP but he was the first to admit that for  
 16 him this was new ground.  
 17 **A.** Yes.  
 18 **Q.** Then, as you say, you did a lot of research yourself  
 19 into the condition helped along by your GP --  
 20 **A.** Yes.  
 21 **Q.** -- pointing you towards relevant websites?  
 22 **A.** Yes.  
 23 **Q.** You were never referred to a hepatologist but were  
 24 seen by the gastroenterologist who was seeing you, in  
 25 any event, in relation to the colectomy at this stage?

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1 the time, I genuinely think they did not have the  
 2 answers to a lot of the questions I was asking. That  
 3 was my impression.  
 4 I honestly can't remember what was said but  
 5 I did come away feeling that didn't go very well and  
 6 then since have found in my notes his wording --  
 7 **Q.** Which we're going to come to in just a moment but  
 8 before we go there can you just tell us some examples  
 9 of the questions you were asking.  
 10 **A.** Okay. Some of it was directly, you know, I've  
 11 obviously been carrying this virus now for a period of  
 12 time. I'm beginning to get information about its  
 13 impact. There was I think at the time this phrase  
 14 "slow burner", so to start off with the conversation,  
 15 it was trying to be reassuring I believe and saying,  
 16 yes, you know, people have lived with this for a long  
 17 time and I was lucky to have been told early and I do  
 18 believe that's true. But that stuck in my mind.  
 19 I was also asking about treatments and I was  
 20 also asking about the impact on my children, you know,  
 21 should they be tested and -- well, it was a longer  
 22 list than that and I can't remember them all.  
 23 **Q.** That's okay. But you didn't particularly receive any  
 24 answers to any of those questions?  
 25 **A.** No. It was admitted that I could get my children

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1 tested, although it most probably wasn't necessary.  
 2 **Q.** Before we come to the letter from one of your treating  
 3 doctors, I want to look at something first to  
 4 understand a little bit more of what your situation  
 5 was at the time?  
 6 **A.** Yes.  
 7 **Q.** Before we even go there, can you describe how you were  
 8 feeling in the sort of years of '95, '96 through to  
 9 '98? What symptoms, physical symptoms, were you  
 10 facing?  
 11 **A.** I work in images so bear with. Some of them are quite  
 12 simplistic and I've heard other people use them so  
 13 it's universal.  
 14 Partly trying to explain to my daughters,  
 15 I found the image of a car. I'd got the car polished,  
 16 it was fit, there was muscle tone but if I put my foot  
 17 on the accelerator there was not the power there there  
 18 used to be and that is how I was trying to describe  
 19 stamina. It's also the flat battery syndrome.  
 20 Aches and pains for no reason, noticing joints  
 21 were an issue. As I said before, my glands swelling,  
 22 stiff neck, and the other thing, and I just hold on to  
 23 this and for me it is a very specific thing, as  
 24 a people-working person one of the greatest skills,  
 25 one of the greatest gifts you can give somebody is to

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1 addition to this she suffers from low back pain. This  
 2 is a pain in her lower back and shoulders radiating to  
 3 her legs on occasion. It is usually present when she  
 4 wakes first thing in the morning ..."  
 5 Then if we go to the next paragraph:  
 6 "She is able to do most things physically but  
 7 she is unable to cope with the fairly strenuous  
 8 physical exertion she used to do as part and parcel of  
 9 her life and career prior to these episodes."  
 10 Is that what it was like?  
 11 **A.** Yes, yes.  
 12 **Q.** Then if we go over the page to the final paragraph:  
 13 "The fact that her liver is not particularly  
 14 inflamed or scarred at the moment may indicate she has  
 15 less of a chance of developing chronic liver disease  
 16 in the future. I think her low back ache are probably  
 17 not related to hepatitis C. However, it is well known  
 18 that a large proportion of patients with chronic  
 19 hepatitis C virus infection do suffer from quite  
 20 profound general malaise and lack of energy. The  
 21 cyclical nature of these symptoms in Mrs Taylor and  
 22 the fact that she is otherwise a very sensible lady  
 23 who clearly does try to push herself to the best of  
 24 her ability would lead me to suspect that these  
 25 symptoms are related to her continuing viral

