

1 **Wednesday, 10 July 2019**

2 **(10.07 am)**

3 **SIR BRIAN LANGSTAFF:** My apologies to you and to Mr X who  
4 is our next witness for there having been a slight  
5 technical hitch this morning, which meant that we've  
6 started a little late.

7 As I've indicated by calling him Mr X already, he  
8 is giving evidence anonymously and therefore the usual  
9 order will be made. Let me tell you what it is.

10 The name and address of witness W2137, Mr X to you  
11 and me, and any other identifying information, such as  
12 the witness's image or a description of their  
13 appearance, cannot be disclosed or published in any  
14 form unless express permission is given by me or by  
15 the Solicitor to the Inquiry acting on my behalf.  
16 Witness W2137 must be referred to only as Mr X.

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

21 With that introduction, may we have Mr X, please.

22 **MR X, affirmed**

23 **Questioned by MS RICHARDS**

24 **MS RICHARDS:** Mr X, in 1976 you had an accident. Can you  
25 tell us what happened.

1   **A.** Yes. I was working as a logger for the [redacted] in  
2       the forests of sort of Dumfries and Galloway, chain  
3       sawing and snedding and felling and I had an incident  
4       with a log that had come down and got lodged in  
5       another tree, and it went a bit wrong and I sort of  
6       grabbed the branch, the very large branch, and  
7       wrenched my left groin area during that mishap.

8   **Q.** You had to have surgery.

9   **A.** Yes.

10 **Q.** Which took place on 26 May of 1976.

11 **A.** Yes.

12 **Q.** What kind of surgery was it?

13 **A.** It was a left inguinal repair.

14 **Q.** And you've been left with a sizeable scar, 6-inch  
15       scar?

16 **A.** That's correct, yeah.

17 **Q.** What do you recall being told by the surgeon after you  
18       came round following the operation?

19 **A.** Drowsy as I was, my mother was there, one of the few  
20       times she could attend because he lived in a small  
21       town not too far away but in those days there was very  
22       little buses, but she was there with me and the  
23       surgeon came round and had said that there had been  
24       a minor complication and that everything's absolutely  
25       fine and okay, but there was an administration of so

1 many units of blood, and three units of blood is what  
2 I remember, and it is what my mother remembered as  
3 well, is three units of blood was administered during  
4 the complication of the procedure.

5 **Q.** In the days that followed on the ward there was some  
6 friendly banter with you and the nursing staff. Can  
7 you tell us about.

8 **A.** Yeah, banter it was, it was purely, you know, good fun  
9 and they had said that, you know, the blood was from  
10 America and I would start to speak in a Yankee Doodle  
11 accident, so I did, much to the consternation of the  
12 nursing staff, for a few days.

13 And they said that, you know, there was other bits  
14 of banter that I would have to, you know, drink three  
15 pints of Guinness to make up for the poor blood that  
16 came from America because it wasn't as good quality as  
17 good old Scottish blood. It was kind of banter like  
18 that and my Mum was present when that was happening  
19 for that part of the time she was there, and nothing  
20 more than just friendly comical banter.

21 **Q.** And how was your recovery from the operation?

22 **A.** It was -- I found it very difficult being a young fit  
23 man and, you know, the nursing staff and everyone said  
24 that I was putting it on and milking a bit but  
25 I really was in agony and pain. I couldn't lift my

1 head up. The muscle tension as soon as I lifted my  
2 head up was very sore, and there was a lot of bleeding  
3 in the wound and there was a lot of pain. I had to  
4 get administered with painkillers, and I was kept in  
5 extra time at the hospital for that recovery.

6 At one point I was wheeled next door to the next  
7 ward to visit this gentleman who was 76 years old who  
8 had the same operation as me on the same day and he  
9 was up and walking and they said, "Well, if he can do  
10 it, you can do it", and I remember that.

11 So it must have been something to try and  
12 encourage me to get up and try walking and get moving  
13 but I found I couldn't do that for many days and,  
14 unfortunately, the gentleman died the next day, so  
15 I hoped I wasn't going to go through that experience  
16 at the age of 18.

17 **Q.** We've got your discharge letter. 2137002.

18 **A.** Mmm-hmm.

19 **Q.** And we can see that refers to you being admitted for  
20 the surgery. It refers to making a satisfactory  
21 recovery and being allowed home on 3 June 1976.

22 **A.** Yes.

23 **Q.** Is it right that you went directly home or did you go  
24 to a [redacted] for a further recovery first?

25 **A.** No, it was kind of my first of my negotiation skills

1 with the hospital, that I wanted to get out of the  
2 hospital I was in and go nearer home so that my  
3 friends and my family could visit me, but they  
4 wouldn't allow me to go because I had a longer period  
5 to recover for whatever reason that was, and I went to  
6 the local [redacted] for that recovery. That was the  
7 deal that was done, that I would go there for --  
8 I think I was in total in hospital for 12 days,  
9 I think, four days five days in the [redacted] and  
10 seven or eight days at the main hospital where I had  
11 my operation.

12 **Q.** And whilst this letter doesn't refer in its text to  
13 you having any transfusion, you have a clear  
14 recollection of the doctor telling you so after the  
15 operation and of the conversations that followed with  
16 the nurses in the way you've described.

17 **A.** I do, yes, yeah.

18 **Q.** And the handwritten addition we see on the letter:

19 "Had three units of blood."

20 That, as I understand it, is an addition made in  
21 2002 by your then GP following discussions you had  
22 with that GP?

23 **A.** That's correct, yeah.

24 **Q.** Can we also have up on screen, Paul, 2137011, and it's  
25 not a very clear document.

1   **A.** No.

2   **Q.** But this, as I understand it from your statement,  
3       Mr X, is your GP notifying the Royal Infirmary of  
4       Edinburgh of your operation in November 1976 when you  
5       moved to Edinburgh in case you needed any further care  
6       arising out of it?

7   **A.** Yes, yeah. There was some sort of very sort of light  
8       fluid coming from the wound for many months after, so  
9       this -- this may have been in relation to that.

10  **Q.** And you got on with your life, you worked, you had  
11       a partner, you had two children.

12  **A.** Correct, still have.

13  **Q.** Mountain climbing and triathlons became one of your  
14       great passions.

15  **A.** Yes.

16  **Q.** But around 1997 you were starting to feel unwell.  
17       What can you tell us about that?

18  **A.** My recollection I had -- when I was doing preparation  
19       for a triathlon competition was that, you know, you'd  
20       be obsessed with your times, you know, swimming,  
21       running, cycling, and it felt that the time -- my  
22       timings were going down. I wasn't achieving what  
23       I wanted to achieve for the competitions and I felt  
24       that after each sort of hard training session I would  
25       just feel completely absolutely wiped out and

1 exhausted.

2 I was young at the time and I did have a sort of  
3 quite a good social life, so I was out, you know, on  
4 the town and I probably drank too much at that time,  
5 but I remember as well that the next day, you know,  
6 after a few pints I would feel just absolutely awful  
7 with a raging hangover that would sedate an elephant  
8 and all my friends, you know, seemed to be in good  
9 shape and good form when we went out for our early  
10 morning sort of ten-mile run and I would be lagging  
11 behind I just felt I had really no energy and  
12 I couldn't keep up the level that I know I was capable  
13 of.

14 **Q.** So you went to see your GP.

15 **A.** Mmm-hmm.

16 **Q.** What were you told first of all?

17 **A.** Well, she did checks, et cetera, and blood pressures  
18 and all that kind of thing. I mean, again, she just  
19 said I'm probably training too hard and drinking too  
20 much and everything is fine. You know, that my heart  
21 and everything was in excellent condition and just  
22 ca canny a bit and, you know, leave off drinking too  
23 much and don't push yourself into the ground by  
24 training too much and working too hard.

25 **Q.** But the symptoms didn't go away or get better and so

1           you went back to the GP a while later.

2   **A.** Yeah. Yes, that's correct that was triggered with  
3           a bit of a panic attack after a session on -- I think  
4           I was trying to do a half marathon at the time and  
5           I collapsed halfway through and I just went into a bit  
6           of a panic attack, is the best way to describe it.  
7           That kind of triggered me going back to see my doctor,  
8           yes, because the same set of circumstances were still  
9           there, that I just felt that my legs were full of  
10          lead. I wasn't achieving the times that I wanted to  
11          achieve and I was getting left behind with my -- with  
12          my friends, which was really annoying.

13   **Q.** We'll look at your records later in your evidence when  
14          we deal with issues about the accuracy of what's  
15          recorded in there, but what do you recall happened  
16          when you went back to your GP on this next occasion?

17   **A.** Much the same thing was said that, you know, I was  
18          probably training too hard and that I was probably,  
19          you know, burning my candle at both ends a bit too  
20          much and I should sort of slow down with that.

21                 More tests were done, blood pressures and suchlike  
22          and I remember saying, you know, we should maybe run  
23          further tests and I said -- I can't remember what  
24          I said and that's all my recollection was, that I felt  
25          I needed -- there was something wrong with me. I knew



1           there was something not quite right and I said, "Okay,  
2           whatever you think".

3   **Q.**   And your statement explains that she took some bloods  
4           for testing, but you --

5   **A.**   Yes.

6   **Q.**   -- weren't sure what the tests were going to be.

7   **A.**   No, no.

8   **Q.**   What information was then given to you by the GP about  
9           the results of the blood test?

10  **A.**   I was brought in, I can't remember how many days or  
11           weeks later, and told that I was hepatitis C positive.

12  **Q.**   What can you recall of your reaction, first of all?

13  **A.**   I was a bit in shock, a bit sort of speechless, which  
14           is unlike me, and slightly out of kilter with what is  
15           this thing that I've got, not quite sure what it was.  
16           I hadn't really a clue. I'd never heard of it before.

17           I'd kind of heard of hepatitis, you know,  
18           I believe it was all to do with maybe people  
19           travelling to India and coming back a bit yellow, but  
20           I didn't know anything about it. It was a kind of  
21           a stereotypical knowledge of what hepatitis was, you  
22           got it on the hippy trail to Afghanistan and India if  
23           you went there and came back a bit yellow and  
24           recovered from it.

25  **Q.**   And you say in your statement that you recall the GP

1 asking you questions about IV drug use.

2 **A.** Yes, yeah, I was kind of taken aback by that as well.

3 It didn't bother me but, yes, there was a kind of, you

4 know, overemphasis on the questioning regarding have

5 I taken intravenous drugs before or any other kind of

6 drugs before. Have I ever injected drugs before?

7 "Are you sure you haven't done this before?" And

8 there was just no way that I'd done that.

9 **Q.** Was the GP in a position to give you or did she give

10 you information and advice about your condition and

11 about hepatitis C and its prognosis or the risks of

12 infecting others?

13 **A.** No. No, to be fair, you know, looking back at it now,

14 it was new to even doctors and I think we were both in

15 the same kind of situation that we didn't know very --

16 anything about it really.

17 **Q.** You were referred to a consultant --

18 **A.** Yes.

19 **Q.** -- at the Royal Infirmary of Edinburgh but it took

20 some months before you recall seeing that consultant?

21 **A.** Yes, it took a while. It seemed like a lifetime.

22 **Q.** And what did he tell you?

23 **A.** He said that I had a very serious condition that would

24 affect the quality of my life if it got any worse, and

25 that it would probably lead to some serious

1 complicated health conditions, cirrhosis was one of  
2 them, and he also said you can get that from drinking  
3 as well, but it's the main, sort of, victim of  
4 hepatitis C was a deterioration in liver function and  
5 leading to cirrhosis and hepatocellular carcinoma.  
6 All these words were thrown at me. I was only  
7 18/19(*sic*), I was completely confused and dazed.  
8 I thought I was going to die within the next few  
9 months.

10 He didn't seem to say anything about that. I was  
11 worried about my family and obviously my life ahead of  
12 me, so ...

13 **Q.** And in the years that followed prior to the first  
14 course of treatment that you underwent, what were the  
15 physical symptoms that you experienced?

16 **A.** Prior to treatment, it -- I suppose it was again  
17 a very adverse reaction to alcohol, so my alcohol  
18 intake dropped significantly and stopped.

19 I felt that the energy levels were really, really  
20 low and moods as well were quite low, because I wasn't  
21 getting out doing what I wanted to do. And I think --  
22 I do believe at that time it might have been more  
23 anxiety and stress and fear of the unknown that was  
24 probably affecting me more than the actual disease  
25 was.

1           Once I came to terms with it, once I found out  
2           more about it, once I sort of managed to grab the  
3           beast with, you know, with both hands and confront it,  
4           and learn about how it behaved and what I could do to  
5           benefit myself in the fighting of this disease,  
6           I seemed to feel that I got some control back in my  
7           life and started to train again. Not as well as  
8           I did, but ...

9   **Q.** Your liver, however, continued to deteriorate and  
10          there came a point in 2005 when you were advised to  
11          start treatment.

12   **A.** Yes, yeah, up until that point I was doing everything  
13          I could with my own resources to improve my health and  
14          my liver but that clearly wasn't working, so the  
15          consultant said you should really seriously be  
16          thinking of possible treatment regimes, and went  
17          through those treatment regimes with me and said that  
18          my liver was getting to a point of cirrhotic and you  
19          know, compensated.

20   **Q.** And what was the first course of treatment that you  
21          underwent?

22   **A.** It felt a bit like being napalmed from the inside out.  
23          It was a combination of alfa interferon and ribavirin.  
24          That was subcutaneous injections put into my stomach,  
25          I had to do it myself, kept in the fridge. Every

1 three days you would inject yourself into the stomach  
2 with alfa interferon and take ribavirin every day and  
3 then life deteriorated rapidly.

4 **Q.** And how long did that course of treatment last?

5 **A.** It felt like an eternity but it was 48 weeks.

6 **Q.** You said in your statement you were warned of the side  
7 effects or that there would be side effects?

8 **A.** Yes.

9 **Q.** But the reality of the side effects was horrific.

10 **A.** Yes, yeah, it was completely inconsistent with what  
11 I'd been told to expect.

12 **Q.** And what kind of side effects did you experience?

13 **A.** Well, I mean, I think emotionally I felt that I'd been  
14 taken over by Genghis Khan on steroids with permanent  
15 toothache. It was like a one-person Mongol horde. My  
16 ability to stay calm and relaxed had gone. I was very  
17 irritable. I was very aggressive and quite angry, not  
18 with my family or my partner but just with life in  
19 general.

20 Some of the worst things were the suicidal  
21 thoughts and my body came out on -- in suppurating  
22 pustules and blisters which got infected. I didn't  
23 really want to meet anyone, because my face was  
24 covered in horrific boils and I had insomnia.  
25 I couldn't sleep. Sleep deprivation was obviously

1 affecting me emotionally as well and my skin was just  
2 unbelievable, itchy, I couldn't sleep because of that.  
3 I remember going out in the middle of the night at  
4 3 o'clock in the morning because I had to wear gloves  
5 in bed to stop me scratching and knocking the boils --  
6 the heads off the boils and, actually, standing at the  
7 garden shed under the tree in the garden with my bare  
8 back, rubbing my back against the shed because it was  
9 a dry shed with wood and it felt really great on  
10 my -- I thought I'm not scratching, am I? And, you  
11 know, thinking if the neighbours saw me right now they  
12 would probably definitely think there was a full moon  
13 out somewhere.

14 But it was that kind of desperation and obviously  
15 just had no energy. I was cold all the time, even  
16 through the summer I had to go to bed with all my  
17 clothes on. I just shivered and shook all the time.  
18 It was just horrendous.

19 **Q.** And did that treatment clear the virus?

20 **A.** No.

21 **Q.** You said in your statement that you felt the stigma of  
22 the disease greatly and that your mental health was  
23 affected particularly badly during and following the  
24 treatment.

25 **A.** Yes.

1 Q. What can you tell us about that?

2 A. I suppose, you know, going right to the nub of the  
3 whole issue was the kind of homicidal and suicidal  
4 thoughts. I felt the world was against me. I just  
5 wanted to -- it felt like ripping heads off of people  
6 that I came across that irritated me a bit and I tried  
7 to sort of rationalise those kind of feelings and  
8 thoughts, because I'm not an aggressive person but,  
9 you know, you turned into something that was just  
10 horrific. I didn't really like myself much, and  
11 I thought I was putting through -- putting my family  
12 through hell.

13 So I went back on a sort of programme of how best  
14 to kill myself.

15 Q. Were you able to access mental health services or  
16 psychological support or counselling during that time?

17 A. No.

18 Q. Do you think that would have helped?

19 A. On reflection, definitely, but being a -- probably  
20 a Scottish male and not willing to admit defeat,  
21 I didn't really -- I felt I could manage it myself and  
22 if I couldn't, then I'd just disappear.

23 Q. And you've said in your statement that it -- the  
24 treatment and the infection had turned you from  
25 a fun-loving and gregarious person to someone who just

1 wanted to lock himself away in isolation.

2 **A.** Yeah, without a doubt, yeah. Suffice to say, I'm back  
3 to that fun-loving gregarious person, but at the time  
4 I didn't want to have contact with much really.

5 **Q.** It was a number of years, in 2013, before you had  
6 a second course of treatment.

7 **A.** Hmm.

8 **Q.** How was your physical and mental health in the years  
9 between those two courses of treatment?

10 **A.** Yes, I think I'd done a really good job -- well,  
11 certainly my family had in helping me recover and  
12 again turned to fitness and exercise and, you know,  
13 climbing mountains, getting out in the Scottish hills,  
14 and I had the opportunity to go and work in Nepal as  
15 a mountain guide for a while.

16 My fitness improved. My health -- my own personal  
17 health management systems were great and my food  
18 intake was good, my drinking had stopped, you know, so  
19 I was in a -- quite a good position and felt ready for  
20 the next onslaught, if it was an onslaught, but  
21 positive in the fact that it was presented as a much  
22 better chance of curing this bloody disease than the  
23 first lot of treatment.

24 **Q.** And so the second course that you embarked upon was  
25 triple therapy in 2013?



1 **A.** That's right, yes.

2 **Q.** What side effects did you experience in the second  
3 course?