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1 remember her name.  
 2 If you are working with young, disaffected  
 3 teenagers who are used to being "Oi you", to be able  
 4 to go up to them and say, "Hi Chris, how's it going?  
 5 How's the dog", or whatever it is you remember about  
 6 them, I was losing that facility and I was putting  
 7 that down to being tired. I've never really regained  
 8 that facility in as much as I know that was a real  
 9 skill and I have worked at putting that back. I have  
 10 to write it down now if I want to really remember  
 11 somebody's name.  
 12 **Q.** You were involved in litigation concerning the blood  
 13 transfusion, subsequently, and some expert reports  
 14 were written about you. I wonder if we can look at  
 15 one of those now. It is document 0065010. If we  
 16 could go down to the third paragraph, which starts at  
 17 "As far as her present health ..."  
 18 It says there:  
 19 "Although she found she wasn't able to recover  
 20 her previous levels of stamina, she finds she gets  
 21 cyclical symptoms, which essentially the major  
 22 component of which is lack of energy and mild general  
 23 malaise. At times these are associated with a range  
 24 of further flu-like symptoms, failure of body  
 25 temperature regulation, some joint pain, dry skin. In

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1 infection."  
 2 That view wasn't accepted, as you have alluded  
 3 to, by others who were treating you, was it?  
 4 **A.** It's really difficult to shuffle the time zones but it  
 5 did feel that if you were talking to a specialist  
 6 versus a nonspecialist there was quite a gap in the  
 7 understanding. I think that's fair to say.  
 8 **Q.** You said it wasn't just a gap in understanding, it was  
 9 also a gap in attitude.  
 10 **A.** Yes, yes.  
 11 **Q.** Can we look at 0065008, please, and the third  
 12 paragraph "She expressed herself ...":  
 13 "She expressed herself rather put out that I do  
 14 not attach such importance to her non-specific  
 15 symptoms as to have reported them to some central  
 16 authority responsible for hepatitis C. I have  
 17 explained to her that her symptoms are very  
 18 non-specific and of low discriminant value, probably  
 19 occurring in up to 30 per cent of most patients with  
 20 most diseases attending my clinics."  
 21 That's what was written to your GP at the time  
 22 unbeknownst to you?  
 23 **A.** Absolutely.  
 24 **Q.** But I think you have said that was representative of  
 25 the attitude that you were facing at this time?

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1 A. And it's interesting to see the response to my list.  
 2 That top one:  
 3 "She was emotionally a bit more stable, although  
 4 still very intense."  
 5 That means I came in with a list of questions.  
 6 Q. How did it make you feel when you attended those  
 7 appointments and were faced with that attitude?  
 8 A. If I hadn't had a really kind, caring GP I would have  
 9 really struggled because at the time the information  
 10 on the net wasn't that brilliant either and it was  
 11 very easy to get drawn into chat groups that were  
 12 being extremely negative. Yeah, thank goodness for my  
 13 GP.  
 14 Q. Having obtained your records recently, you've also  
 15 found another letter. Could we have up 0065009,  
 16 please. This is letter is dated 3 July 19 --  
 17 A. Do you mind can I -- I hang on to thoughts rather  
 18 fragiley and I was going to save it to the end but,  
 19 Sir Brian -- it's going now because it's important.  
 20 Let me look at my notes.  
 21 Part of the thing that I have continued to  
 22 struggle with is the so-called non-specific symptoms.  
 23 I totally understand that a medical professional  
 24 person cannot take action until there is clinical  
 25 evidence. What I'm beginning to understand is if

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1 it.  
 2 **SIR BRIAN LANGSTAFF:** Just give me one moment. Yes, thank  
 3 you very much.  
 4 **MS FRASER BUTLIN:** Just to pick that up, it's a little bit  
 5 more than that, though, that you have had, isn't it?  
 6 In 2010 you had a possible transient ischaemic attack,  
 7 mini-stroke.  
 8 A. Yes.  
 9 Q. 2013, you had a kidney infection requiring three  
 10 courses of antibiotics. That's when you had the very  
 11 high white cell count and abnormal bone marrow biopsy?  
 12 A. Yes.  
 13 Q. And the doctors thought you may have some form of  
 14 leukaemia?  
 15 A. Yes.  
 16 Q. And December 2017 you had what seemed to be like flu  
 17 but you were then left with very severe fatigue  
 18 thereafter.  
 19 A. Yes.  
 20 Q. Since then you've been unable to work --  
 21 A. Yes.  
 22 Q. -- because it's been so severe.  
 23 A. Yes.  
 24 Q. You don't know whether they are related to hepatitis C  
 25 but you wonder, as you said, whether there is a link

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1 nobody is recording all our non-specific post  
 2 treatment, post infection symptoms, there never will  
 3 be any clinical evidence.  
 4 So there's a whole bunch of us out there going  
 5 to specialists, going to different departments, trying  
 6 to describe our symptoms over and over again, only to  
 7 have, quite rightly, these physicians saying, well, it  
 8 isn't whatever their specialty is, I can't help you.  
 9 So I personally over the last few years have been to  
 10 rheumatology, I do not have lupus. Thank you.  
 11 I didn't think I did.  
 12 I was -- yes, rheumatology. I was under  
 13 haematology because my platelets spiked very high  
 14 after a kidney infection. I was within a fortnight of  
 15 taking chemo for a leukaemia-related illness and then  
 16 my platelets dropped of their own accord. It was just  
 17 my body overreacting to three lots of antibiotics due  
 18 to the kidney infection.  
 19 If there was somebody somewhere, please,  
 20 recording and cataloguing the evidence we now have of  
 21 possibly -- I will say that, possibly -- permanent  
 22 post interferon or post treatment and post infection,  
 23 that would be such a help.  
 24 Q. Just to pick that up with you, Joan --  
 25 A. Sorry to drop it in there but I was scared of losing

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1 either with the hepatitis C or with the treatment  
 2 you've received.  
 3 A. Yes. Sorry to interrupt the flow.  
 4 Q. Not at all. It's such an important piece, Joan,  
 5 I want to just read part of your statement and ask you  
 6 to confirm it or comment further on it. You've said:  
 7 "Whether these symptoms and others were as  
 8 a result of the interferon or the hepatitis C I do not  
 9 know. I just know that I have not been well since the  
 10 blood transfusion and I used to be a very fit and  
 11 determined person. I knew that the treatment had side  
 12 effects but the possibility of long-term or possibly  
 13 permanent side effects were never discussed with me.  
 14 I know that there was enough research in the US for  
 15 them to have doubts about the treatment and I am not  
 16 aware of any information being withheld from me but if  
 17 you don't know the questions to ask, it's difficult to  
 18 say."  
 19 You now reflect whether you would have pushed so  
 20 hard for the treatment if you had known about the  
 21 effect of it in a longer term sense; is that right?  
 22 A. Yes, and thank you for that prompt.  
 23 Nothing happens in isolation and if I just give  
 24 you a thumbnail sketch, I knew I was infected, I was  
 25 aware it was impacting on me in unknown ways. I was

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1 a single parent. My Mum died when I was 22/23. I had  
2 two girls approaching that age and I was just  
3 absolutely determined to be well.

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

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

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

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

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1 How did you feel physically during that  
2 treatment?

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

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

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

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

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1 they were too ill.

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

9 Q. Before you got on the trial you say:

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

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

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

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

6 Yeah --

7 Q. They were out of the house?

8 A. Exactly.

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

10 A. Yes, yes, totally doable I felt.

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

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

20 Q. Your statement says:

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

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

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1 Q. You love to read, don't you --  
 2 A. Yes.  
 3 Q. -- Joan, but during the treatment there were times  
 4 when you couldn't even do that.  
 5 A. I started this trial with a group of people, some of  
 6 whom just had to do the six months and I do remember  
 7 getting to six months and realising I had a whole  
 8 other six months to go and that was bleak. By then my  
 9 body was really struggling.  
 10 I think technically my platelets and everything  
 11 else that they looked at were fine. My body was  
 12 obviously under stress but there was no clinical  
 13 reason to stop, so I was determined to keep going.  
 14 But by then the symptoms had intensified.  
 15 My eyes -- I wouldn't need another prescription  
 16 but the ability to focus, fine focus and read, would  
 17 come and go. So I couldn't get lost in novels which  
 18 when I was really poorly was something that was  
 19 something I liked to do.  
 20 Q. So you've described setting up a chair in front of the  
 21 window where you could simply sit and look out at  
 22 nature.  
 23 A. Yeah, and that was another thing. Part of the  
 24 contraindications is you've got to be very careful  
 25 about sunlight and I keep myself sane by walking and