4 **A.** In some way they were very similar to the first lot of  
5 treatment but much more intensive psychological  
6 effects, which was hard to imagine, really, never  
7 having any kind of emotional or psychological problems  
8 in my life before, other than the ones that everyone  
9 has during the course of their journey through life.

10 This was -- it was just like Dante's hell  
11 circle -- first circle of limbo. I felt -- I felt  
12 nothing. I felt like a nothing person. I felt what's  
13 happening here is going the same way as the first lot  
14 of treatment, but I must keep going and I must try and  
15 complete the course.

16 **Q.** And did you receive in that second course of treatment  
17 any psychological support or access to mental health  
18 services of any kind?

19 **A.** It was, to be fair, in terms of a managed clinical  
20 network mentioned to me with the nurse specialist and  
21 the professor, but it was kind of said that that's  
22 there if you need it and I probably just needed  
23 somebody to say to me, "You're coming and you're going  
24 to have it", rather than me deciding whether I needed  
25 it or not. I wasn't macho, but there was that kind of

1 I can get through this myself.

2 **Q.** Now, that -- that second course of treatment stopped  
3 after 36 weeks.

4 **A.** Yes.

5 **Q.** Why was that?

6 **A.** Well, the deterioration in the white blood cells and  
7 the platelets and my haemoglobin counts were  
8 worryingly low and the professor said, oh, I had  
9 a week's holiday from it to see if things would  
10 recover but they didn't and they were deteriorating  
11 rapidly so I was taken off it, the treatment was  
12 stopped.

13 **Q.** And it was then in 2016 that you embarked upon a third  
14 course of treatment this time with Harvoni.

15 **A.** Yes.

16 **Q.** How was that first of all in terms of side effects?

17 **A.** Fantastic. Very little side effects. Headaches,  
18 a bit of nausea, a bit of anorexia, you were put off  
19 your food a bit. I was still going out on my bike.  
20 I was still managing to -- you know, my wife and  
21 I have a small farm that we work so I was still  
22 managing to get out and do the kind of heavy labour  
23 during that course of that drug. I certainly couldn't  
24 have done that with other two treatments, so it was  
25 good compared to the other treatments. It was

1 a breeze. It was a doddle, a walk in the park.

2 Q. And what was the outcome of that third course of  
3 treatment?

4 A. Woohoo, cleared!

5 Q. But you have been left with damage to your liver.

6 A. Yes.

7 Q. Cirrhosis?

8 A. Yes.

9 Q. Portal hypertension?

10 A. Yes.

11 Q. An enlarged spleen?

12 A. Yes.

13 Q. Oesophageal varices?

14 A. Yes.

15 Q. And also some cardiac problems?

16 A. Yes.

17 Q. And do you know whether those cardiac problems bear  
18 any relationship with the treatment that you  
19 underwent?

20 A. The cardiologist said they were probably, you know,  
21 because it was an isolated sort of minor chronic heart  
22 condition, there was some plaque and calcification in  
23 my lower -- in my left anterior descending and because  
24 it was isolated, you know, if it had been coronary  
25 heart disease generally speaking, he said, it would

1 have been little parts all over the heart but it was  
2 in one specific area that would suggest a damage to  
3 that area somehow, and he did allude to the fact that  
4 it could have been to do with extra hepatic  
5 manifestations of hepatitis C and the treatment and  
6 interferon.

7 There was no -- I've never smoked in my life, you  
8 know. There's no history of heart disease and I've  
9 been sporty and healthy all my days, so the chance of  
10 it being related to something congenital was low and  
11 he said it was probably a result of some extra hepatic  
12 manifestation.

13 **Q.** You said in your statement that you feel that you live  
14 under a constant threat of cancer. That's something  
15 that preys on your mind?

16 **A.** Yes.

17 **Q.** And you're called the miracle man at hospital and that  
18 worries you. What can you tell us about that?

19 **A.** I know I'm certainly not a miracle man but I was at  
20 the hospital the other day and, in fact, I met  
21 [redacted] there and, you know, the nurse specialist  
22 had said that, you know, I am an anomaly. I prefer  
23 that one rather than "miracle man".

24 I seem to survive, and I think due to the good  
25 offices of the National Health Service that I'm

1 monitored regularly and everything's, you know, kept  
2 vigilant on any developments. I have four groups of  
3 lesions in the top left-hand side of the lobe of my  
4 liver which they're worried about, but they don't  
5 think they're malignant at this moment but obviously  
6 they're going to -- they are monitoring that and  
7 keeping an eye on that, which is good, and the  
8 oesophageal banding has stopped, so I still get  
9 monitored for varices in the oesophagus due to the  
10 portal hypertension from the deteriorating liver.

11 It gives a kind of back pressure, if you like, on  
12 the oesophagus and it makes your blood vessels come  
13 into you oesophagus like varicose veins, so they band  
14 them, they fire microscopic elastic bands at them and  
15 strangle them and, you know, hopefully that's, you  
16 know, abated since the hepatitis C virus has gone.

17 But my liver is still cirrhotic but, touch wood,  
18 it's not getting any worse, other than just general  
19 ageing, because I'm not abusing it in any way but it  
20 is getting slowly but surely worse and they don't  
21 really know how long, you know, it will be before it  
22 goes into decompensation.

23 I don't think the sophistication of the monitoring  
24 equipment can tell you that. All they can do is keep  
25 monitoring your blood, see how your liver's

1 functioning, see how your alkaline phosphate is, see  
2 how your ALTs are doing and your liver functions are  
3 doing, and that's a better indicator than anything and  
4 at the moment mine are going well, so ...

5 **Q.** And how often are you monitored?

6 **A.** I seem to be probably taking up residence in hospitals  
7 and I'm sure most of my patient colleagues here feel  
8 the same sometimes.

9 This has been the best period for about 20 years.  
10 I go six-monthly for the main check-up, which I just  
11 had two days ago. I go every six months for an  
12 ultrasound and then I go every six months for an MRI  
13 scan for the lesions in my liver, and then I go for  
14 other bits and pieces of related conditions.

15 The most recent one is -- I've been diagnosed with  
16 osteoporosis in the lower five lumbar of my spine and  
17 osteopenia in my hip so I'm going to get checked up  
18 for that on a regular basis as well to see if that's  
19 deteriorating because I'm beginning to get back  
20 problems and suchlike.

21 **Q.** And in terms of your mental health, how has that been  
22 since the virus cleared following the third course of  
23 treatment?

24 **A.** I think it's been absolutely wonderful because just  
25 knowing that I haven't got that bloody virus is

1           fantastic and it allows me to have a much clearer head  
2           and mind about what lies ahead of me, and that I have  
3           got a lot of positivity to look forward to.

4   **Q.** You say in your statement, however, that you do still  
5           think about the infection and you've thought about it  
6           every day of your life since you were diagnosed.

7   **A.** Yes. I think -- you know, I do think about it all the  
8           time and how lucky -- how unlucky I have been but also  
9           at the same time how lucky I have been to clear the  
10          virus thanks to the NHS.

11 **Q.** Did you feel able to tell people of your diagnosis?

12 **A.** It was very difficult in the early stages, early doors  
13          of the -- of the disease. There was a lot of stigma  
14          around. I had to protect my children at nursery and  
15          at school, so there was a lot of kind of secrecy about  
16          it. It was a kind of, you know, a social disease as  
17          well. You didn't want to be telling too many people.  
18          It was unfortunately, you know, sidelined into a kind  
19          of druggie disease and that carried with it  
20          unfortunately lots of stigma and negativity.

21                I did worry about job interviews and whether  
22                I should be upfront with my employers, which I was,  
23                and explained to them, so I felt that, you know, part  
24                of that was part of the education and my campaigning  
25                work on hepatitis C for -- since I've been diagnosed

1 I've been an active campaigner just making the public  
2 more aware of it, that this disease affects everyone.  
3 It's not just -- and it can't just be sidelined into  
4 a disease that only affects one section of society.  
5 It's all of society's disease and we need to treat it  
6 in that way and approach it in that way.

7 **Q.** What was the impact of the illness, the infection and  
8 the treatment you received for it and the consequences  
9 you've described on your family, your wife and  
10 children, your family life?

11 **A.** I can't believe my wife's still -- still wants to be  
12 with me. Horrific, really, especially for my partner  
13 and my wife [redacted].

14 **Q.** Sorry can we just stop the live transmission for  
15 a moment.

16 **A.** Oh, right, right. Mrs X, sorry.

17 **Q.** Yes, Mrs X. So we'll stop it if we just wait for  
18 a moment, Mr X, we'll start again.

19 **A.** I feel like a James Bond movie.

20 **Q.** Okay. We will start again. I was asking you about  
21 the impact on your wife and on your children and on  
22 your family life.

23 **A.** Yes, I think the impact it has that on Mrs X has been  
24 horrific. She's had to take the burden of my illness  
25 as much as I have, and that's been really difficult,



1 but amazing that she's coped with it. And

2 I definitely don't think I'd be here without her.

3 **Q.** And your children, one of your children, your eldest  
4 child, again we won't mention any names --

5 **A.** Oh, yes. Daughter X.

6 **Q.** Yes. During your first course of treatment in  
7 particular went through a difficult time?

8 **A.** Yes, yeah, quite a rebel without a cause, or maybe she  
9 did have a cause, seeing her Dad sort of deteriorate  
10 and possibly not at the age of fully being able to  
11 comprehend or understand what was happening.

12 It was probably one of the few times that my wife  
13 and I disagreed on how to approach this. She felt  
14 that we should be telling daughter X all about it, and  
15 I was more of the opinion that we shouldn't to protect  
16 her, but she was -- she was told because she was  
17 15/16, so she was mature enough to understand the  
18 whole disease and the progression of the disease and  
19 what it could do and what I had to do to try and stop  
20 it killing me by taking treatment, and what the  
21 treatment made me do, and it was that time, you know,  
22 adolescence, you know, at school and got in with the  
23 wrong crowd and became quite difficult and  
24 unmanageable, and I think probably because  
25 displacement of what she saw me go through, perhaps.

1 Q. What about the impact of your infection and your  
2 treatment and the symptoms and side effects on your  
3 employment and your career development. Again,  
4 without mentioning any particular employers.

5 A. Yes, yeah, I mean, I was fortunate to have  
6 employment -- consistent employment with the one X  
7 organisation with 30 years and they understood fully  
8 about that, and I was upfront with them about all my  
9 treatment and issues that related to the disease and  
10 the disease progression.

11 I think what it did do during the course of that  
12 employment -- employment and my working life, I was  
13 with that organisation for 30 years. It kind of --  
14 I suppose it put a bit of a damper on any kind of  
15 aspirational career development. I just felt I didn't  
16 want to risk putting myself through more stress by  
17 getting promotion and going up the kind of ladder  
18 of -- promotional ladder, as they say.

19 So I suppose my aspirations and my enthusiasm to  
20 get more money, to earn more salary, to do all that  
21 was -- was put on hold -- well, was stopped. I just  
22 didn't feel that I could do that and I didn't --  
23 I felt that, you know, if I did get that kind of, you  
24 know, career development, that kind of promotion, that  
25 I might die in the middle of it all and that would be

1 sad for my work as well as me and my family, of  
2 course, but, yeah, I think there was a bit of a damp  
3 squib on my career opportunities.

4 I work that different ways but, yeah, in terms of  
5 professional career development, I didn't -- it didn't  
6 rest easily with me to do that while I was infected.

7 **Q.** Can I ask you about access to dental care.

8 **A.** Hmm.

9 **Q.** Did you experience any difficulties in accessing  
10 dental care?

11 **A.** Yeah, fortunately again I had another long-term  
12 relationship with my dentist. It was my wife and my  
13 children that seemed to have the problem more than  
14 I did with that because my wife sort of was upfront to  
15 the dentist that her husband had hepatitis C and their  
16 approach was that, well, we'll make appointments for  
17 you and the children at the end of the day so we don't  
18 have to autoclave and clean up so much through the day  
19 and it makes -- it makes no sense to me because there  
20 could be somebody in the surgery at 9 o'clock that was  
21 hepatitis C positive that they didn't know was  
22 hepatitis C positive.

23 So there was issues with dentistry and I've kind  
24 of pursued that one. It's been a bit of a bugbear of  
25 mine through the campaign work and through the

1 educational work I've been doing with hep C that  
2 I think we need to address more issues relating to  
3 dentistry as possible sources and routes of  
4 transmission, particularly for people who have no idea  
5 how they got hepatitis C.

6 Because when you think of dentistry, you think of  
7 high-pressure, high-speed equipment that goes in the  
8 mouth with the sensitive gums, gums bleed easily.  
9 There's tissue in the drill heads. There's tissue in  
10 the sort of tool heads as well, and if they're not  
11 autoclaved correctly then that is a possible serious  
12 route of transmission that I think as a society we  
13 haven't really sort of looked into enough.

14 **Q.** You've also been involved, I understand, with your  
15 consent, in a number of medical research projects.

16 **A.** Yes, yes, that's right.

17 **Q.** And what was the purpose of your involvement in those?

18 **A.** I suppose altruistically to make it better for others  
19 that followed me with hepatitis C and maybe to make it  
20 better for me as well but I'll know that until five  
21 years down the line when the research is complete.

22 I've been involved in three or four different guinea  
23 pig trials.

24 **Q.** Now, you've referred to your campaigning work, and you  
25 were involved in the establishment of a hepatitis C

1 support group. The particular aspect of that you  
2 address in your statement was involvement in the  
3 Lord Ross expert group.

4 **A.** Yes.

5 **Q.** Can you tell us about that and what the work entailed?

6 **A.** Yes. We had set up the support group and we'd then  
7 linked up with other similar support groups throughout  
8 the central belt, in Glasgow and Fyffe and felt that,  
9 you know, there was issues that needed to be addressed  
10 from a strategic and legislative and political and  
11 policy kind of aspect, and we lobbied the Health  
12 Minister at the time, Malcolm Chisholm, to try and  
13 give us some sort of stage or floor space to be able  
14 to deal with the many, many issues that still exist  
15 with hepatitis C as a means of looking at those that  
16 were infected through blood and blood products through  
17 NHS procedures, and to try and support them as best we  
18 could in their life journey and in their deterioration  
19 because they had hepatitis C and, at that point, there  
20 was no cure for it and people knew that the treatment  
21 was pretty low in terms of cure. It was 40% at the  
22 time.

23 So the long and the short of that was that  
24 Malcolm Chisholm decided to set up the expert group  
25 which was chaired by Lord Ross and I was asked to be

1 on that group [redacted].

2 **Q.** And we've got some of the recommendations that you've  
3 exhibited to your witness statement. Paul, it's  
4 2137003 please. We see it is the report of the expert  
5 group on financial and other support, March 2003.

6 **A.** Yes.

7 **Q.** If we turn to the next page, please, Paul, there are  
8 a number of recommendations that you've identified and  
9 mentioned in terms of recommendations that you thought  
10 important that hadn't been fully implemented or  
11 implemented in some respects at all.

12 **A.** Yes.

13 **Q.** And I understand the first recommendation that you  
14 wanted to draw attention to is recommendation 1C.

15 **A.** Yes.

16 **Q.** Which was the recommendation that those who  
17 subsequently suffer serious deterioration in their  
18 physical condition because of the hepatitis C  
19 infection, cirrhosis, liver cancer or other similar  
20 serious conditions should be entitled to full  
21 compensation calculated on the same basis as common  
22 law damages.

23 **A.** Yes.

24 **Q.** That was one of the recommendations that was made but  
25 not adopted; is that right?

1 **A.** Yeah, that's correct, yeah. In a general sense I do  
2 believe that if the recommendations -- excuse me --  
3 from Lord Ross were implemented we might not be here  
4 today because I think there was a lot of good in that.  
5 I mean, it was a long time ago but, yes, certainly one  
6 of the key ones, C, has not been implemented.

7 **Q.** If we go to the next page please, Paul,  
8 recommendation 2. You've drawn attention to -- my  
9 attention to recommendations 2(a):

10 "Access to understandable information on HCV.

11 "(b) Counselling services.

12 "(d) Advice and assistance in securing appropriate  
13 and adequate assurance and insurance", and (f):

14 "Improved access to palliative care and symptom  
15 management services when appropriate."

16 And I understand your view is that those are all  
17 important recommendations that haven't been  
18 implemented or fully implemented?

19 **A.** Fully, yes, yes, I do believe that, yes.

20 **Q.** And then you also I understand wanted to draw  
21 attention -- the next page, please, Paul --  
22 recommendation 4(d) funding for AvMA to open  
23 a Scottish branch.

24 **A.** Yes, that was agreed as well but hasn't happened. It  
25 was Association of Victims of Medical Accidents and it

1 was agreed that there would be a branch set up in  
2 Scotland because they had a lot of good case study and  
3 track record and positivity about what they'd done for  
4 patients in England and Wales and Northern Ireland and  
5 they would be offered to open a branch in Scotland.

6 **Q.** And then the more general concern that you've  
7 expressed in your witness statement was that following  
8 the work of the expert group and the recommendations  
9 of Lord Ross, the issue was, in terms of financial  
10 payments at least, was devolved back to Westminster  
11 and resulted in the establishment of the Skipton Fund?

12 **A.** That's correct, yes.

13 **Q.** Now, I wanted to ask you next about your own  
14 experiences with the Skipton Fund, because you made  
15 an application to the Skipton Fund which was  
16 unsuccessful.

17 **A.** That's correct, yes.

18 **Q.** We're going to look at some of the documents.

19 Paul, could we have up on screen please  
20 document 2137016.

21 This is the application form you submitted in  
22 December 2004 and if we look just over halfway down  
23 the page we can see in bold print:

24 "All the rest of the form after page 2 must be  
25 completed by a medical professional to whom you should



1 give the form after you have completed and signed the  
2 first two pages. You should also give these guidance  
3 notes to that medical professional."

4 So your form, the bulk of it, was completed in  
5 accordance with that guidance by your GP?

6 **A.** That's right.