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1 on but that I had my treatment in.  
 2 The impact of the stress of worrying about him,  
 3 I think, was part of the trigger but I did walk down  
 4 a corridor -- most -- quite a lot of the hospital is  
 5 now changed so I approached the hospital and it felt  
 6 like a new place but every now and then you turn the  
 7 corner and you're in the same old corridor and I'd  
 8 never experienced this before but it isn't even an  
 9 intellectual process, it's a sheer body impact of --  
 10 it manifests as shaking and sweating, a sense of dread  
 11 and you don't quite know where the danger is coming  
 12 from.  
 13 I thought, perhaps I was -- well, I didn't know  
 14 what I thought. I had to go sit in the loo for  
 15 a while. That happened on one occasion when I walked  
 16 down a corridor and then I realised it had been my  
 17 route to the chemo ward, which is where my treatment  
 18 had been run.  
 19 Then another night I was with [redacted], who  
 20 was actually sleeping quite peacefully. But he has  
 21 learning difficulties, so we had to -- or we took rota  
 22 change so that if he woke up, he wouldn't start  
 23 pulling out his tubes. That was fine. We were  
 24 dealing with that. But then the crash button alarm  
 25 went for somebody else and just that noise ... I had

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1 being out in nature. So if I went out during bright  
 2 sunlight it was hat, long sleeves, sunscreen, or --  
 3 and I thought this was quite smart -- I'd go out  
 4 really early in the morning or in the evening but  
 5 there were times when I needed to be outdoors but  
 6 couldn't really walk. So then the next best thing was  
 7 to sit by the window.  
 8 Q. You also had substantial hair loss and numb toes and  
 9 fingers and you still have some residual partial  
 10 numbness?  
 11 A. Yes, and the hair hasn't grown back on the nape of my  
 12 neck. It's a minor thing but when people then say  
 13 there's no evidence of permanent damage, actually  
 14 there is. Perhaps we're just not looking in the right  
 15 places.  
 16 Q. Emotionally, it's been very difficult as well and more  
 17 recently you were seen by your GP and a counsellor and  
 18 they diagnosed you with PTSD. Do you feel able to say  
 19 any more about that?  
 20 A. I do and this is what I mean about life -- things  
 21 don't happen in isolation, do they? Goodness knows  
 22 how this set of combination of events could ever have  
 23 come together but [redacted], he was on holiday in  
 24 Somerset, became critically ill with pancreatitis and  
 25 landed up in the hospital that not only I was operated

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1 another visit to the toilet to shake.  
 2 Q. You have had some counselling. You've had three  
 3 blocks of counselling over the years but, on each  
 4 occasion, there's been a very long wait between the  
 5 referral and actually getting to see the counsellor.  
 6 A. Yes, yes.  
 7 Q. I just want to go back to when you were undergoing the  
 8 treatment. You claimed Incapacity Benefit while you  
 9 were undergoing the treatment and, for the year after,  
 10 when you were recovering and you were required to go  
 11 for a medical assessment during that time.  
 12 Can you tell us what happened during that first  
 13 assessment.  
 14 A. The first assessment, I believe, was after the  
 15 six-month benchmark. So I know I'm struggling.  
 16 A friend very kindly drove me to the appointment and  
 17 it was a tremendous effort just to get there, and  
 18 I got ready for the battle, went in and was actually  
 19 seen by a GP, and I don't know if everybody is  
 20 anymore, and the first thing he said as I sat down is  
 21 "I'm terribly sorry, had I seen your file before you  
 22 would not have been called in", and I'd been ready for  
 23 a fight and there he was being nice so I burst into  
 24 tears.  
 25 Q. What did he advise you do?

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1 A. He advised that I talk to whoever was in charge of my  
2 treatment and get them to write a letter.  
3 Q. Which they did?  
4 A. They did.  
5 Q. But you were still called for a second assessment?  
6 A. Yes.  
7 Q. The DWP insisted on assessing you during the year you  
8 were supposed to be recovering and you found the whole  
9 benefits system horrendous?  
10 A. Yes. I ... I have professionally supported people  
11 claiming benefits and been their supportive other and  
12 seem them struggle. I'd never expected to be in that  
13 position myself. At best, even if you are treated  
14 with common courtesy and politeness, it is a difficult  
15 place to find yourself in but I did on one occasion  
16 have quite a difficult conversation with a woman who  
17 basically said, "Well, it's not chemo, what's the  
18 problem?"  
19 Q. You've said:  
20 "I hadn't perceived myself as having a lot of  
21 pride but the one thing I did pride myself on was  
22 being resilient and I found the whole process of  
23 applying for benefits and attending the assessments  
24 really demeaning."  
25 A. Yes.

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1 already experienced issues about having hep c, feeling  
2 that I would have to declare it, and I know because  
3 it's a small network within the people-working field  
4 that there's at least two jobs that I didn't get  
5 because of hep c.  
6 So here I am out the other side of a really  
7 horrendous couple of years, talking to my GP and just  
8 basically saying, feeling, I had this battle again.  
9 At what point -- you see, sorry, I'm interrupting  
10 myself but one of the hard things with the treatment,  
11 you do not get a certificate and well done madam you  
12 are now clear. We slipped into a limbo of we have to  
13 wait to see if it might not come back. So it was  
14 years before I actually got to the point where I could  
15 say I have absolutely cleared hep c.  
16 Q. But you went to your GP to ask that question?  
17 A. I did.  
18 Q. And said, "Who's going to employ me now."  
19 A. And he said he would.  
20 Q. So you went to work for the GP as a receptionist in  
21 the surgery?  
22 A. *(The witness nodded)*  
23 Q. You've since had to give that up because the fatigue  
24 is simply too much?  
25 A. Yes. This is now a different surgery and I've moved

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1 Q. A year after you had finished treatment, you couldn't  
2 face another assessment and so you decided to find  
3 some part-time work. You went to your GP to ask when  
4 you'd receive confirmation of having cleared the virus  
5 because you had cleared the virus --  
6 A. Yes.  
7 Q. -- and whether you had to tell employers about it.  
8 What else did you say to the GP at that point?  
9 A. Do you know, I've got sidetracked by some memories so  
10 I'm not quite sure what we're referring to there.  
11 Q. That's okay, don't worry. You've said in your  
12 statement you also asked "Who's going to employ me  
13 now?"  
14 A. Oh, yes, bless him. If I put that all into context,  
15 I had -- having had to give up the youth work post and  
16 whilst I was waiting for treatment, I'd cobbled  
17 together various jobs and I had found one project job  
18 that I'd really loved and then I'd had to give that up  
19 because of the treatment.  
20 There was a real issue for me about employment  
21 because I have people skills, I work for the  
22 Government in teaching, youth work, and the criteria  
23 about offering up your medical history is just  
24 a given.  
25 Prior to this completion of the treatment, I'd

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1 and things have happened but because of that kind man,  
2 I had another career in which I was accepted. I've  
3 only ever been able to work part-time but I have  
4 worked through every single health thing until now  
5 and, yeah, it was a job. Believe it or not it was  
6 a job I enjoyed because I was the right side of the  
7 table to deal with people who were struggling.  
8 Q. As you spoke a moment ago, you alluded to having tried  
9 to apply for work involving young people in the 1990s  
10 in that hiatus between having been diagnosed and  
11 having your treatment and not getting those jobs.  
12 Can you tell us a little bit more about what  
13 happened then.  
14 A. I found myself in the position where I wasn't too sure  
15 about my health. There was quite a lot of project  
16 work going on at the time and I applied for one which  
17 would have been short-term and was, in fact, basically  
18 overqualified for, knew somebody on the panel who  
19 afterwards very kindly took me to one side and said,  
20 "You were doing really well. It was just the question  
21 of your health".  
22 Actually, I took that on the chin because  
23 I thought that particular project, maybe that was  
24 fair. It would have been really intense. So the next  
25 job I remember applying for would have been I think it

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1 was two days face-to-face and a day admin reporting  
2 for whatever it was, 18 months, and I think it was  
3 somebody on the panel actually raised the question of  
4 my health and energy, which surprised me but thinking  
5 on my feet I said, "Thank you very much for asking  
6 that question because I can affirm that I'm doing  
7 okay", or words to that effect but, no, I didn't get  
8 that job either.