7 **Q.** If we turn to -- Paul, it's the fifth page of this, it  
8 should be -- part 4B, we can see the last question on  
9 that page, the GP is asked:

10 "In your view is it probable that the infected  
11 person's HCV infection was acquired in consequence of  
12 NHS treatment received before 1 September 1991?"

13 The answer there is "Yes".

14 **A.** Yeah.

15 **Q.** So your GP completed the form setting out his view  
16 that it was probable that your infection was the  
17 consequence of NHS treatment pre-September '91?

18 **A.** Yes.

19 **Q.** If we then, please, Paul, have 2137017, we can see the  
20 letter that your GP wrote in support of your  
21 application and he refers to the surgery that you  
22 underwent in 1976.

23 **A.** Yeah.

24 **Q.** Then in the paragraph, the fourth paragraph down, he  
25 refers to you remembering the receipt of three units

1 of blood and he refers to your mother backing that up,  
2 writing a letter to this effect and enclosing a copy  
3 of your mother's letter.

4 **A.** Yes.

5 **Q.** And if we have the next page, please, of this exhibit,  
6 we can see there the letter that your mother wrote.

7 It's not completely easy to read but she says this:

8 "I remember that due to a minor complication he was  
9 given some blood during this procedure. I also remember  
10 that as a joke between the nursing staff and my son  
11 he ..."

12 And then she describes you putting on an accent as  
13 they told you that you had blood that came from  
14 America. So that was your mother's independent  
15 recollection. She set that out in this letter. The  
16 GP provided that to go to the Skipton Fund --

17 **A.** Yes.

18 **Q.** -- in support of your application.

19 **A.** Yes.

20 **Q.** If we go back to the first page of this exhibit,  
21 please, Paul, to the letter from the GP, we see in the  
22 last two paragraphs he explains your efforts to obtain  
23 further information in terms of any contemporaneous  
24 records, and then the GP concludes:

25 "It does strike me that his mother's written memory

1 of the blood transfusion at the time of the inguinal  
2 hernia repair [Mr X's] memory of the blood transfusion  
3 and the documentation relating to the surgery are at  
4 least reasonably supportive evidence towards  
5 ascertaining the infecting event."

6 What was -- sorry, before I ask you the next  
7 question one more document, 2137018, we can see here  
8 this was your attempt to obtain hospital records and  
9 you were told:

10 "Unfortunately, after a thorough search, I'm sorry  
11 to inform you that we do not hold any records for  
12 you."

13 At that was from the Dumfries and Galloway Royal  
14 Infirmary?

15 **A.** Yeah, and I also had many other requests for my  
16 records from various other GP practices that I'd  
17 attend and they also came back saying there was no  
18 records held for me.

19 **Q.** And you provided those documents --

20 **A.** Yes.

21 **Q.** -- to the Skipton Fund in support of your application?

22 **A.** Yeah.

23 **Q.** What was the outcome of the application?

24 **A.** I was not awarded the Skipton Fund.

25 **Q.** And if we have up on screen 2137019, we can see

1 a letter 2 March 2005, this is after your  
2 application's been rejected, and we can see that  
3 because it's an acceptance of the fact that you want  
4 to appeal and the third paragraph tells us:

5 "The Department of Health is currently working on  
6 the establishment of the Independent Appeals Panel.  
7 I have been advised that this may take a few months.  
8 When this work is completed we will write to notify you  
9 accordingly."

10 That was March 2005.

11 Then if we have up on screen 2137020, please,  
12 Paul.

13 We can see that you then received a letter,  
14 19 September 2006, so approximately 18 months later,  
15 telling you that the Independent Appeal Panel had now  
16 been established.

17 **A.** Yes.

18 **Q.** "Will begin to consider cases from 3 October ..."

19 You are told who is going to be on the panel, be  
20 dealt with in writing and then that a maximum of 30  
21 cases will be reviewed at the first meeting.

22 **A.** Yeah.

23 **Q.** If we then up on screen, please, 2137021, you put in  
24 some further information in support of your  
25 application.

1   **A.** Mmm-hmm.

2   **Q.** And we can see from the second paragraph of this  
3       document the basis upon which your application had  
4       been refused. It was refused on the grounds -- sorry,  
5       Paul, it's just above that:  
6                "Skipton Fund application 20 December 2004 refused  
7       on grounds of medical records do not confirm that blood  
8       product was administered."  
9                We can see that towards the top of the page.

10  **A.** Sorry, I'm getting a bit lost here.

11  **Q.** Yes. Paul, could we have highlighted, it's the second  
12       section:  
13                "Skipton Fund application refused ..."

14  **A.** Oh, got you.

15  **Q.** Thank you.

16  **A.** Yes, got you.

17  **Q.** Yes. So that was the grounds of refusal, that your  
18       medical records do not confirm that blood product was  
19       administered, and the reality was you had no medical  
20       records other than the discharge letter?

21  **A.** Just the discharge letter, yes.

22  **Q.** Because those records had been lost or destroyed?

23  **A.** Yes, correct.

24  **Q.** And then you pointed that out:  
25                "There are no medical records relating to this

1 incident. All attempts to locate [them] have been  
2 unsuccessful."

3 You refer to the efforts you have made and then  
4 you refer to your GP and your GP's view about the  
5 probability of the cause of infection.

6 **A.** Hmm.

7 **Q.** If we then have up on screen, please, Paul, 2137022.

8 You've got a further letter from the Skipton Fund  
9 dated 17 October 2006 and the appeal panel asked for  
10 further information. They wanted evidence from your  
11 GP how the letter of 14 June '76, that's the discharge  
12 letter, came to be written on.

13 **A.** Yeah.

14 **Q.** Wanted hospital records to be followed up, wanted to  
15 know more about the procedure, asked you how you knew  
16 it was three units, who -- exactly who said blood was  
17 from the USA:

18 "Please give as much detail as possible of that  
19 conversation."

20 And then if we look at 2137023, we will see you  
21 gave over the course of two pages as full an account  
22 as you could. You referred in the third paragraph to  
23 your attempts to find your medical files. You then  
24 refer to your own memory about being told about the  
25 three units of blood and your recollection of the

1 exchanges with the nurses. You refer in the bottom of  
2 the page, if you can put the last paragraph, thanks,  
3 Paul, the surgeon told you that they had to give you  
4 blood and you say:

5 "I was a young lad of only 18. I didn't think to  
6 ask any more."

7 **A.** Mmm-hmm.

8 **Q.** And then you then refer to -- in the second paragraph  
9 of that second page -- your mother witnessing it and  
10 the banter and to the letter that was written by your  
11 mother, who by then had died.

12 **A.** Mmm-hmm.

13 **Q.** And you gave further detail about the circumstances in  
14 which you were kept in hospital and so on.

15 And then if we turn finally to 2137024, please,  
16 Paul. We can see the response that you received dated  
17 1 December 2006. If we go towards the bottom of that  
18 page, please:

19 "In order to succeed on an appeal the appellant must  
20 satisfy the Panel that it is probable, that it is more  
21 likely than not, that the infection of hepatitis C was  
22 indeed caused either directly through NHS treatment  
23 before 1 September 1991 or indirectly by contact with  
24 a person who was so infected. In order to be satisfied  
25 that this is the case, the panel will pay particular

1 attention to the treatment records of the person  
2 concerned."

3 Then it says that your appeal was considered by  
4 the panel at its meeting on 1 December. Then if we go  
5 over the page please we see the panel's decision:

6 "The panel reviewed the entire file of papers held  
7 by the Skipton Fund ... including the additional  
8 information supplied for the purpose of the appeal. We  
9 noted that there were no records of any transfusion and  
10 that it was not likely that a transfusion would have  
11 been administered for the condition for which you were  
12 treated. There was a discharge summary on your leaving  
13 hospital that would have mentioned a transfusion, had it  
14 occurred."

15 That was the sum total of the explanation that you  
16 were given for rejecting the account you'd put forward  
17 in support of your appeal.

18 **A.** Yes, yes.

19 **Q.** You observe in your witness statement that the way in  
20 which your application was dealt with was contrary to  
21 what you understood had been intended when the scheme  
22 was established.

23 **A.** Yes.

24 **Q.** Can you explain what you meant by that?

25 **A.** Yes, I can. I think there was great expectations from



1 the Lord Ross expert group that people who were  
2 infected through NHS procedures would get their day  
3 and be compensated or given an *ex gratia* payment or  
4 however you want to call it for the pain and suffering  
5 that they felt and continue to feel today, those that  
6 are still alive, that is.

7 It then turned completely on its head and I'm not  
8 quite sure why that is. I would probably really like  
9 to know why, but the minister at the time,  
10 Malcolm Chisholm, in the setting up of a fund, it was  
11 a devolved responsibility for NHS Scotland through the  
12 Scotland Act and the Parliament to be able to deal  
13 with the setting up of our own Scottish-based fund.  
14 There was nothing to stop that happening, but  
15 unbeknown and for whatever reasons I'm not quite sure  
16 about that was then re-devolved back down to  
17 Westminster and I'm not entirely sure why, because it  
18 would make it much more appropriate for Scottish  
19 patients to have their own, you know, Skipton-type  
20 fund based in Scotland, where people from Scotland  
21 knew the NHS scene in Scotland better than they would  
22 in Westminster. People wouldn't have to, you know,  
23 travel so far or whatever it may be at that time, they  
24 thought maybe appeals would come in and all sorts of  
25 things.

1           We were dumbfounded really at to why it was then  
2 re-devolved, a devolved issue was then re-devolved  
3 back to Westminster. I still don't know the answer to  
4 that.

5           Speculatively, I've -- I was told that it was  
6 because Tony Blair had said to Malcolm Chisholm, if  
7 you set up your own scheme in Scotland in that kind of  
8 progressive way the Scotland does sometimes and give  
9 out, you know, payments, we'll be inundated in England  
10 and we can't afford it and John Reid kind of at the  
11 time was -- was a main mover and shaker in that, being  
12 that, you know, Skipton Fund being brought down to  
13 Westminster for its -- for its formulation.

14 **Q.** And you've said in your statement that what you had  
15 understood would be the basis for decision-making was  
16 that if a doctor who knew the patient confirmed that  
17 their view on the balance of probabilities, the  
18 infection had been caused by NHS treatment in the  
19 relevant period, that would suffice rather than it  
20 being an exercise of discretion on the part of the  
21 Skipton Fund?

22 **A.** Yeah, that's correct. I mean, that was something --  
23 I mean, I was along with Philip Dolan, who sadly is no  
24 longer with us, we were the patient representatives  
25 that travelled to London to meet the

1 Department of Health, along with Scottish Office  
2 officials, Scottish Office at the time officials, to  
3 you know, you know, have an influence on how that  
4 Skipton Fund would -- you know, what the criteria  
5 would be, what the questioning would be, what the sort  
6 of protocols would be basically to help set it up. We  
7 insisted if it wasn't happening in Scotland we had to  
8 have some sort of, you know, input to that. It would  
9 only have been fair to do so.

10 So we went down to London several times and along  
11 with Charles Gore, who was also a patient rep from the  
12 Hepatitis C Trust in London, we argued vociferously  
13 for that clause to be put in. Home Office  
14 officials -- sorry, Department of Health officials  
15 were very against it. I'm not sure why but we had to  
16 fight tooth and nail to make sure that, on the balance  
17 of probabilities, along with the absence of any -- of  
18 medical records being lost or destroyed, and with the  
19 authorisation of a medical professional that knew the  
20 patient well, that her or his signature would be  
21 suffice enough to say that on the balance of  
22 probabilities most likely route of infection was  
23 through NHS procedures, that should automatically  
24 trigger the payment because the Skipton Fund -- and  
25 again this is something that we were very, very clear

1 about, that the Skipton Fund was a non-discretionary  
2 sort of fund.

3 So that would trigger an instant payment and it  
4 turns out that the Skipton Fund was a very  
5 discretionary fund, so it failed in its protocols. It  
6 failed in its set-up procedures and processes, failed  
7 miserably in being a non-discretionary fund. It  
8 seemed to take a lot, as patients have probably said  
9 up and down the country at various inquiries and  
10 reviews, that they were treated unfairly and  
11 inconsistently unfairly with Skipton Fund being far  
12 too discretionary and not a non-discretionary fund as  
13 it was originally intended to be and agreed upon.

14 **Q.** Your appeal having been rejected by the Skipton Fund  
15 in the documents we've seen in late 2006, did you ever  
16 attempt to try again to make an application to them or  
17 have you subsequently sought to make any application  
18 to the current Scottish scheme?

19 **A.** No, I've -- no, I've no intention to either. I've had  
20 enough.

21 **Q.** Well, the last issue that I wanted to explore with you  
22 is the question of the accuracy of your medical  
23 records.

24 **A.** Hmm.

25 **Q.** And this is in relation to your GP records. You

1           obtained a number of your GP records in 2002, and what  
2           did you find when you looked at those records?

3   **A.** I've found glaring concerns of inaccuracy and I was  
4           quite taken aback by what I read, not knowing that  
5           that had been in my records until then. I suppose  
6           gobsmacked really.

7   **Q.** You found references to a former sexual partner with  
8           hepatitis C and you found references to intravenous  
9           drug use?

10 **A.** Yes, I did.

11 **Q.** What's your response -- we'll look at a handful of the  
12          documents but what's your response to the accuracy or  
13          otherwise of those entries?

14 **A.** Trying to think through all this, again, flummoxed  
15          completely by it. There were some kernels of truth,  
16          little grains of truth in that that I can explain that  
17          I was present at in a flat that I had a room in with  
18          two medical students who were intravenous drug users  
19          and regularly used intravenous drugs and perhaps at  
20          some point I had mentioned that to my GP or my  
21          consultant or whatever and I don't know how that then  
22          got translated into, you know, factual statements  
23          about what I said that I was -- I put -- I partook in  
24          that. I mean, it was quite gobsmacking really.

25                 When I looked at the records and then tried to

1 marry updates and times, there was other inaccuracies  
2 that came to light as well, not just about that, but  
3 about the status of my wife and the children, about  
4 dates getting mixed up, about the age I was when  
5 I went to various places, about when I allegedly had  
6 tried intravenous drugs, that the sexual partner was  
7 hepatitis C positive, which she never was, you know,  
8 in terms of my -- she was a landlady. That was it,  
9 you know, no more, no less.

10 And I then felt that I needed to do something  
11 about that, so I embarked on a personal crusade to  
12 right what I felt were wrongs.

13 **Q.** We'll just look at -- we won't look at all the  
14 documents because you've given a very detailed account  
15 in your supplemental witness statement --

16 **A.** Yes.

17 **Q.** -- of what you say are errors in the records.

18 You've identified, for example, it being said that  
19 your partner was pregnant when she wasn't. You've  
20 identified it being said that you had one child when  
21 you had two.

22 **A.** Yes.

23 **Q.** That you had a baby when your children were older than  
24 that and so on.

25 **A.** Yes, it was a bit of a dog's breakfast in terms of

1 factual accuracy.

2 **Q.** And we can see that in 2003 you wrote to one of your  
3 consultants about inaccuracies. Could we have up on  
4 screen please 2137005. And we can see that you --  
5 your letter is headed "Inaccuracies in personal health  
6 file", and you explain that you've been pursuing the  
7 above issue for some time:

8 "... because it had come to my attention whilst  
9 looking at my medical file that there were some very  
10 worrying inaccuracies and value judgments made about  
11 my life and personal integrity."

12 And you refer to amending these inaccuracies with  
13 Dr Dobson, that was your then new GP.

14 **A.** Hmm.

15 **Q.** And you have signed and dated them and you asked about  
16 your hospital records, because you wanted to ensure  
17 that those accurately and clearly reflected the  
18 correct position; is that right?

19 **A.** That's right. Could I just -- a point of  
20 clarification, Jenni, what did you say about Dr Dobson  
21 he was my ...?

22 **Q.** He was the GP with whom you looked at the records in  
23 2002?

24 **A.** Yes, sorry, yeah, that's correct.

25 **Q.** Not the GP who you say made the inaccurate records --

1 **A.** That's correct, yes, sorry.

2 **Q.** -- in 1996?

3 **SIR BRIAN LANGSTAFF:** You did say his then new GP.

4 **MS RICHARDS:** Yes.

5 **A.** Oh right, yes, that's what confused me about the new  
6 part. Sorry about that.

7 **MS RICHARDS:** My apologies, Mr X.

8           Then if we just have up on screen, please,  
9           2137006, we can see you then writing the following  
10          year, August 2004, to Dr Dobson and you're asking  
11          for -- for his confirmation whether your amended  
12          records:

13                 "... agreed in August 2003 had been communicated  
14                 to Professor Hayes because it would appear that  
15                 they've not yet been amended in my Royal Infirmary  
16                 file ..."

17                 And you say this:

18                 "It is of the utmost importance to me that all my  
19                 records are consistent and reflect accurately my medical  
20                 history, as this is crucial to future medical  
21                 intervention, my own peace of mind and for the  
22                 consistency and credibility of the NHS and its  
23                 management of sensitive and personal information."

24                 Then we'll just look at perhaps one of the  
25                 examples of the records that you've provided to the



1 Inquiry, Mr X.

2 Paul, can we have 2137007.

3 We can see here an entry in your GP records for  
4 3 December 1996, and we can see it says there:

5 "Enquired re risks of hep C -- previous partner has  
6 it. Will check hep C status in future if decides."

7 **A.** Oh right, yes, yeah.

8 **Q.** So just pausing there, that's an entry made by your  
9 then GP in 1996, and then if we look to the side we  
10 see written on the side with the date of  
11 25 November 2002:

12 "Never had [sexual intercourse] SI with lady  
13 concerned. Never used IVDs [intravenous drugs]."

14 **A.** Yeah.

15 **Q.** Can you just tell us how that handwritten entry on the  
16 left came to be added to your records.

17 **A.** Yes, it was in consultation and discussion with my  
18 doctor, Dobson. I think just to be clear, that this  
19 was a medical practice and one wasn't specifically my  
20 GP and one wasn't a new one or an old one, they were  
21 all part of the same practice, and I got a junior GP  
22 or registered doctor, you know, quite a lot of the  
23 time but my main -- you know, the main senior  
24 practitioner was Dr Dobson and I went directly to him  
25 to say, "I am not happy about what has been written

1 about me and, you know, what can I do about that?  
2 I've nothing to hide in terms of it remaining on my  
3 records what the other GPs' interpretation of what  
4 I said was, but I want to put my side on the record so  
5 that if anyone comes to look at it, there is at least  
6 two, you know, approaches to how we perceived what had  
7 happened", and he agreed to that and that's how he has  
8 written the amendments at the side of this document.

9 **Q.** And he and you have gone through the handful of other  
10 letters or documents in your GP records which contain  
11 what you have said are inaccurate references either to  
12 IV drug use or to a previous partner who was, in fact,  
13 your landlady you say.

14 **A.** Yes, and information about my children and wife and  
15 dates.

16 **Q.** And you and Dr Dobson have essentially annotated those  
17 records back in 2002 --

18 **A.** That's correct.

19 **Q.** -- to say that they're not correct in a similar form  
20 to the annotation we see here.

21 **A.** That's correct, yes.

22 **Q.** And what you've said about it in your statement, Mr X,  
23 is this:

24 "These inaccuracies in my medical records are  
25 concerning to me. I've made a number of efforts to have

1           them rectified over the years. I've never had sexual  
2           intercourse with anyone with hepatitis C to my  
3           knowledge. I've never used intravenous drugs. I do not  
4           know of any way I could have contracted hepatitis C  
5           other than the blood transfusion which I had in 1976.  
6           I can only assume that there was some discussion around  
7           the time of my diagnosis with hepatitis C of my  
8           knowledge of the condition and of people who had it as  
9           well as my knowledge of and connection to intravenous  
10          drug use. It seems that the doctors with whom I spoke  
11          have misunderstood me when I have spoken to them about  
12          this. This has led to the inaccuracies in my records.  
13          They have made other errors in my records. I am  
14          concerned about the inaccuracies. I am concerned that  
15          they suggest that these doctors and any other medical  
16          professionals who have read my notes over the years have  
17          assumed or thought that I had contracted hepatitis C by  
18          IV drug use or by sexual contact with someone who was  
19          infected. This was not the case. I have tried to have  
20          these issues resolved over many years but have been  
21          unable to do so."

22       **A.** That's correct.

23       **Q.** And all you have been able to achieve effectively is  
24          the annotations that we have seen that your GP made in  
25          2002 --

1   **A.** Yes.

2   **Q.** -- to set out what you say is the correct position.

3   **A.** That's correct, yeah.

4   **Q.** Mr X, those are the questions I have for you. Is  
5   there anything further you would like to say?

6   **A.** There is. I think a lot of this, particularly the  
7   latter -- let's look at the last one and I think if  
8   I had to do anything it would be to try and make sense  
9   of the complexity and the quagmire of individuals'  
10   medical records because the GP have got medical  
11   records of the individual, the hospitals that you may  
12   have attended have got a different set of records and  
13   they need to be brought together into the one sort of  
14   coherent medical record, because the medical record of  
15   an individual from, you know, birth to death is  
16   crucially important to that individual and their  
17   families and the treatment they receive from our  
18   wonderful and glorious NHS.

19           And you can see just by what I've highlighted in  
20   some of the inaccuracies that there maybe needs to be  
21   a look at the value judgments sometimes made or  
22   clarification on some of the -- the statements that  
23   are made so that its signed by both the patient and  
24   the GP, or maybe we have to go to the Women's  
25   World Cup and go for video assisted GP counselling,

1       you know, I don't know. But there needs to be some  
2       bringing together of very sensitive data, very  
3       important data, so that that can be accessed and  
4       retrieved at the press of a button.

5               Now, to me, who is not very IT-minded, I do know  
6       how to work a computer, but it seems to me that  
7       that's -- that shouldn't be that difficult to do, in  
8       particular when you see companies that can change your  
9       electricity in days, you know, minutes, I mean, you  
10      know. You'd think it would be easy enough to get the  
11      data on to the one system that the NHS could then  
12      manage on your behalf and it could be regularly  
13      checked by you with an access code and a PIN number so  
14      if anything did come up and you had been to the  
15      doctors' and then the next day you wanted to have  
16      a look at what she or he said, you could easily go  
17      into that with your code or the National Insurance  
18      number or whatever may be, look at that and say,  
19      "Yeah, that's accurate. I'm happy with that".

20              I think that would be one of the things I would  
21      like to say about future work of people's medical  
22      files and then we wouldn't be here discussing who said  
23      what, why, when and where, what was inaccurate and  
24      what was true, what wasn't true. It would be  
25      something that I'd use to highlight the need for this

1 to happen in future.

2 **Q.** Is there anything else you would like to say?

3 **A.** There are a few things. We have mentioned a lot the  
4 Lord Ross report and I welcome that. There's just  
5 a couple of things I would want to sort of  
6 re-emphasise about palliative care, that people who  
7 have been infected through NHS procedures, we will  
8 deteriorate, we will -- even though I have been cured,  
9 I will deteriorate, you know, significantly more than  
10 if I had a healthy liver, there's no doubt about that,  
11 and the burden that that could put on families and  
12 spouses and friends is very -- is enormous and I think  
13 there needs to be look at, in particular, palliative  
14 care for people in those categories when they reach  
15 the stage of, you know, decompensated liver and  
16 heading towards a transplant or heading towards death  
17 or hepatocellular carcinoma, whatever that may, liver  
18 dysfunction, end-stage liver disease is a very slow,  
19 painful, enduring death and I think, you know,  
20 palliative care needs to be looked at in relation to  
21 that for those people. And it was something that, you  
22 know, Lord Ross mentioned that I would like to  
23 re-emphasise that.

24 And also on treatment, I think we have something  
25 very important here. We have new cases presenting

1 themselves. We are treating very small amounts of  
2 people, you know, in terms of hepatitis C prevention.  
3 That does break the cycle, but mutation potential is  
4 possible if we don't hit that hard and quickly, it  
5 could create very quickly a new genotype or  
6 a resistant strain and we all know the outcomes of  
7 what that could be. We could be back to square one  
8 again and I think we need to look at serious  
9 elimination strategy of hepatitis C.

10 It is within our grasp to do that. Scotland  
11 government in 2015 committed themselves to  
12 an elimination strategy and that seems to have lost  
13 its way a bit. We had the announcement just the other  
14 week there with the National Institute for Clinical  
15 Excellence in England and a lot of the drug companies  
16 that they have signed up to an elimination strategy by  
17 the year 2030.

18 So I think we need to do the same. We have the  
19 expertise, we have the knowledge and we have the cure  
20 to actually eliminate hepatitis C from our midst. If  
21 we approach it the same way as we approached  
22 foot-and-mouth disease, where it was collaborative, it  
23 was consensual, it was collective, it was immediate,  
24 it was sustained, and it was progressive response to  
25 that terrible disease that affected farmers and their

1       beasts for -- I'm not for one saying we all get put in  
2       a big funeral pyre and burnt, but we have got the  
3       ability to eliminate hepatitis C from our society and  
4       I think we need do that sooner rather than later, or  
5       else we'll end up in the same situation ten years down  
6       the line, where we're having people re-presenting with  
7       hepatitis C.

8             If you don't get rid of the infection pool, you  
9       will continue to have hepatitis C and I think it's  
10      something that's within our grasps and hopefully this  
11      Inquiry will add to that, sort of, you know, pressure  
12      to do that.

13            I mentioned dentistry. The one other thing that  
14      I would just like to mention to finish up and to say  
15      that I do believe there is a very deep hepatic crack  
16      in our society and those of us who have been infected  
17      and then neglected and then dejected fall into that  
18      crack, and I think we need to do all we can to ask the  
19      right questions to the right people and the right  
20      organisations to stop that from happening.

21            As a patient, I would like to say that if people  
22      not used to speaking are heard by people not used to  
23      listening, then real changes can take place and happen  
24      and I welcome this Inquiry for that reason.

25      Q. I'm just going to ask Mr Dawson and O'Neill if there's



1 anything they would like me to ask. (Pause)

2 **A.** I must be calling Mrs X.

3 **Q.** Mr X, there's just a handful of matters that Mr Dawson  
4 asks me to raise with you.

5 Just going back to the operation in 1976.

6 **A.** Yes.

7 **Q.** Were you warned pre-operatively or told anything about  
8 either the possibility of bleeding or of blood  
9 transfusion or any risks of infection associated with  
10 transfusion?

11 **A.** No, I wasn't, no.

12 **Q.** You've told us about the friendly banter that you had  
13 with the nurses. Have you subsequently been told  
14 anything about blood being taken from Americans in  
15 Scotland that might have underpinned that banter?

16 **A.** Yes, actually. I was an outdoor instructor as part of  
17 my career and I was based very near the -- the Dunoon  
18 American base in the Cowal Peninsula and we got to  
19 know a lot of the troops that are stationed there and  
20 a lot of them -- and I read subsequently as well that  
21 it was a big source of donated blood from the American  
22 troops there to the Scottish Blood Transfusion  
23 Service. So there may be some -- some reference to  
24 American accents there and suchlike but I do believe  
25 that that was, up until the point they left, a major

1 source of donated blood.

2 **Q.** And then the third question which Mr Dawson asks is  
3 whether -- is for you to confirm that you were not  
4 picked up in terms of the possibility of you being  
5 infected on any look-back exercise.

6 **A.** I was not, no.

7 **Q.** It came about through your feeling unwell and  
8 proactively going to the GP.

9 **A.** Yes, yeah.

10 **Q.** And then that leads to the fourth and final question.  
11 We looked at the entry for 3 December 1996 in your GP  
12 records, which referred to that you might ask to have  
13 your hepatitis C status checked in the future if you  
14 decided.

15 **A.** Yes.

16 **Q.** Did you ever decide or ask to have your hepatitis C  
17 status checked?

18 **A.** Never, no. I did not.

19 **Q.** And so your testing came about through the description  
20 you've given in your first witness statement of the GP  
21 telling you that she was going to do some further  
22 blood tests --

23 **A.** Blood tests.

24 **Q.** -- and that was all you knew until you received the  
25 diagnosis?

1     **A.** Yes, yeah.

2     **SIR BRIAN LANGSTAFF:** It looked from the medical records  
3     of the time, if necessary we can put them back up,  
4     that the doctor had indicated that you might wish  
5     a test, if you wanted it, you could have it, but then  
6     the next entry immediately after that, it's not very  
7     clear on the date but it looks like the very end of  
8     1996 says that you tested -- there was a test which  
9     was positive, not that you tested but that your blood  
10    had been.

11           I think the next entry is early '97 when it looks  
12    as though there may have been discussion with you.

13    **MS RICHARDS:** Yes, and Mr X --

14    **SIR BRIAN LANGSTAFF:** That's what the record shows, is it  
15    not?

16    **MS RICHARDS:** It is and Mr X has made the observation in  
17    his supplementary statement in which he has talked  
18    about these records but there was nothing which shows  
19    him going back and asking for a test, simply the test  
20    result itself.

21    **SIR BRIAN LANGSTAFF:** And the way it is written looks as  
22    though it may simply have been a sample which has then  
23    been tested, having been taken earlier.

24    **MS RICHARDS:** That's one inference certainly, sir, yes.

25    **SIR BRIAN LANGSTAFF:** It's a possible interpretation.

1 **MS RICHARDS:** Thank you, Mr X. There's nothing further  
2 from me.

3 **SIR BRIAN LANGSTAFF:** There's one question which is more  
4 of a correction I think than a question, one comment,  
5 and then I shall thank you as I usually do.

6 But the question/correction is this, on the  
7 transcript as it was typed out and I thought at the  
8 time it was what I was hearing, you had said that when  
9 you'd been told your diagnosis of hepatitis C, it came  
10 as a bit particular blow because you were 17 or 18  
11 years of age.

12 I don't think that could be right, could it,  
13 because you had your infection --

14 **A.** Yes.

15 **SIR BRIAN LANGSTAFF:** -- in 1976, you were tested in 1997.

16 **A.** Yeah.

17 **SIR BRIAN LANGSTAFF:** So it was 38/39, thereabouts.

18 **A.** Yes, it couldn't have been 17 or 18, yes.

19 **SIR BRIAN LANGSTAFF:** That's just plainly an error in the  
20 transcribing or whatever.

21 **A.** Yes.

22 **SIR BRIAN LANGSTAFF:** But it needs to be put right,  
23 particularly as we must keep records right.

24 **A.** Yes, I agree.

25 **SIR BRIAN LANGSTAFF:** And the observation is in relation

1 to hepatitis C testing. I understand or I understood  
2 before this week and it was confirmed to me during the  
3 course of the week by Professor Dillon from Tayside  
4 who is here and one of our experts to the Inquiry that  
5 the process of eliminating hepatitis C in Tayside, at  
6 any rate, where the target date is 2025 is going well.

7 **A.** Yes, I think if we could all take a leaf out of the  
8 Tayside example we would be one of the world leaders  
9 in how we are approaching elimination.

10 **SIR BRIAN LANGSTAFF:** But your evidence gave me the  
11 opportunity to say that, so thank you for that.

12 **A.** Yes.

13 **SIR BRIAN LANGSTAFF:** Thank you for your evidence and, in  
14 particular, your description of what it is like living  
15 with this dreadful disease and for your thoughtful  
16 observations upon matters which relate to that and  
17 relate to matters we are enquiring into. Thank you  
18 very much.

19 **A.** Thank you.

20 **SIR BRIAN LANGSTAFF:** We will take a break now before the  
21 next witness, who again is anonymous, and come back at  
22 12.15 pm.

23 **MS RICHARDS:** Thank you, sir.

24 **SIR BRIAN LANGSTAFF:** 12.15 pm.

25 **(11.34 am)**

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**(A short break)**

**(12.20 pm)**

**SIR BRIAN LANGSTAFF:** Our next witness is Mrs Y and in her case too I make an order of the same sort that you're now very familiar with. It reads like this, the name and address of witness W2288, that's Mrs Y to you and me, the name of her husband who died and the names of any other member of the witness's family and any other identifying information, such as the witness's image or a description of their appearance cannot be disclosed or published in any form unless express permission is given by me or by the Solicitor to the Inquiry acting on my behalf.

Witness W2288 must be referred to only as Mrs Y. The order remains in force for the duration of the Inquiry and at all times thereafter unless otherwise ordered, and I may vary or revoke the order by making a further order during the course of the Inquiry.

Well, that said, Mrs Y.

**MRS Y, sworn**

**Questioned by MS RICHARDS**

**MS RICHARDS:** Sir, before Mrs Y starts her evidence I should say that Mrs Y is going to be talking about her late husband and she's going to be referring to him by his first name because it would not be

1 practical for her to be able to talk about him  
2 otherwise.

3 As a result of that, there is no live-streaming of  
4 her evidence and the transcript and the audio  
5 transmission of the evidence that will be subsequently  
6 uploaded onto the website will have the names redacted  
7 and so whilst those are sitting here will hear his  
8 name, it is covered by the restriction order and is  
9 not to be repeated outside.

10 **SIR BRIAN LANGSTAFF:** Thank you.

11 **MS RICHARDS:** Mrs Y, you are going to be talking about  
12 [redacted], your late husband. You met when you were  
13 both 14 years old at school.

14 **A.** Yeah, that's right.

15 **Q.** And you got married in 1982 at the age of 17.

16 **A.** Yeah, uh-huh.

17 **Q.** And you've described him in your statement as the love  
18 of your life.

19 **A.** Yes.

20 **Q.** What was he like?

21 **A.** He was a typical Glaswegian, so he was, just loved  
22 being out with his friends. He was a doo flyer, used  
23 to fly the doos, so he loved doing that. He was just  
24 a good guy, I would say, that's the way to describe  
25 him, would you? Hard-working and just loved us.

1 Q. Now, he had mild haemophilia A?

2 A. Yeah, mild.

3 Q. And that was diagnosed in childhood, not in early  
4 infancy but you're not sure exactly when. You've seen  
5 some references that suggest it might have been at the  
6 age of nine or ten or thereabouts?

7 A. Yeah, uh-huh.

8 Q. The records of his treatment from Yorkhill no longer  
9 exist or if they do you've not been able to get of  
10 them?

11 A. No, no.

12 Q. But the GP records which you've seen suggest that he  
13 was treated with cryoprecipitate at Yorkhill in 1977,  
14 that he was treated with Factor VIII concentrate in  
15 1980 at Yorkhill and we'll just look at a document to  
16 confirm that if we may, Mrs Y, to confirm that if we  
17 can, 2288003. *(Pause)*

18 It should come up on screen, I'm hoping. 2288003.

19 I'll read the relevant passage out whilst we try  
20 and sort that out. That he says:

21 "He has in the past required cryoprecipitate for  
22 a possible head injury in 1977. He also received  
23 Factor VIII concentrate for hemarthrosis of his right  
24 elbow in July 1980."

25 A. Uh-huh.



1 Q. Then you have a recollection of when you were together  
2 with [redacted] of some form of injury after  
3 a football game. What you can recall about that?

4 A. I remember him and his pals were quite keen on  
5 football so there was a kind of red ash just along  
6 from us, they would meet there and play their football  
7 and I remember this night he had went down, he had  
8 quite a bad cut and it was into the knee, so he come  
9 back and up -- it wasnae, it's not that it wasnae  
10 stopping, it just looked bad. It was bleeding heavily  
11 and it looked bad and I kind of thought -- I says to  
12 him I think you'd better go up and get it checked.

13 So he'd actually phoned ahead and he says right,  
14 come up. He went up and got his treatment. I was  
15 more worried as well because it was red ash and I'm  
16 thinking, what's went into the wound. I says, "You're  
17 going to go and need to go and get it treated anyway",  
18 and that's when he went up but that was roughly --  
19 I lived in Govan at the time and I moved out of there  
20 just after [redacted] was born. She was born in '86  
21 so I would think it was roughly before then.

22 Q. And which hospital did you go to?

23 A. That was the Royal Infirmary.

24 Q. In Glasgow?

25 A. Yeah, uh-huh.

1 Q. As I understand it, you can't recall whether on that  
2 occasion he was given cryoprecipitate or a Factor VIII  
3 product?