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

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

14 A. *(The witness nodded)*

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

17 A. Yes.

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

20 A. Yes.

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

23 A. No.

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

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

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

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

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

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

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

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

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

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

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

24 The reason I'm not working now is I had bad flu  
25 2017 and it's taking me this long to get to a point

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

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

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

17 A. Yes.

18 Q. You have since more recently had copies of your  
19 medical records and in those records there was  
20 a document we can have up, 0065009. It's dated  
21 3 July 1998 and can we highlight the first paragraph  
22 to begin with.

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

25 A. I think this was to the consultant.

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1 Q. That's exactly, it's to your consultant -- apologies.  
 2 It's to your consultant and it says at the top:  
 3 "As relatively little is known about HCV  
 4 infection, transmission or the clinical course of the  
 5 resultant disease, a national register of HCV  
 6 infections is being created ... funded by the  
 7 Department of Health and will provide a facility for  
 8 the future monitoring and long-term assessment of HCV  
 9 infection within the UK."

10 Then the third paragraph, please, Paul.  
 11 "I have enclosed an information sheet explaining  
 12 the purposes of the registry which you may like to  
 13 pass to your patient. No patient will be contacted  
 14 directly. However, this information sheet has been  
 15 provided for clinicians who feel they would like to  
 16 notify their patients of their inclusion in the  
 17 register."

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

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

25 A. No.

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1 somewhere my name had been shared and I don't remember  
 2 even how I was approached, whether it was a telephone  
 3 call -- I eventually had a letter and liaised locally  
 4 with Clarke & Son and they were linked with whoever  
 5 was organising the action.

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

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

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

12 A. No.

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

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

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

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

24 SIR BRIAN LANGSTAFF: Thank you.

25 A. That's the only register I'm aware of where my

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

2 A. No.

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

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

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

17 A. No. But this piece of paper then made sense of  
 18 something else that had happened in my life, in that  
 19 I was approached in about '94 -- no, it must have been  
 20 after '96, whenever it was -- by the group that were  
 21 taking that first action that eventually ended in the  
 22 Skipton Fund and I did join in that process but I at  
 23 no point had looked to join. Life was too full.  
 24 I wouldn't -- it had not even crossed my mind to look  
 25 at sort of litigation or anything. So somehow

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1 information has been shared.

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

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

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

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

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

22 SIR BRIAN LANGSTAFF: Thank you very much.

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

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1 A. Yes.  
 2 Q. Financially things have been difficult for you and  
 3 particularly in relation to having to claim benefits  
 4 and not being able to work to the extent you would  
 5 have liked.  
 6 Have you ever applied for insurance?  
 7 A. No, is the short answer.  
 8 Q. Why not?  
 9 A. Part of the reasoning that I even joined the original  
 10 litigation was that I became aware how little I knew.  
 11 One of the useful bits of information -- and  
 12 I do mean that -- that came through was -- and this is  
 13 me, my interpretation of what I read -- was hold fire  
 14 on requesting any insurance because within the  
 15 time-frame historically the hep c was being lumped in  
 16 with the HIV and it was the time of all the negative  
 17 publicity and I was informed that insurance companies  
 18 were counting them as one and the same, and if I had  
 19 a refusal on an application, that would carry forward  
 20 to any other application.  
 21 Q. In terms of financial assistance, you've received  
 22 a payment from The Skipton Fund?  
 23 A. Yes.  
 24 Q. But then you weren't aware of the England Infected  
 25 Blood Support Scheme until the Inquiry was announced.