4 A. I didn't always go into the room with him. He used to  
5 just go in and Liz, that was his nurse, and Liz would  
6 go -- talking away and they would do whatever they  
7 done, and then I would get him when he came back out  
8 again, uh-huh.

9 Q. And then we've got another letter which suggests in  
10 1988 he received DDAVP and Factor VIII Z8, an SNBTS  
11 product. Apart from those four occasions, in the  
12 period up until 1988 do you recall him requiring any  
13 other treatment?

14 A. No, no.

15 Q. So his haemophilia was indeed mild?

16 A. Yeah, uh-huh, it didnae -- it didnae have a big impact  
17 on his life at all.

18 Q. And do you recall in any of the times that you knew  
19 him or from anything he said whether he was given any  
20 lifestyle advice, for example, about how perhaps he  
21 could manage things to avoid having any bleeds?

22 A. No, not really, no.

23 Q. So you don't think he was --

24 A. No, I don't, no, no.

25 Q. Do you know whether his mother was given any advice or

1 information or warnings about any risks of infection  
2 associated with products?

3 **A.** No, because when we got talking about it when I first  
4 met her she was more -- it was the more the genetic  
5 sort of thing, about the daughters then going down  
6 into sons and things like that.

7 She never ever mentioned anything about lifestyle  
8 things or -- obviously, being a mother and knowing  
9 then that he had haemophilia, she was -- kind of  
10 watched what he was doing and whatever else but that  
11 was from her I would think rather than anything that  
12 she's been told.

13 **Q.** And from either your discussions with [redacted] or  
14 from any occasion when you accompanied him to  
15 treatment, was he given any information or advice or  
16 warnings himself about the possibility of being  
17 infected with any treatment?

18 **A.** No, no.

19 **Q.** Now, in the years between your marriage and 1995 you  
20 and [redacted] had two daughters?

21 **A.** Yeah.

22 **Q.** You bought a house?

23 **A.** Uh-huh.

24 **Q.** And he worked hard, first of all, as a factory worker  
25 and then he tried as a forklift truck driver?

1   **A.** Yeah, uh-huh.

2   **Q.** And he very much enjoyed his work?

3   **A.** Well, he worked, he worked in the -- he was a very  
4       hard worker.

5   **Q.** You said he would work 12-hour shifts.

6   **A.** Uh-huh.

7   **Q.** He seemed fit and fit and healthy.

8   **A.** Yeah.

9   **Q.** You'd go and watch live music together.

10  **A.** Yeah, that was our thing.

11  **Q.** You said he was happy, outgoing and sociable. It was  
12       a simple life but you both enjoyed it?

13  **A.** Yeah, uh-huh.

14  **Q.** In late 1995, November 1995, you and [redacted]  
15       attended a routine check-up at the Haemophilia Centre  
16       at the Royal Infirmary in Glasgow?

17  **A.** Yes, mm-hmm.

18  **Q.** What can you recall about that appointment?

19  **A.** I remember that when we got to the clinic at the Royal  
20       the actual haemophilia unit wasn't opened, they were  
21       doing something in it or something like that, so  
22       this -- I'd never seen the doctor before and neither  
23       had [redacted] because the two of us were kind of  
24       like, "Who's this?" And he was with a lady, so they  
25       says, we'll take -- they used to take you upstairs to

1       ward 23 when the clinic wasnae opened so up we went  
2       and they tried to find a room for us to take us in and  
3       we were kind of no knowing what was going on.

4               We ended up in a room that I can only describe as  
5       a storage room. It looked like a cleaners' room  
6       because it had stacks of things on it. It was nae,  
7       there was no seats for us to sit or anything else. It  
8       was the size of a tuppence. It was really small.

9               So we were taken in here and then that's when it  
10       came out saying that the -- a previous blood test or  
11       whatever it was that had been taken before had been --  
12       they'd checked for hepatitis C and that it had come  
13       back positive.

14              We just looked at each other, because this is the  
15       first that we had ever even heard anything about  
16       hepatitis C. We didnae know -- for a start we didnae  
17       know he had been tested for it and we didnae realise  
18       that that's the reason why we were going there that  
19       day, so we were absolutely shocked. We didnae know,  
20       we just looked at each other and then looked at these  
21       people and he says, "Have you got any questions that  
22       you want to ask us?" And we were like, "We don't  
23       really know, because we don't know anything about  
24       hepatitis C for a fact. We didnae realise that was  
25       the reason that we were coming here", so the two of us

1           were just kind of standing.

2           Then he came away with just telling us just a wee  
3 bit about how in the house watch his razor, the  
4 toothbrush, things like that, just generally things,  
5 and then it was kind of says to me that I should get  
6 tested. They gave us three leaflets and that was it.

7           He says, "You'll probably get -- you'll get  
8 a follow up appointment to come in to see Dr Lowe.  
9 You shouldnae wait too long for that", and that was  
10 it. So out we went. We walked outside and and the  
11 two of us just looked at each other and says, "What  
12 just happened there?" We didnae have a clue, and it's  
13 a bit of a distance from the Royal down to the city  
14 centre and we just walked straight down Castle Street  
15 without even hardly saying a word.

16           The two of us went into a wee pub and sat and,  
17 what do you do? We didnae-- because what he says to  
18 us was -- he didn't say it was any in way going to  
19 change our life significantly, he just kind of says --  
20 he just kind of -- they told us that it should be  
21 okay, it wouldnae change our life that much, more or  
22 less, and we just left.

23           I had a look at these leaflets and one of them was  
24 for drug addicts and we were like, "Why are they  
25 giving us this?" Because we didnae know if they

1 thought he was a drug addict or if it was through his  
2 haemophilia. We just didn't know.

3 Q. You'd gone along thinking this was a routine  
4 appointment.

5 A. Yeah.

6 Q. In the period between 1988 when we see that [redacted]  
7 had attended and received DDAVP and Factor VIII in  
8 1988 and this appointment in 1995, had [redacted] been  
9 attending clinics --

10 A. He would go up, just your normal clinic, just go in  
11 and have a quick word with Liz or whatever. He didnae  
12 need an awful lot of treatment, he didnae, but he  
13 would still maybe pop in. That's just the way the  
14 haemophilia unit was in the Royal.

15 Q. When you say have a quick word with Liz, that was the  
16 nurse --

17 A. That was the one that --

18 Q. -- who he would see --

19 A. Yeah.

20 Q. -- when he would attend for reviews in that period  
21 prior --

22 A. Yeah.

23 Q. -- to late 1995.

24 A. Uh-huh.

25 Q. I don't know whether we've -- whether we've now got

1           that document, 2288003. I'm just going to read aloud  
2           to you something from it --

3   **A.** Yeah.

4   **Q.** -- because I know you've seen it, Mrs Y. The  
5           appointment that you've just been talking about, which  
6           was in November 1995, as if by magic we have it.

7           So we can see this is a letter 27 November 1995.  
8           It's to your husband's GP.

9   **A.** Yeah.

10   **Q.** And it's from a Dr Hung, a haematology registrar, and  
11           it says in the second paragraph:

12           "As you know, he failed to attend his previous  
13           clinic appointment and, as a matter of fact, has not  
14           been seen since 1988."

15           As I understand it from you're evidence you say  
16           that's not correct --

17   **A.** No, that's no right, no.

18   **Q.** -- because he'd regularly been seeing the nurse  
19           specialist?

20   **A.** Yeah, used to go in, uh-huh.

21   **Q.** And then it refers to him being well, but then it says  
22           this:

23           "However, after the recent media publicity on  
24           hepatitis C, he felt that he should re-attend the clinic  
25           to be checked for this virus as well as for HIV."



1           So that suggests that it was [redacted] himself  
2           raising --

3   **A.**   Definitely not.

4   **Q.**   -- the question of hepatitis C and HIV?

5   **A.**   No, no, we did never, we just thought it was a normal  
6           clinic we were going up to.

7   **Q.**   Then if we look at the last paragraph on that page it  
8           says:

9           "I informed him about his risk of previous infection  
10           and he was agreeable to being screened for HIV and  
11           hepatitis B, C and A serology."

12           As far as you can recall was [redacted] asked --  
13           had he been asked for his consent to any of those  
14           tests?

15   **A.**   Nothing, nothing, especially not on that day. It was  
16           more just to do with the hepatitis C that we'd been  
17           spoken about. Nothing like that had been spoken  
18           about.

19   **Q.**   And then it says:

20           "As suspected, hepatitis C screen was positive with  
21           hepatitis C virus antigen positive by PCR."

22           Then if we go on to the next page, please, Paul,  
23           it then says:

24           "This new finding of hepatitis C seropositivity  
25           obviously has a great deal of implications for a patient

1 of his age. Though he is aware that he might have been  
2 infected by hepatitis C in the past and there is now  
3 a treatment for it he does not know of the positive  
4 finding. This obviously has important implications for  
5 him and his family and will need to be discussed with  
6 him in the near future."

7 Now, your recollection of that meeting was that he  
8 was indeed told in that very appointment --

9 **A.** Yeah.

10 **Q.** -- of the positive findings?

11 **A.** Yeah, uh-huh, definitely, that's where we found out  
12 that's -- yeah.

13 **SIR BRIAN LANGSTAFF:** Can we just go back to the page  
14 before, Ms Richards. Thank you.

15 In the last paragraph, the sentence beginning:

16 "As suspected, hepatitis C screen was  
17 positive ..."

18 Is there anything in the content of the letter, so  
19 far as you can see, which gives rise to any suspicion  
20 that he might have been?

21 **MS RICHARDS:** Only, sir, I think possibly the fact of  
22 having received Factor VIII products, so in the third  
23 paragraph down it refers to him having received  
24 Factor VIII concentrate in 1980 and it says:

25 "This, therefore, places him at risk of having been

1 infected with either virus."

2 So that's the only clue that's given there.

3 **SIR BRIAN LANGSTAFF:** So it's the period of time since  
4 1980 or either cryoprecipitate in 1977 or 1980 in the  
5 right elbow that might have suspected the risk. There  
6 is nothing to do with any clinical observation.

7 **MS RICHARDS:** There is nothing in this letter, no. And as  
8 I understand Mrs Y evidence he had been feeling fit  
9 and healthy.

10 **A.** He was definitely healthy, yeah. Hm-mm.

11 **MS RICHARDS:** So it was the mere fact of having received  
12 in the past these treatments, sir.

13 **SIR BRIAN LANGSTAFF:** Do we have any evidence of other  
14 people who were called back because they'd had  
15 interventions in the past at this hospital, around  
16 this time?

17 **MS RICHARDS:** Not that I recall having seen, sir, but  
18 that's obviously a matter that we may need to check  
19 more widely.

20 **SIR BRIAN LANGSTAFF:** Thank you.

21 **MS RICHARDS:** Following the appointment that you've  
22 described Mrs Y, and the communication of the  
23 diagnosis to you, you then went and saw Dr Lowe --

24 **A.** Yeah, uh-huh.

25 **Q.** -- not long afterwards.

1   **A.** That's right.

2   **Q.** What can you recall about that meeting with Dr Lowe?

3   **A.** I remember just going in and obviously shaking hands,  
4       whatever else, and then he started discussing with  
5       [redacted] the findings of the hepatitis C, and it  
6       wasn't a long meeting because it was only  
7       matter-of-factly again about personal hygiene in the  
8       house and, again, he says to me about getting checked.  
9       By that time I'd already made an appointment to go and  
10      get checked, and just a quick discussion again.

11           And then I had asked -- [redacted] had asked about  
12      where did they think he'd -- because he kind of -- he  
13      was like, "How could I have got it?" And he says to  
14      him -- he asked him when he got it and he was like,  
15      "I can't actually tell you. We don't know. I suspect  
16      it's obviously been through your blood treatment or  
17      your thingy treatment", he says, "But we don't know  
18      when it was that you actually were infected".

19   **Q.** And you have recorded in your statement, Mrs Y,  
20      Dr Lowe saying this:

21           "He did tell us that all haemophiliacs have been  
22      infected with hepatitis C through infected blood."

23   **A.** Yeah, uh-huh.

24   **Q.** And then you describe the conversation really being  
25      about hygiene and how hepatitis C could be passed on

1 and a need for some liver monitoring.

2 **A.** Yeah, that was that.

3 **Q.** And again we -- we may I hope have this letter,  
4 2288006, this is a letter from Dr Lowe,  
5 7 December 1995, and it describes to -- it describes  
6 Dr Lowe reviewing [redacted], this man with mild  
7 haemophilia A at the haemophilia unit on  
8 5 December 1995:

9 "I explained to him that his HIV antibody test was  
10 negative, but that he is a carrier of the hepatitis C  
11 virus: having both a positive antibody and positive  
12 hepatitis C antigen by the PCR test. Liver function  
13 tests are still not available but we have repeated  
14 these ..."

15 Then there's a reference to hepatitis B and then  
16 in the next paragraph it says:

17 "I gave him the hepatitis C booklet produced for  
18 patient information by the Haemophilia Society and had  
19 a long discussion with him about the implications of  
20 carrying the hepatitis C virus and the risk of possible  
21 liver disease. He was given advice about precautions  
22 with blood and body fluids and will discuss the  
23 implications with his wife."

24 And he says he's arranged to see both of you in  
25 two weeks' time to answer questions and offer testing.

1           Then in the last paragraph it says:

2           "His two daughters aged 13 and 9 attended with him  
3           and we took blood to check their own Factor VIII  
4           levels."

5   **A.** That never happened.

6   **Q.** Did your daughters attend with [redacted] this  
7           appointment?

8   **A.** No, no, they weren't with us.

9   **Q.** They weren't --

10 **A.** I wouldn't have taken my daughters, especially he was  
11           awfully protective towards them, wasn't he. I  
12           wouldn't have taken them with us to that appointment.  
13           There's no way on this earth they would have been  
14           there, and they certainly weren't tested there.

15 **Q.** And the letter -- one implication of the letter might  
16           be that you weren't there, but you say --

17 **A.** I was there.

18 **Q.** -- you were there?

19 **A.** Uh-huh.

20 **Q.** Do you recall there being a long discussion about the  
21           implications of hepatitis C --

22 **A.** No.

23 **Q.** -- and the risk of possible liver disease?

24 **A.** No, no because I just find it strange how it doesn't  
25           say that I'm there. In other words [redacted] took my

1 daughters to that meeting with him. That just didn't  
2 happen, any of that.

3 **Q.** And I should say, sir, Dr Lowe has been invited to  
4 respond to Mrs Y's statement and we understand will be  
5 filing a response.

6 Your description in your witness statement is it  
7 was a short appointment and really all that was said  
8 was about confirming the diagnosis?

9 **A.** Yeah, uh-huh.

10 **Q.** Answering [redacted]'s question about when he became  
11 infected by saying he didn't know.

12 **A.** Didn't know.

13 **Q.** Saying that all haemophiliacs had been infected  
14 hepatitis C through infected blood and then just  
15 a conversation about hygiene and the risks of  
16 infection?

17 **A.** Uh-huh.

18 **Q.** And you said in your statement that you think  
19 [redacted] should have been told much earlier --

20 **A.** Yeah.

21 **Q.** -- than 1995 of the risks.

22 **A.** Yeah. Looking through, I found it quite uncomfortable  
23 looking through [redacted]'s medical notes because  
24 that's a very personal thing, your medical notes, even  
25 though he's not here any more, I just find it

1           uncomfortable looking things and things I did look  
2           through, I noticed he had been tested, was it '88 or  
3           something like that, for hepatitis B and he could have  
4           been tested then for HIV, but luckily enough he didn't  
5           have. So why was he no tested them for HIV? What if  
6           he had HIV, do you know what I mean? He'd have been  
7           going from then away to 1995 with that and possibly  
8           moved it on to me, the kids, anything could have  
9           happened then.

10                  Plus for the fact I know of other haemophiliacs  
11           that were tested long before 1995. I feel as if they  
12           should all have been tested long before that.

13   **Q.** What initially was the impact of [redacted] -- on  
14           [redacted] of the diagnosis? You said that the two of  
15           you were very shocked --

16   **A.** Yeah.

17   **Q.** -- and found it very difficult to understand?

18   **A.** Yeah, uh-huh.

19   **Q.** But as the weeks and months went on --

20   **A.** As the weeks and months went on, we kind of went back  
21           to our life. He went back to his work, he done what  
22           he'd always done, go to his work, looked after the  
23           kids, went to our gigs, anything like that, just  
24           normal life again until it followed up on to the start  
25           of his treatment.



1 Q. You've described in your statement how as time passed  
2 he began to feel angry.

3 A. Yeah, oh yeah, uh-huh.

4 Q. He began to lose trust in the medical professional?

5 A. He definitely, yeah, uh-huh.

6 Q. He became fanatical about hygiene --

7 A. Yeah.

8 Q. -- because he was devastated by the fear he could have  
9 passed it on to you or your daughters.

10 A. Yeah, he was -- he was a very vain man, wasn't he? He  
11 looked after himself and he liked -- worked hard -- he  
12 wore -- he liked nice clothing and everything like  
13 that. That's just the way he was. It used to drive  
14 me nuts at times, the way he was with it, but he  
15 became even worse. Everything had to be just done  
16 right because he was absolutely obsessed at passing it  
17 on to us.

18 Q. What was his attitude to telling others?

19 A. No, we couldn't. The only people we spoke to was each  
20 other. At that time the kids didnae know, they  
21 didnae. He didn't even really talk about his being  
22 an haemophiliac to very many people. He wasnae  
23 embarrassed about being a haemophiliac or anything  
24 like that. He just didnae discuss it. He was a very  
25 private person, weren't he?

1           But I remember once when it did start to come out  
2           about the haemophiliacs and the risk of AIDS/HIV it  
3           was actually one of my family members knew that  
4           [redacted] was a haemophiliac and put two and two  
5           together and come up with ten, and started saying that  
6           he must have AIDS then, "He's a haemophiliac he must  
7           have AIDS". So even after that he became even more  
8           like nobody got to know everything, so we were living  
9           in a wee bubble, just ourselves so we were. Anything  
10          that happened it happened between us.

11       **Q.** It was 1997 when [redacted] embarked upon his first  
12          course of treatment?

13       **A.** Yeah, it was.

14       **Q.** What can you remember about that?

15       **A.** I think it only lasted maybe 12 weeks that one and  
16          just the usual sort of things, flu-like symptoms, the  
17          tiredness, but he did still manage to still go to his  
18          work. He did cut down his hours quite a bit but he  
19          was still going to his work all the way through that,  
20          so he was, but lethargic all the time and just the  
21          usual symptoms of interferon.

22       **Q.** You said he did struggle to get out of bed.

23       **A.** Yeah.

24       **Q.** He became a bit verbally aggressive and snappy.

25       **A.** Yeah.

1 Q. And to some extent depressed, felt as though the  
2 weight of the world was on his shoulders?

3 A. Uh-huh, that was nearer the end, that was nearer the  
4 end of that treatment.

5 Q. But that was just a 12-week course.

6 A. 12 weeks.

7 Q. And you've said that he would tell the nurse that  
8 everything was great.

9 A. Fine.

10 Q. Why was that?

11 A. He didn't want taking off the treatment. He wanted to  
12 try and clear the hepatitis, so every time he went in,  
13 everything was fine, because he would go away and  
14 Margaret was his nurse, he we would go in with  
15 Margaret and just, no, everything is fine, just a bit  
16 tired, but no to the extent -- I didnae know this at  
17 the time, I didnae, but when I looked at his medical  
18 notes again, there it was, everything's fine and he's  
19 managing okay, which wasnae true.

20 Q. That first course of treatment didn't work.

21 A. No, it didn't.

22 Q. And what was [redacted]'s reaction he learnt it hadn't  
23 worked?

24 A. I think he thought then even, "I'm never going to get  
25 this, this is never going to clear". He thought he

1 was going to die, to be honest. That was the first  
2 time I had ever heard him talking about what would  
3 happen if he did go, because obviously, as well, being  
4 a haemophiliac he didnae have -- life insurance was  
5 through the roof even just being a haemophiliac so he  
6 didnae have life insurance.

7 Oh no, I'm lying there, we ended up when we got  
8 our house we had a brilliant financial adviser and she  
9 got life insurance with the house so she did, but it  
10 was only enough to cover that. There wasnae a lot  
11 that would have been left over for us. That is the  
12 first time I ever heard him talking about if he wasnae  
13 here any more.

14 **Q.** Then in 2003 he learnt of the possibility of a further  
15 course of treatment, this time with interferon and  
16 ribavirin?

17 **A.** Yeah, uh-huh.

18 **Q.** And you've said in your statement he wanted to give  
19 this a go.

20 **A.** Yeah, definitely.

21 **Q.** And he thought it would be similar to the first.

22 **A.** Well, he was told it would be similar to the first,  
23 yeah.

24 **Q.** If we look at document 2288011 please, Paul.

25 We can see this is a letter, 24 October 2003. It

1           refers to reviewing [redacted] in the clinic.

2           "He has hepatitis C with genotype I. Failed  
3           treatment in 1997. He remains very keen for  
4           consideration of treatment with interferon and  
5           ribavirin. He has no contraindication to therapy at  
6           present. I explained he has a 25% chance of response  
7           but he remains very keen to go ahead with treatment."

8           Then the next paragraph:

9           "He did not experience too much in the way of side  
10          effects on his the previous treatment."

11          Same sentence repeated:

12          "I explained that they are likely to be much the  
13          same this time."

14   **A.** Yeah, uh-huh.

15   **Q.** The second course of treatment was a 12-month course  
16          of treatment?

17   **A.** Yeah, uh-huh.

18   **Q.** You've said in your statement:

19          "I wish we'd never heard of it. He signed his own  
20          death certificate."

21   **A.** Yeah, that's what took him away. It wasnae -- I feel  
22          as if wasnae hepatitis that took [redacted] away from  
23          us. It was the second round of treatment, that was  
24          the nail in the coffin you could say, definitely.

25   **Q.** You've used the word "brutal" to describe it. What

1 can you tell us of the effects which he suffered in  
2 that treatment?

3 **A.** Oh, it was just unbelievable. The physical effects,  
4 he didnae work, he couldn't work, because this one  
5 happened straightaway, so it did.

6 So most days it was upstairs in his room, lock the  
7 door and you've never seen him, he locked himself  
8 away, because he did not want the lassies seeing him.  
9 He was verbally abusive, he was -- no physically  
10 abusive but the way he spoke, his mannerisms.

11 He lost -- he didnae want to eat. He would walk  
12 in and he'd be sitting like this and I thought,  
13 "What's the matter?" And he's like the itching. He  
14 says, it felt as if it was coming from inside. He  
15 says it's like this constantly everywhere, and you  
16 could tell it was on here, in his brain, it was  
17 actually getting that bad that he would be sitting  
18 like this, it's this itchy and he'd be sitting in --  
19 and it does not sound like much, itching, but this  
20 literally drove that man -- it was just -- it was  
21 terrible.

22 **Q.** He couldn't sleep either?

23 **A.** He couldn't sleep, no. Fatigue. Anybody who gets  
24 fatigue knows, the very end of it can be insomnia.  
25 You've got the fatigue, you're so exhausted, but then

1           you can't sleep, so, you know, it's ...

2   **Q.**   And he became extremely depressed?

3   **A.**   Extremely depressed, yep, yep, uh-huh.

4   **Q.**   You've said in your statement he became a different

5           man?

6   **A.**   Uh-huh.

7   **Q.**   He became antisocial, his mood would change?

8   **A.**   Yep.

9   **Q.**   He became aggressive.

10  **A.**   Yep.

11  **Q.**   There was an episode in which one of your daughters

12           was locked out of the house?

13  **A.**   Yeah. [redacted]. I come home from my work one day.

14           I came down the hill to come into the street and there

15           I kind of seen -- we had a seat at the side of the

16           house and I just happened to see her and she was in

17           her pyjamas. I walked round and I was like, "What's

18           the matter", and she went, "I said something to Dad

19           and he just lost it". He says -- and it wasn't even

20           anything specific, wasn't it? Just grabbed her,

21           opened the front door and threw her out of the house

22           and she's sitting there absolutely in tears, and

23           I just got the two of them at that stage and went to

24           my sister's. We stayed the night at my sister's

25           because I knew it couldn't keep going on like this.

1 It couldnae, because it was getting to the point,  
2 I don't know if we he would have turned violent,  
3 because that's how bad it was getting and it wasnae--  
4 it was breaking my heart because that wasnae my  
5 [redacted], he just -- do you know, he loved his  
6 family so much it was turning him into something that  
7 he wasnae, he hadnae been.

8 **Q.** You went on holiday in July of 2004.

9 **A.** Yeah.

10 **Q.** And you'd arranged a surprise party.

11 **A.** It was his 40th birthday, yeah.

12 **Q.** And what was his reaction when he came home?

13 **A.** He went crazy. We got off the plane and I had -- it  
14 wasnae a big party. It was only his family, a couple  
15 of mine, and just a few amount of friends that were  
16 there, and we got off, we'd got a taxi home and in the  
17 door and that was it, he seen them, he didnae even  
18 speak. He went straight up the stair, in the room and  
19 slammed the door, and I went up and he was like, "What  
20 you have done?" And I was like, "It's your birthday.  
21 You've got to at least" -- because he had been in  
22 a great mood, hadn't he, all the way through the  
23 holiday.

24 He had been more relaxed. He was still taking his  
25 medication on holiday, took everything with him.



1 A couple of wee times he just took himself away, but  
2 it wasnae to the extent that it had been, so it had  
3 been a good two weeks but that day I walked in and  
4 I'll never forget the look on his face. He went, "I  
5 don't want them" -- he didn't want people to see him.  
6 He'd lost that much weight. He had blisters on his  
7 arms, blisters -- he just didn't want people to see  
8 the man that he'd turned into and his mother had been  
9 up and tried to speak to him and he was like "You,  
10 just get home", and he would never have spoke to her  
11 like that, because you're brought up with your mother,  
12 you've got respect, you don't talk to your mother like  
13 that but he did, and he says, "You may as well go  
14 downstairs and just tell them all to go". So it  
15 didnae -- he ended up calming down.

16 He went downstairs and he spoke to people and  
17 people -- I don't know whether they were shocked or  
18 not when they see them, because some of them hadn't  
19 seen him for a wee while but certainly naebody  
20 mentioned it and he sat and -- but once it was over,  
21 he was like, "Don't ever do that again". He was just  
22 totally -- I think he just felt as if it was  
23 demoralising to him. He was just shocked that there  
24 was anybody in the house.

25 Q. You've shown me and the Chair has seen two photos of

1 [redacted], one which shows him when he was well.

2 **A.** Uh-huh.

3 **Q.** And you've said, "That's my husband."

4 **A.** Yeah.

5 **Q.** And one which shows him much gaunter.

6 **A.** That was during the holiday, yeah.

7 **Q.** And you say, "That's not the man that I married."

8 **A.** It's the man that I loved, I can look at that photo

9 and say I still love that man with all my heart but he

10 wasnae the man that I married. He had changed into --

11 I don't know what he'd changed into but wasnae the man

12 that I married.

13 **Q.** In November of 2004 [redacted] was told that this

14 treatment hadn't worked?

15 **A.** Yeah, yep.

16 **Q.** What was the effect of that on him?

17 **A.** He was absolutely devastated. I think he was just --

18 because he'd been through that much and I remember

19 we'd went in and we'd been taken in and Margaret had

20 said that he was sorry but it had come back that the

21 treatment hadnae worked, and he didn't even want to

22 speak to Margaret anymore. It was just like okay,

23 because it's one of the only times that anybody had

24 ever offered him -- I had actually says to Margaret

25 that day, because I knew the state he was in, and

1 I said, "I think he should have some sort of  
2 counselling" and she says, "I can arrange that for  
3 [redacted] for you, if you want to", and he looked and  
4 he was like, "No, I don't want it." And that was the  
5 last, we just walked out and he was devastated, locked  
6 himself away again in the room and I think it was four  
7 days later, he left us.

8 **Q.** He left the house.

9 **A.** Yeah.

10 **Q.** You didn't know where he was to start with?

11 **A.** No, no.

12 **Q.** And then I think you received a phone call --

13 **A.** I was in at my own doctor because I was in such  
14 a state, that I've got a good -- I get on really well  
15 with my doctor and I'd been down to her. She knew  
16 what [redacted] was going through although that wasnae  
17 her doctor, she knew what was happening so  
18 I decided -- I hadnae ate or anything and I went in  
19 and my phone -- my phone went in the room and I says  
20 to her, "I've got to take this". It was from  
21 [redacted] Dad and he says, "We've found out where he  
22 is [redacted], but just you wait, we'll talk to him  
23 first".

24 I was like I'm no waiting so I ran out of the  
25 doctor's surgery, got a taxi and seen him on

1 [redacted] and, oh my God, it was just heartbreaking  
2 to see and then when he seen me, he was like, "I'm not  
3 coming back to yous", and we sat down and he says to  
4 me, "Do you know what I've got in my pocket", and I  
5 says "What?" And he went, "A half bottle of vodka",  
6 and I was like, "What's that for?" He went, "That's  
7 what I want to do". I think in his mind he then  
8 thought, "Do you want to know what? See, if that  
9 hasnae worked I'm going to die anyway." He didnae  
10 want us to be round about to see it, so he was going  
11 to drink himself to death and that's the way it went  
12 from there, that was.

13 **Q.** And you told that he didn't want to see you.

14 **A.** No.

15 **Q.** He told you he'd had enough of his life.

16 **A.** Yeah.

17 **Q.** And he didn't return to live at the family home after  
18 that.

19 **A.** He says he can't putting us through what his life was  
20 then, he couldnae put us through that, I think, and  
21 looking back on it now, there was never any big  
22 argument, we never had a big falling out that day, he  
23 just left and then we got him again and there was  
24 never anything like that.

25 So we still had the connection. We were best

1 friends, so -- and I think sometimes the girls as well  
2 cannae understand. They say to me, "Why were you  
3 never angry", because they at times got angry and  
4 I was like, "Because I knew your Dad and I knew that  
5 that wasnae your Dad, that was whatever that  
6 medication had turned your Dad into", and he could  
7 still talk to me about things, so even though he was  
8 drinking heavy, whatever else, we still phoned each  
9 other, we still see him, and there was still a good  
10 relationship there, so there was.

11 **Q.** But --

12 **A.** He turned into an alcoholic, yeah, an absolute  
13 alcoholic. He went from being, as I said, a vain man,  
14 to a man that you could probably say he was a man that  
15 you see sitting at the side of the road, so he was.

16 His appearance, he didn't bother about his  
17 appearance whatsoever. I remember one day I was with  
18 my work and one of my friend's Mum's came in and  
19 she -- because people were so surprised when we split  
20 up because -- and that's another thing. I never  
21 actually says we split up. I had to let people know  
22 that [redacted] left me, [redacted] left us and I made  
23 sure that people know. They'd say -- and I went, "No,  
24 [redacted] left us. We didnae leave him, he left us".

25 And she came in and she was like, "I seen

1 [redacted] in the shop", and she was like, "Oh my  
2 God", and I felt just like grabbing and saying to her,  
3 "This is the reason. Do you want to know the reason  
4 why he's turned into the way that he is?"

5 But his house -- he ended up getting a wee house  
6 beside his Dad's house, he went and his Da ended up  
7 getting taken into a wee home so he took over the  
8 house, the house was just -- I cannae describe it,  
9 I cannae describe the way he turned to -- it was  
10 heartbreaking.

11 **Q.** And you've said [redacted] still didn't want people to  
12 know that he had hepatitis C?

13 **A.** No, no.

14 **Q.** And so you had to let people believe that the  
15 alcohol --

16 **A.** Yeah.

17 **Q.** -- was somehow the --

18 **A.** Yeah, we'd split up and the alcohol was the reason.

19 **Q.** You've said this in your statement:

20 "I wanted to scream that we were no longer together  
21 because of the hepatitis C and that [redacted] had  
22 become an alcoholic because of the hepatitis C."

23 **A.** Because of the last treatment.

24 **Q.** But you couldn't say that because he didn't want  
25 anybody to know.

1 **A.** Couldn't say anything to anybody, yeah.

2 **Q.** He neglected himself very severely over the following  
3 years.

4 **A.** Yeah, very severely, yeah, mmm-hmm.

5 **Q.** And you've just described life from on become  
6 a complete nightmare?

7 **A.** Yes, it was, to watch the man that you had married, I  
8 know we married -- everybody thought we were --  
9 married at 17, they would say, and I had my kids but  
10 we were happy. We werenae -- I still to this day am  
11 not a very materialistic person. As long as my kids  
12 are happy. I've got a wee house. We worked hard to  
13 get us our wee house and I was more than happy but to  
14 watch him then, and he didnae press a self-destruct  
15 button. That was just I think his life was over by  
16 then, so it was, to be honest. That was -- the day  
17 that he had been in and got that answer that the  
18 treatment hadnae worked, that was it.

19 **Q.** You said in your statement that you lost your husband  
20 at that point.

21 **A.** Yeah, that was the day I lost him, I feel.

22 **Q.** "I had to watch the man I love slowly destroy himself  
23 through alcohol abuse as a way to self-medicate his  
24 illness."

25 **A.** Yeah.

1 Q. You say, "His personality altered but I've never  
2 stopped loving him or missing him."  
3 A. No.  
4 Q. What ultimately happened to [redacted]?  
5 A. I was very lucky in the fact that his mother lived  
6 quite close by, so he'd go up to his mums's and maybe  
7 fall asleep or whatever, and this weekend -- he always  
8 went on a Sunday. She made sure he had a good Sunday  
9 dinner and whatever else, but he had been in the  
10 Friday and she says he'd fell asleep but by the  
11 Saturday afternoon he still hadnae woke, woken up by  
12 3 o'clock, he was still sleeping. So she woke him and  
13 she said, "[redacted], are you okay?"  
14 "Yeah, I'm fine". Away he went back down to his  
15 own place. He didnae turn up on the Sunday for his  
16 Sunday dinner. In itself it isnae -- she though like  
17 why has he not turned up. Still didn't turn up by the  
18 Monday. On the Tuesday off she went down and looked  
19 through the door and she could see him, he was lying  
20 on the floor, so she could.  
21 So she got the police, who then got the fire  
22 brigade who went in and [redacted] had taken a brain  
23 haemorrhage, but he was still alive at this time. So  
24 they got him up and they got him into the intensive  
25 care but they told us that it was -- there wasnae very



1 much hope at that time and eight days they treated him  
2 for, wasn't it, and the staff in that intensive care  
3 unit couldn't have done any more for us. They were  
4 making beds up for us at night and everything, weren't  
5 they, and just going out of their way to totally help  
6 us, but then on the Wednesday we had a wee word with  
7 his doctor and he says that, "We don't think, with  
8 [redacted]'s state of mind -- the way things are" --  
9 they done another scan, they said that if he did pull  
10 through, he would be in a vegetative state. There  
11 wouldn't have been any sign of life there for him.

12 So we then took the decision to take him out of  
13 the intensive care, as a family we took the decision  
14 with his parents, and they took him out that night.  
15 We thought if he's going to be in a vegetative state  
16 that's God's will, more or less, that's the way he'll  
17 be. If he doesnae survive that's it as well.

18 We took him out. All my family, my family were  
19 just -- they loved your Dad so much, didn't they?  
20 They were just -- I've got a massive family, and the  
21 hospital allowed all them to come up, so there must  
22 have been about 30 people there that night and they  
23 allowed everybody to come in and out and they all went  
24 away. We were there until I would say about ten  
25 past 1 style, and they says, "Right, we'll just go --

1 they were going to stay in the room, we'll just go  
2 home, get a sleep and be back up in the morning".