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1 original points which was this thing of if nobody is  
 2 recording our chronic fatigue-like symptoms, there is  
 3 no recognition of them as a condition. If you don't  
 4 tick the right box on the conditions list, then you  
 5 don't get benefits, you don't get the next notch up.  
 6 Q. You've described the process as:  
 7 "... incredibly humiliating and demeaning. My  
 8 feeling is if they have decided we qualify for some  
 9 kind of compensation support, they should stop making  
 10 us jump through the hoops to get it."  
 11 A. Yes. You're left in this position where if -- to be  
 12 left with any modicum of sort of dignity, if I go out  
 13 of my front door, I hold my head up, I dress well and  
 14 I try and present well. If you turn up at a benefit  
 15 office like that, you're immediately disqualified. So  
 16 what do I do? Do I then go in still upright but then  
 17 tell them of the bad days? To tell them of the bad  
 18 days is doable but you're talking to a stranger,  
 19 you're talking to somebody who has no concept of what  
 20 I mean when I say I'm having a bad day. To them, that  
 21 maybe means they stubbed their toe. To me, that means  
 22 I'm in pain, my joints ache, I'm potentially running  
 23 a temperature. If I push it, I will get the shakes.  
 24 If I push that beyond that threshold -- I have issues  
 25 with body temperature regulation, so I can go cold or

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1 A. Yes.  
 2 Q. How did you come to hear up hear about it?  
 3 A. Thank heavens for Facebook and the networking.  
 4 I dug out my folder that still had the Skipton  
 5 information and emailed just wanting to know what the  
 6 current state of affairs was and within that -- and  
 7 I didn't think to print it off -- it was basically  
 8 stated they hadn't passed on my information to this  
 9 new body because I had never granted them the  
 10 authority to do so, which is good. But then they  
 11 didn't contact me to tell me they needed my authority;  
 12 so nothing got passed.  
 13 Q. How did that make you feel?  
 14 A. I realise I must be quite punch-drunk with all of this  
 15 now because I just remember laughing. I mean, how  
 16 ridiculous is that?  
 17 Q. Since then, you have applied to the EIBSS --  
 18 A. Yes.  
 19 Q. -- and have received some payments but how do you feel  
 20 about the process of applying for financial  
 21 assistance?  
 22 A. It feels like the benefit system again in that, above  
 23 and beyond the basic payment, anything else you need  
 24 to fill out forms, you need GPs to qualify and state  
 25 how ill you are or not. It comes back to one of my

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1 hot. If I push that, then I'm in bed.  
 2 Q. You feel that the process to obtain payments or  
 3 different levels of payments from the EIBSS is the  
 4 same system and requirements that are on you then?  
 5 A. Because they are looking for the same clinical  
 6 tick-box exercise and, no, I do not have lupus and no,  
 7 I do not have ME and no, I do not have MS. "I cannot  
 8 tick your box for you, madam" is what I land up saying  
 9 but, no, that does not mean I'm fit to work.  
 10 Currently, I've worked really hard to get back  
 11 to a certain level of fitness. The only reason  
 12 I haven't been able to return to my job is what  
 13 I cannot do is guarantee to you that every morning for  
 14 my 9 o'clock shift I can turn up and do five hours.  
 15 Q. Joan, those are the questions I have for you. Is  
 16 there anything else you would like to say?  
 17 A. Thank you.  
 18 Q. I am just going to turn my back and ask Mr Lock if  
 19 there's anything else.  
 20 (Pause)  
 21 Just one more thing, Joan, Mr Lock would like me  
 22 to raise. Do you feel anyone should act as a care  
 23 co-ordinator given that hepatitis C produces so many  
 24 different symptoms?  
 25 A. It loops back, Sir Brian, to what I was trying to say.

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

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

14 **MS FRASER BUTLIN:** Can I just take a moment, sir, to check  
 15 one other matter. *(Pause)*  
 16 There's a second matter that I think I did ask  
 17 you but we can't instantly find it on the transcript;  
 18 so if I have, I apologise.

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

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

25 What I would like is to know that things are

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1 **A.** Oh thank you so much.

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

7 **A.** Thank you.

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

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

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

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

17 **MS FRASER BUTLIN:** Thank you.

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

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1 that.

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

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

9 **A.** Yes, thank you.