3 We'd literally just got home and the nurse had  
4 phoned us and she went, "You need to come back", and  
5 back up we went but we got there I think it was ten  
6 minutes too late and he had passed. And I think --  
7 you hear people saying this, but I think he waited for  
8 us to go before he passed and he was away, that was  
9 him at rest.

10 **Q.** That was 2010.

11 **A.** That was 2010, uh-huh.

12 **Q.** And how old was [redacted] when he died?

13 **A.** [redacted] was 45.

14 **Q.** And you said he had turned from this hard-working  
15 fastidious family man to a non-working alcoholic who  
16 completely neglected himself.

17 **A.** Yes, that's what it turned him into.

18 **Q.** And the cause of his death, you feel, should have been  
19 recognised ultimately as --

20 **A.** Yeah.

21 **Q.** -- the hepatitis C?

22 **A.** The cause of his death on (1) is the haemorrhage and  
23 his haemophilia and (2) then goes on to say the  
24 hepatitis C and the drug abuse -- no, the drug  
25 abuse -- the alcohol abuse, and I feel as if that is

1 totally wrong because I don't think -- I know the  
2 alcohol abuse wouldnae have been there if it hadnae  
3 have been for the hepatitis C and his treatment,  
4 because, all right, he used to work six days a week,  
5 he'd have a drink at the weekend, one day a week, so  
6 he would.

7 He was nowhere anywhere near any sort of -- he  
8 wasnae even -- wasnae he allowed to have a drink on  
9 a Saturday if he wasnae working on the Sunday or vice  
10 versa? But that was that. So he went from that into  
11 being a major alcoholic after that, and I feel as if  
12 that is what caused that. So I feel as if the alcohol  
13 and the hepatitis C should have been also in with (1)  
14 because that was cause of his death.

15 **Q.** [redacted] had received back in 2004 a letter about  
16 vCJD.

17 **A.** Yeah, uh-huh.

18 **Q.** And we'll just put that on screen. It's 2288007.

19 It's dated 20 September 2004 and it says:

20 "We have been asked by the UK Department of Health  
21 to send the enclosed letter and information to all  
22 patients born with bleeding disorders ... who are  
23 currently registered at our Centre.

24 "According to our current records, we have no  
25 evidence that you received clotting factor concentrates

1 (Factor VIII, Factor IX, Factor XI or von Willebrand  
2 factor concentrates) from UK blood donors between 1980  
3 and 2001."

4 Now vCJD or the risk of it was not something that  
5 had made a great difference to [redacted]'s own life.

6 **A.** No.

7 **Q.** But you have identified that what's set out in that  
8 letter is inaccurate?

9 **A.** Yeah, it is, uh-huh.

10 **Q.** Whatever the current records were, [redacted] had  
11 received --

12 **A.** Yeah, uh-huh.

13 **Q.** -- clotting factor concentrates --

14 **A.** Between that time.

15 **Q.** -- between that time.

16 **A.** But thankfully he never knew about, no.

17 **Q.** What was the impact of [redacted]'s ill health and his  
18 decline into alcoholism following the failed treatment  
19 on your daughters?

20 **A.** Well, during his treatment, as I say, we tried to hide  
21 everything from them, so they'll say to this day, "But  
22 we didnae know that that was happening", but then it  
23 got to a point you couldnae hide anything. So he  
24 idolised the two of them and they idolised him, like  
25 any family we would have our wee screaming matches,

1 wouldn't we, at each other, so we would, especially  
2 about football, haven't we? So we were like any other  
3 family. We had our wee ups and downs but for them to  
4 watch their Dad go the way that he did was  
5 heartbreaking and cruel, that's what it was, it was  
6 cruel and he couldnae do anything about it.

7           It didnae -- if anything, these two have been my  
8 rock. We've always been a close family but oh my God,  
9 I don't know what I would do without them, and him as  
10 well, do you know, as much as it used to get them  
11 angry, they never ever stopped loving their Dad. From  
12 what was happening they would get angry with it but it  
13 never -- it tore apart my family as in living in  
14 separate places but it did not tear us apart as  
15 a family, in fact, if you can understand what I mean,  
16 we still loved that man the day he died. I still do  
17 love him to this day but it took away our family life  
18 as in living together, being together, doing the  
19 things that we did together and having to watch that  
20 man like that, it wasnae right.

21 **Q.** You explained in your statement you lost the man you  
22 loved, you still love?

23 **A.** Yep, yes, yep.

24 **Q.** And your best friend?

25 **A.** My best friend. We'd been together since we were 14.

1        We were -- I mean, we had friends. I had my friends,  
2        he had his, but he wasnae one for going out with the  
3        guys and for a pint, doing whatever, because he  
4        worked, but he'd sometimes -- he had his pals, didn't  
5        he, but he --

6        **MISS Y:** But we would choose -- he would rather --

7        **A.** He would rather us go -- we went to -- the Barrowlands  
8        was our second home. We went watching live music, so  
9        we were best friends as well as everything else and  
10       I lost all that.

11       **MS RICHARDS:** And you lost the house that you --

12       **A.** I lost the house. I had to eventually sell the house  
13       and luckily enough we've lived where we live, we've  
14       lived there for over 30 years, luckily enough  
15       I managed to get social housing that they call it now,  
16       call it council housing, but it's directly, more or  
17       less, across from where I -- I can look straight into  
18       our house from where I live now and as I says before,  
19       I'm not materialistic, it wasnae anything to do with  
20       you've got your wee house or all this. It was what  
21       I know we put in to buy that house, to furnish the  
22       house and everything, we lost -- we lost that. We  
23       just lost -- and he eventually lost his job because he  
24       couldnae work again after that, so everything was  
25       wiped out.

1 Q. You've referred to [redacted] having been offered some  
2 form of counselling in 2004 --

3 A. Yeah, yeah.

4 Q. -- when he was struggling with the side effects of the  
5 second course of treatment?

6 A. Uh-huh.

7 Q. Had he been offered any support or counselling prior  
8 to that time?

9 A. No, no, that's the only time and, as I say, that's  
10 because I had asked, but no.

11 Q. And what about you and your daughters, had you been  
12 offered any?

13 A. No, no.

14 Q. You received a one-off payment from the Skipton Fund  
15 in 2004, most of which went on paying off debts?

16 A. Yeah, because he hadnae been working and whatever  
17 else.

18 Q. And your information about that had come from  
19 The Haemophilia Society?

20 A. Yeah, uh-huh.

21 Q. And it was then only many years later that you found  
22 out about other possibilities of financial assistance,  
23 not from any of the funds themselves but through the  
24 Scottish Infected Blood Forum.

25 A. Blood Forum, yeah.

1 Q. The support group.

2 A. Yeah, they have been a lifeline to us, so they have,  
3 an absolute lifeline. I don't know where we would be  
4 without that group. They've just been there for us,  
5 haven't they? And hopefully we've been there for  
6 them.

7 Q. And you say you were informed you could be entitled to  
8 a modest regular payment.

9 A. Uh-huh.

10 Q. You started getting that money in 2015 but the  
11 payments stopped in October 2018, why was that?

12 A. Because I work part-time and I also get a benefit that  
13 put me up over the mark that they -- it wasnae very  
14 much, it put me over the mark that I would have been  
15 allowed to claim that, so it was, so I lost that.

16 Q. And you've also made some observations in your witness  
17 statement about the different treatment of stage 1 and  
18 stage 2?

19 A. Very much so.

20 There's no way -- I feel as if this is  
21 a Government thing, that brought these stages out,  
22 I don't know where, 1 and 2, and I feel as if it was  
23 made to divide our community, because any -- any sort  
24 of payment that any stage 2 widow or anybody else gets  
25 isnae enough. They deserve a hell of a lot more than



1        what they've ever been given but to them, just  
2        recently we were given £30,000 but that was only  
3        because of the hard work of both the  
4        Haemophilia Scotland and the Scottish Infected Blood  
5        Forum and the other people that fought for us and  
6        stage 1 widows to get that £30,000, because when  
7        everybody was given it -- we were (*unclear*) and they  
8        refused to give us it and they made us feel, yet  
9        again, they were taking our dignity off us again by  
10       having to sit there and say, "But why are we not  
11       getting it, you now? Why is everybody else getting it  
12       and we are left out and you're making us feel as if we  
13       need to beg for anything".

14                But I also feel that the stages -- I'm a stage 1  
15       widow because [redacted] didn't go on -- I don't know  
16       if he went on to have cirrhosis of the liver because  
17       when [redacted] died he didnae turn yellow, as I say,  
18       he turned green, his body turned green in a matter of  
19       an hour, maybe, if it was, we sat with him for hours  
20       after it and his body was green, so there was  
21       definitely some sort of -- whatever with the liver  
22       there, the liver just -- to me he must have it, but  
23       it's no open wide enough stage 2 for the other -- what  
24       did you call it earlier?

25                Just the other things like he's got his -- we

1           having had the treatment and then that no working.  
2           The mental health issues that people have. To me that  
3           should all be included into whether or not they get  
4           stage 2, in fact, don't think there should be any  
5           stages.

6       **Q.**   Indeed what you've said in your witness statement,  
7       Mrs Y, is that the way in which the payments were  
8       structured meant that account wasn't being taken of  
9       [redacted]'s mental health --

10      **A.**   No, no.

11      **Q.**   -- as a result of being infected with hepatitis C and  
12      receiving the treatment?

13      **A.**   I had applied stage 2. I had actually sat one day,  
14      one of the doctors in the intensive care and we were  
15      just sitting there. He was asking me about what had  
16      been going on. I was talking to him and I said to  
17      him -- he asked me actually what the stages were and  
18      I told him. He'd never heard of the stages thing and  
19      he says "Well, why have you never applied for it?"  
20      I says, "Because as far as I know, [redacted] doesnae  
21      fall into that".

22            He says, "I really think you should apply", so  
23      I did. After [redacted] passed away I did and  
24      I didn't get it because they said although there was  
25      definitely liver damage there, it wasn't to the limit

1 that took you over that thingy to get the stage 2.  
2 But they only went by the bloods. They never --  
3 obviously being a haemophiliac, he hadnae had the  
4 biopsies, he hadnae had the fibroscan or anything like  
5 that, so that was that.

6 Can I just say as well, though?

7 **Q.** Yes.

8 **A.** See this, with the money thing, that isnae what this  
9 is all about, isnae the money. It is the recognition  
10 of what we have been through, so it is, recognising  
11 what they took away from us. Do you know what I mean?  
12 Just giving us back what they took away, and it's  
13 horrible to say but as far as I can see that's the  
14 only thing that the governments care about is their  
15 money, so that's the only way that I can get them to  
16 recognise what they done to my husband, then I've  
17 always, in my heart, I've been like I couldn't even  
18 talk about money side of things, I was don't talk to  
19 me about money, that's not what that's about.

20 Then I learnt through time, do you know what,  
21 that's the only thing they care about. So that's the  
22 only way I can get them to turn round and show me that  
23 in some way well, then aye -- uh-huh, I will.

24 **Q.** You've said in your witness statement that [redacted]  
25 was stripped of any self-respect he had.

1   **A.** Yeah.

2   **Q.** And I understand that by giving your evidence to the  
3       Inquiry you've wanted to give him back the dignity  
4       which the infection --

5   **A.** To give it back --

6   **Q.** -- and the treatment stole from him.

7   **A.** Yeah, that's what today's about for us. I mean,  
8       I married who was a great guy, who, as I say, was the  
9       love of my life. I miss him every day. The girls  
10      miss him every day, but he needs to be able to get his  
11      self-respect back and the dignity that was stripped  
12      from him and that's the reason why we're here today.

13   **Q.** Those are the questions I have for you. Is there  
14      anything you would like to add?

15   **A.** It was really just everything that you have just said,  
16      as I want to be able to walk out of here the day and  
17      feel as if I've done everything that we could to give  
18      him that wee bit of dignity back, and -- because he  
19      deserves it and so does every -- there's so many  
20      people that I know for a fact that are going through  
21      the same thing that we went through. The husbands  
22      with the anger management, and they're living with  
23      that the now, and people say to us, "But you've lost  
24      your husband. There's nothing worse than that".  
25      There is living with it, living with it, I know that

1       their living with it is worse because it's a living  
2       nightmare, an absolutely living nightmare, it is, and  
3       I just wish today people could get some sort of  
4       closure and be able to ...

5               That's it as well, people need to get closure with  
6       this. They can't keep going on forever, they cannae,  
7       they need to get closure and move on with their lives,  
8       still remember -- they'll never forget, I'll never  
9       forget my husband. He'll be in my heart every day to  
10      the day I die, but then I can let my two daughters --  
11      I mean, [redacted] got married five weeks ago.  
12      [redacted] has been married. We've had a grandchild.  
13      He's missed out on all that, so he has, and we need to  
14      be able -- they need to be able to go on with their  
15      lives, they do.

16   **Q.** Thank you. I'm just going to ask Mr O'Neill and  
17      Mr Dawson if there's anything they want me to ask.  
18      There's nothing further.

19   **A.** Okay.

20   **MS RICHARDS:** Sir?

21   **SIR BRIAN LANGSTAFF:** Earlier on in her questioning,  
22      Ms Richards mentioned a photograph.

23   **A.** Yes.

24   **SIR BRIAN LANGSTAFF:** Can I tell you that, as I understand  
25      was your request, that photograph was shown to me.

1     **A.** Uh-huh.

2     **SIR BRIAN LANGSTAFF:** And it compared a photograph of him  
3         as he was and as he became.

4     **A.** Yeah.

5     **SIR BRIAN LANGSTAFF:** I have to say that my impression of  
6         them was that they were two different people.

7     **A.** Yeah.

8     **SIR BRIAN LANGSTAFF:** You've given a powerful account of  
9         the destructive effects of hepatitis C physically,  
10        socially, financially, on dignity and in particular on  
11        your family. Thank you very much indeed.

12    **A.** Can I just say, though, that it needs to be pointed  
13        that it was the treatment. Hepatitis C didn't kill  
14        [redacted]. It was the treatment, the second lot of  
15        treatment that made such an impact.

16    **SIR BRIAN LANGSTAFF:** I should have said the destructive  
17        effects of hepatitis and its treatment.

18    **A.** Thank you.

19    **SIR BRIAN LANGSTAFF:** That's what I meant to say and  
20        I missed out those words.

21    **A.** Okay, thank you.

22    **SIR BRIAN LANGSTAFF:** So you've corrected me, thank you.

23    **A.** Thank you. And thank yous for giving us this  
24        opportunity because I didn't think -- I sat there and  
25        I says to [redacted], "I can't believe this day's

1 finally came that we can get his wee bit across."

2 There's just thousands like us, there is, just

3 ordinary people. Thank you.

4 **SIR BRIAN LANGSTAFF:** Ms Richards, when, first of all,  
5 Dr Lowe responds he might wish to consider that it is  
6 open to me, I think, on the evidence to draw  
7 an inference. It arises partly out of the evidence  
8 which was given that when he spoke to [redacted] he  
9 indicated that because he was a haemophiliac he almost  
10 inevitably would have hepatitis.

11 That is confirmed as the general view of the  
12 department on one view by the terms of the letter to  
13 which I made reference during the course of your  
14 questioning from Dr Hung of 7 November 1995 where it  
15 spoke of the reason for them suspecting or "as  
16 suspected" [redacted] had hepatitis C, even though the  
17 only reason for suspecting it apparent from the letter  
18 was the fact that he'd had treatment from as early as  
19 the late '70s/early '80s on three occasions as  
20 recorded with cryoprecipitate or factor product.

21 The reason also recorded in that letter for  
22 [redacted] coming in was his own wish to be tested,  
23 and it would follow that this particular hospital  
24 thought, if those inferences are correct, that anyone  
25 who had been treated as a haemophiliac with a factor

1 product was likely to suffer hepatitis C. They did  
2 nothing about it, except at the request of the  
3 individual person who felt they might be suffering,  
4 and, if so, I'd like an explanation of why that was.

5 **MS RICHARDS:** Sir, certainly we will ensure that that is  
6 asked for.

7 **SIR BRIAN LANGSTAFF:** But since that is an inference which  
8 I may draw, it depends obviously what is said about  
9 it, then it should be drawn to his attention at this  
10 stage for him to make an answer, should he wish.

11 **MS RICHARDS:** Yes, and those who represent Dr Lowe are  
12 present and I am sure they will have taken due note of  
13 your request, sir.

14 **SIR BRIAN LANGSTAFF:** Shall we take a break until shall we  
15 say 2.30 pm?

16 **MS RICHARDS:** Yes.

17 **SIR BRIAN LANGSTAFF:** We have two more witnesses to hear  
18 this afternoon, so a slightly shorter lunch break, if  
19 you don't mind.

20 **(1.23 pm)**

21 **(The luncheon adjournment)**

22 **(2.33 pm)**

23 **SIR BRIAN LANGSTAFF:** Now, our next witness is unusual  
24 today in the sense that she's not anonymous.

25 **MS FRASER BUTLIN:** That's right.



1     **SIR BRIAN LANGSTAFF:** And wishes to be known as Pauline.  
2     Pauline, please.

3                             **PAULINE REID, sworn**

4                             **Questioned by MS FRASER BUTLIN**

5     **Q.** At the outset of your evidence, Pauline, I should say  
6     that the names of your family and your location are  
7     redacted in your witness statement. They've been  
8     blanked out.

9             We're going to try and avoid using them, but if  
10    they slip out you've said that you're not particularly  
11    concerned and we won't be stopping the live-stream --

12    **A.** That's fine.

13    **Q.** -- if they do slip out and that's what you'd prefer.

14    **A.** Yes.

15    **Q.** Pauline, you have von Willebrand's disease?

16    **A.** I do.

17    **Q.** You were tested when you were 12 years old?

18    **A.** That's correct.

19    **Q.** What were you told?

20    **A.** I was borderline.

21    **Q.** And then in 1985 when you were about 18 --

22    **A.** That's correct.

23    **Q.** -- you were diagnosed with von Willebrand's?

24    **A.** Yes.

25    **Q.** And at that time you were also tested for HIV and

1 hepatitis B?

2 **A.** Not to my knowledge, no.