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

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

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

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

17 **SIR BRIAN LANGSTAFF:** We will start then at 10.30 on  
 18 Tuesday. I've already told you that we will start at  
 19 10.30 next week. There's a slight change to that.  
 20 Let me explain: it's going to be 10.30 on Tuesday;  
 21 10.30 on Wednesday; it will be 10.00 on Thursday,  
 22 that's for reasons of witness convenience; and it will  
 23 be 10.00 on Friday. That's because I know that some  
 24 of you may well be staying over and it makes it easier  
 25 for you to get home in time for the weekend.

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1 So 10.30 Tuesday/Wednesday, 10.00 on  
2 Thursday/Friday. Thank you very much. I look forward  
3 to seeing as many of you as would like to be here on  
4 Tuesday.  
5 (2.40 pm)  
6 (Adjourned until 10.30 am on Tuesday, 7 May 2019)  
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(37) go... - hopefully



<b>H</b>	33/14 34/22 37/4 37/14	54/22 60/9 61/4 61/5 67/9 67/14 76/1 77/12 77/13 79/12 80/5 86/11 89/23 90/17 91/21 92/3 95/3 97/15 97/21 99/17 113/16 114/14 115/17 <b>I didn't [24]</b> 17/1 26/7 26/9 27/15 27/15 27/16 34/2 34/3 34/17 38/4 46/18 48/7 51/12 55/2 60/11 74/25 75/3 76/11 86/11 95/13 99/4 101/7 110/7 115/11 <b>I die [3]</b> 19/12 19/12 19/13 <b>I do [15]</b> 23/24 28/15 59/17 77/10 77/14 80/17 86/10 88/8 90/14 93/6 94/20 109/12 111/16 113/23 115/22 <b>I don't [29]</b> 6/7 6/7 9/8 9/8 21/15 22/25 23/2 25/15 25/18 28/6 28/19 29/10 29/12 30/13 30/14 30/19 30/20 31/18 36/25 39/20 44/25 64/15 96/19 102/9 103/21 107/1 107/23 108/7 113/1 <b>I dress [1]</b> 111/13 <b>I dug [1]</b> 110/4 <b>I enjoyed [1]</b> 100/6 <b>I even [3]</b> 22/22 89/5 109/9 <b>I eventually [2]</b> 79/4 107/3 <b>I explained [1]</b> 60/22 <b>I fall [1]</b> 25/7 <b>I feel [3]</b> 20/14 26/20 37/21 <b>I fell [1]</b> 2/4 <b>I felt [5]</b> 50/11 50/11 72/18 90/8 92/10 <b>I finished [1]</b> 49/17 <b>I for [1]</b> 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[2]</b> 56/23 77/14 <b>I hold [1]</b> 111/13 <b>I honestly [1]</b> 80/4 <b>I hope [2]</b> 29/6 29/7 <b>I inject [1]</b> 54/4 <b>I injected [2]</b> 46/2 92/16 <b>I joined [2]</b> 67/17 114/6 <b>I just [16]</b> 23/1 28/8 29/5 29/18 37/3 46/19 49/19 50/2 70/17 71/22 81/22 88/9 88/23 89/12 96/7 110/15 <b>I keep [1]</b> 93/25 <b>I knew [8]</b> 37/23 41/22 50/11 56/3 88/11 88/24 91/20 109/10 <b>I know [11]</b> 9/9 16/3 29/4 30/17 64/15 82/8 88/14 96/15 99/2 107/8 116/23 <b>I land [1]</b> 112/8 <b>I laughed [1]</b> 43/7	<b>I led [1]</b> 43/8 <b>I left [1]</b> 71/14 <b>I liked [1]</b> 93/19 <b>I look [2]</b> 37/6 117/2 <b>I looked [4]</b> 33/8 43/7 44/23 58/22 <b>I love [2]</b> 25/21 29/3 <b>I made [2]</b> 51/12 74/11 <b>I managed [1]</b> 91/12 <b>I mean [3]</b> 94/20 110/15 111/20 <b>I mentioned [1]</b> 36/22 <b>I met [2]</b> 51/24 75/21 <b>I might [1]</b> 40/23 <b>I missed [1]</b> 12/4 <b>I must [1]</b> 110/14 <b>I need [3]</b> 53/9 78/10 103/19 <b>I needed [1]</b> 39/9 <b>I never [2]</b> 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