3 **Q.** But subsequently you've discovered --

4 **A.** It's been discovered in my medical records that are

5 later confirming von Willebrand's and the testing for

6 these other things but not -- not with prior consent

7 or knowledge and, in fact, I only found this out eight

8 days ago.

9 **Q.** When you got your records eight days ago.

10 **A.** Yeah.

11 **Q.** Because at the point that you were diagnosed with von

12 Willebrand's in 1985 you'd had no treatment?

13 **A.** No.

14 **Q.** Rather obviously.

15 **A.** Yes.

16 **Q.** And there was no reason to test for HIV or hepatitis

17 B?

18 **A.** No, the von Willebrand's goes back at least five

19 [redacted]. [Redacted], I kind of escaped.

20 [Redacted]. There has been genetic research done

21 because normally it affects half the family members.

22 [Redacted].

23 **Q.** But for you --

24 **A.** But for my health I was lucky, I had good health.

25 I never had any accidents. I'd never even been in

1 a hospital. Any bleeds were contained at home. I had  
2 never, ever had any treatment, nothing.

3 **Q.** Were you -- you've said you didn't even know you'd  
4 been tested until eight days ago. From that we can  
5 also assume you were never told about any results of  
6 those --

7 **A.** No.

8 **Q.** -- the HIV or hepatitis B?

9 **A.** Not at all, no.

10 **Q.** Before 1990, so between 1985 and 1990 did you receive  
11 any treatment for your von Willebrand's?

12 **A.** No.

13 **Q.** In 1990 you were pregnant with your first child?

14 **A.** That's correct.

15 **Q.** You were known as a bleeder at that point. What were  
16 you told that you would need?

17 **A.** I had several routine and antenatal appointments at  
18 Glasgow Royal Infirmary and also at Ayrshire Central  
19 Hospital and Crosshouse Hospital. In the  
20 consultations I knew that I would receive some form of  
21 treatment pre-birth while I was in labour, as  
22 a precaution.

23 **Q.** You were advised that you would need something but you  
24 weren't told the details of what?

25 **A.** No, it was never discussed what it would be and I,

1       like most people, just assumed that the doctors knew  
2       what they were doing. I assumed it was whatever was  
3       the current product at the time.

4   **Q.** Now, until very recently you thought the advice about  
5       what you needed post-partum or before the birth, that  
6       advice had come from your treating hospital in  
7       Glasgow.

8   **A.** Yes.

9   **Q.** But since you've looked at your records, you've  
10      discovered it was a decision made at your local  
11      hospital.

12   **A.** Yes.

13   **Q.** What concerns you about that?

14   **A.** It -- well, Glasgow Royal Infirmary being the  
15      haemophilia unit, are meant to direct all treatment  
16      plans. Anything that my family or myself have had,  
17      the treatment plan has always come from the  
18      haemophilia unit, although the treatment may be  
19      carried out at a local hospital. I thought that was  
20      the case.

21            There are issues with communication between  
22      hospitals in North Ayrshire and the haemophilia unit,  
23      which are ongoing to this day. Although to be  
24      perfectly fair, yes, clearly it's a very good  
25      haematology unit, I am not saying it's not, but they

1 are not specialists in bleeding disorders and  
2 therefore I, until recently, assumed that the  
3 treatment plan came from the haemophilia unit, who are  
4 experts in their field.

5 **Q.** You've just told us that you were meant to be given  
6 the treatment before you gave birth.

7 **A.** Correct.

8 **Q.** And that treatment was going to be cryoprecipitate?

9 **A.** Yes.

10 **Q.** When in fact were you given it?

11 **A.** After birth, about 15 minutes after birth.

12 **Q.** And at that point how had the birth been?

13 **A.** Absolutely normal, no painkillers, very quick labour,  
14 spontaneous delivery, minimal bleeding, normal.

15 **Q.** When you were given the cryoprecipitate, did anyone  
16 warn you of any possible risks of infection?

17 **A.** No.

18 **Q.** Did anyone give you the option of whether to keep the  
19 cryoprecipitate on standby to use if you needed it?

20 **A.** No.

21 **Q.** And if you'd been warned of the risks of infection,  
22 looking back, do you now think you'd have had the  
23 treatment?

24 **A.** Definitely not.

25 **Q.** And why are you so adamant about that?

1 **A.** Would I have taken my chances in childbirth? As  
2 I say, five generations of women, older sisters, no  
3 treatment, survived. I would have rather taken my  
4 chances with childbirth than what I know now.

5 **Q.** And that's largely because until then you'd really had  
6 very limited issues with bleeding?

7 **A.** Correct, yes.

8 **Q.** Can we have document 2247003, please, Paul. This is  
9 a letter from 1992 and we can see a discussion about  
10 your von Willebrand's disease and towards the end of  
11 the paragraph it says:

12 "Viral studies have shown her to be positive for  
13 antibodies to hepatitis C virus."

14 Were you told about this at the time in 1992?

15 **A.** No.

16 **Q.** In 1994 you were pregnant and attended an appointment  
17 with the nurse. Can you tell us what happened?

18 **A.** It was a routine -- although I was pregnant, it was  
19 a routine von Willebrand's appointment at Glasgow  
20 Royal Infirmary.

21 We tended to have it as a bit of a family day out,  
22 so I was accompanied by siblings and mother. It was  
23 completely normal. I went in, I had a wee quick chat  
24 whichever doctor it was, height, weight, arm out,  
25 bloods, and it's very comfortable, familiar setting.

1 Nurses you've known for years.

2 I must have to been due to go on holiday and I was  
3 handed a leaflet and told, "Read that but not until  
4 you come back from your holidays". That was it. So  
5 I went away with a very maybe three-page leaflet which  
6 I proceeded to read straightaway and it told me  
7 something about an infection they'd found which was of  
8 a hepatitis nature called non-A non-B, and there  
9 really wasn't much more information than that at all,  
10 and I read it, didn't think it was given to me  
11 specifically. I assumed that all patients were having  
12 it, went away all holiday, came back, and the next  
13 appointment I had I was on my own, because it was  
14 obviously an antenatal appointment, and that's when  
15 the truth of the situation came out.

16 **Q.** And what happened at that appointment?

17 **A.** I walked in, sat down. I can't remember who it was  
18 and they said to me "You've got the leaflet?"

19 "Yeah."

20 "Did you read the leaflet?"

21 "Yes", and then there was silence, nothing, and  
22 eventually I was told, "Well, you have it", and that  
23 was pretty much the discussion.

24 I think I was told at the time that the most  
25 accurate way of knowing what was going on was to have

1 a liver biopsy but that wasn't being done since I was  
2 pregnant, and it would be done after I had delivered.  
3 That was it.

4 **Q.** At that point, were you told when you'd been tested  
5 for hepatitis?

6 **A.** No.

7 **Q.** And at that point were you given any information about  
8 how you might have been infected?

9 **A.** There -- there were comments to do with intravenous  
10 drug use and sexual transference which, to be  
11 perfectly honest, I have later described as being  
12 basically told I was either a junkie or a prostitute.  
13 There was never any mention that it -- and there never  
14 has been to this day, any direct mention to me that it  
15 could have been from my first childbirth.

16 **Q.** What were you told about treatment options?

17 **A.** At that time, only that a liver biopsy would be done  
18 after my second child was born.

19 **Q.** And were you told anything at that stage about  
20 prognosis?

21 **A.** Nothing, no. There was no other information at all.

22 **Q.** And were you given any chance at that stage to ask  
23 questions?

24 **A.** No, it was a very, very brief one-sided, to be honest,  
25 conversation. It wasn't really a conversation.



1 Q. Later that day you got a telephone call from your GP.

2 A. I did.

3 Q. What did they say?

4 A. It was my GP directly, not the receptionist and he was

5 very angry. He was swearing and shouting and he

6 clearly had been given this information and wanted me

7 to come down to the surgery after it was closed for

8 a discussion.

9 Q. And you've said in your statement that he said, "Why

10 didn't you tell me?"

11 A. Yes, I went down after 6 o'clock when the surgery was

12 closed. Everyone had left, all staff, and he

13 continued to rant and he asked me why I didn't tell

14 him, yes.

15 Q. But we've seen already the letter that we just had up,

16 the letter from 1992, to your GP telling him that you

17 were hepatitis C positive. You've only discovered

18 that very, very recently.

19 A. Yes.

20 Q. What are your thoughts about that?

21 A. As in my statement, I couldn't understand why he was

22 angry because I had only found out at the same time

23 more or less as him.

24 I would clearly have told him as my -- the

25 practice, as my primary carers of this the first time

1 I was down. He was known to be a bit fiery but that  
2 was fair enough. I made the assumption that he had  
3 just been told. I have since discovered another  
4 letter which is from the GP, because obviously I was  
5 pregnant, to obstetrics. There's a phrase in it where  
6 it says this was brought up in 1992, which I wasn't  
7 aware of and I thought when I discovered this only  
8 eight days ago that maybe the GP thought that I was  
9 party to this brought up conversation two years  
10 earlier and had kept it from him.

11 Half an hour after discovering this eight days  
12 ago, I found the letter to the GP more than two years  
13 before and it's addressed to the same -- I did make  
14 excuses and say it's a practice, it might not have  
15 been him, although he should have seen it but it's  
16 addressed to him. So he knew two and a half years  
17 before me, so really the person who should have been  
18 shouting and swearing and asking, "Why did you not  
19 tell me", should have been me but I only discovered  
20 this eight days ago.

21 **Q.** You've said in your statement that after he'd stopped  
22 shouting at you, the only information he gave you was  
23 that you had the Sword of Damocles hanging over you.

24 **A.** Yeah and, as previously stated by other people, yes,  
25 I accept that in those days certainly GPs wouldn't

1        have known much. I can totally accept that and, you  
2        know, in the short space of time when he calmed down,  
3        that was basically all he could say, you know, the  
4        future will be what the future will be.

5        **Q.** Now, at that point in time you were worried but you've  
6        said you weren't particularly terrified of the  
7        diagnosis. We're not going to name any individuals --

8        **A.** No.

9        **Q.** -- but there were others in your much wider family who  
10       were very unwell at this point, and you came to  
11       understand through them a little bit more of what  
12       hepatitis C meant.

13                How did that knowledge then impact your own mental  
14       well-being?

15       **A.** Very detrimentally. Like I said, there was no  
16       information given at the hospital. Nothing to  
17       implicate it was something that was potentially fatal.  
18       The leaflet had made -- it was a very brief statement  
19       of it might affect your liver. The GP didn't really  
20       imply that either and, as previously stated, although  
21       I went up every year to the Royal for my routine  
22       check-up, I didn't have bleeds so I wasn't about the  
23       centre on a regular basis. I therefore wasn't in the  
24       know about any discussions about what hepatitis C  
25       really was, but through my family I discovered exactly

1       how serious and fatal it was and subsequently through  
2       the years how horrible the treatments were and, at  
3       that point, the realisation struck that this wasn't  
4       some maybe insignificant thing. This was potentially  
5       fatal and I had to look at my future, my family's  
6       future, and I saw it in a completely different light.  
7       Yes, by this point I was frightened.

8       **Q.** If we can just rewind slightly, you then -- you gave  
9       birth to your second child.

10      **A.** Yes.

11      **Q.** And you were on the post-natal ward. Can you tell us  
12      what happened when you were there?

13      **A.** When I went into the maternity hospital, I was taken  
14      straight to the labour suite. I wasn't put in any  
15      other room. When I had my son, those were before  
16      everybody had mobile phones and they used to bring in  
17      the payphone, so we made a telephone call to the  
18      grandparents.

19                There was then an out of order sign put on the  
20      telephone, so nobody could use it. I was put on the  
21      furthest -- the nearest ward to the door, I was put in  
22      a side room and I was told that I could use -- so  
23      typical maternity ward, two side rooms for people who  
24      have had sections or problems. The main ward with  
25      eight beds and two bathrooms servicing both. I was

1 told that I was to use the bathroom with the out of  
2 order sign on it.

3 Clearly, although I wasn't there for very long,  
4 everyone in the ward must have seen me using the  
5 bathroom said "out of order", and whether they thought  
6 I was ignoring it or whether they thought, "What's  
7 going on there", I have no idea but I was treated like  
8 a leper.

9 Again, this would have been probably very new in  
10 the first instance, I accept that but there were  
11 being -- they were being very cautious, like I say.  
12 For a patient and other babies but maybe not  
13 particularly looking at the effect it had on me.  
14 I was a leper, it was as simple as that.

15 **Q.** And at one stage you were breastfeeding your newborn?

16 **A.** I think I had my son about approximately 9 o'clock at  
17 night. I had breastfed my first child. No one had  
18 ever discussed my pregnancy and the hepatitis with me  
19 or breastfeeding and anything else and at  
20 approximately 3 o'clock the next day -- in the  
21 afternoon, sorry, I have a hungry baby and he had fed  
22 all through the night and the doctor whom I've never  
23 seen before or since came in and had said, "Oh,  
24 I don't know if you should be breastfeeding", and I --  
25 yeah, I did continue breastfeeding, they'd had nine

1 months to tell me and 18 hours to tell me, so  
2 I continued.

3 **Q.** After your diagnosis, you decided you wouldn't have  
4 any more children.

5 **A.** That's correct.

6 **Q.** Why was that?

7 **A.** There was a comment made to me at Glasgow Royal  
8 Infirmary to do with when you're pregnant, your immune  
9 system shuts down so you don't abort your foetus, and  
10 that may have been when the active virus reared its  
11 head, because I subsequently spontaneously cleared,  
12 although they didn't know. At that point, not knowing  
13 whether I had already infected my two children,  
14 I would have liked more children but I was very, very  
15 scared that a subsequent pregnancy could have led to  
16 the virus returning and staying so there were no more  
17 children.

18 **Q.** In 1996 you went to see a liver doctor. What were you  
19 told at that appointment?

20 **A.** There was a general discussion about the treatment at  
21 the time, and that they thought that the infection was  
22 a very low level, so it wouldn't require treatment,  
23 and that was basically -- that was it.

24 **Q.** Could we have 2247002, please, Paul.

25 This is the letter that you think followed that

1 appointment at the liver clinic, and if we look at the  
2 last paragraph on that first page, we can see that  
3 there is a note that it had been discussed at some  
4 length with you and the potential therapy with  
5 interferon. What it says is:

6 "It's interesting that she was previously PCR  
7 negative on two occasions and now has been PCR positive  
8 on two occasions; the last of which showed a low total  
9 level. It would suggest to me that she has a low level  
10 of viraemia and, as a result, is at low risk of chronic  
11 liver disease and at low risk of having passed this to  
12 her baby. I suspect she converted to PCR positive  
13 during pregnancy ..."

14 If we go to the next page it records that after  
15 careful consideration and discussion with you:

16 "... we have agreed that, for the time being, we  
17 will merely observe her closely in the liver clinic and  
18 see what transpires as to whether she becomes PCR  
19 negative again. For the time being she prefers not to  
20 have interferon treatment."

21 **A.** Okay, so again, I only got a sight of this eight days  
22 ago. The comment there in the previous paragraph  
23 about the virus raising, that will be the comment that  
24 I mentioned before about not continuing to have any  
25 more children.

1           There's a running theme through some of the  
2           letters that -- I haven't obviously read my medical  
3           records but some of them, there's a recurring theme  
4           about all these lengthy in-depth conversations that  
5           have never taken place, not with Dr Morris, not with  
6           my GP which is also in a previous letter.

7           However, I have never until eight days ago ever  
8           heard anything about positive tests, negative tests,  
9           multiple tests. I was told in November 2014 I had  
10          a positive test. I am unaware of multiple tests and  
11          I am unaware of negative tests, to the extent where  
12          actually right now, having discovered this eight days  
13          ago, I am actually not sure what I actually am right  
14          now, to be fair, so I have never, ever been told that.

15       **Q.** Your understanding was that you had cleared the virus  
16          naturally.

17       **A.** Yes.

18       **Q.** And that's why treatment wouldn't be required.

19       **A.** Yes.

20       **Q.** Was your liver assessed at this point?

21       **A.** No, my liver was never assessed and the comment  
22          towards the end of that about being referred back to  
23          clinic, that was the last conversation that anyone  
24          ever had with me about hepatitis C.

25       **Q.** And that's what my next question was: have you ever



1           been seen in a liver clinic again?

2   **A.** I've never been seen in a liver clinic, no.

3   **Q.** Now, since then have you ever been told that your  
4       hepatitis C PCR status was being tested?

5   **A.** No.

6   **Q.** Throughout your understanding was PCR negative. When  
7       you got your medical records a few weeks ago, what did  
8       you find?

9   **A.** I found that -- that letter there, I had positive and  
10       negatives going on and off for some time, I believed  
11       that I had cleared the virus shortly after my  
12       daughter's -- sorry, son's birth, so 1995/1996, and  
13       I was clear. I have discovered that I was still  
14       positive in at least 1999 and that I have been  
15       consistently tested until -- well, there's one in  
16       2012.

17   **Q.** I was going to say, the records indicate, don't they,  
18       that you've been tested throughout periodically until  
19       about 2012?

20   **A.** Yes.

21   **Q.** Have you ever been told about those tests?

22   **A.** No.

23   **Q.** Because you understood you were being checked for your  
24       von Willebrand's and it was just standard bloods that  
25       were being done?

1 **A.** Yes, you go to the clinic, and as far as I know, we  
2 all do, as I say you have a chat and you literally put  
3 your arm out and they take bloods and I assume that  
4 they're taking a full blood count for iron anaemia and  
5 that's all I think they're doing.

6 I believe that they take your liver function,  
7 I believe, but that's all I think they're taking.  
8 I don't ask; they don't say.

9 **Q.** And having obtained your records, you're now concerned  
10 about when you were tested negative, how long you were  
11 positive for, and the state of your liver because you  
12 just don't know?

13 **A.** I don't know. I don't -- there's never been anything  
14 done to my liver so until now I'd have thought it was  
15 fine. No testing has ever been done. Now I'm finding  
16 out that all these year all of testing, positives,  
17 negatives. Am I still positive? I have absolutely no  
18 idea. And as far as, for example, insurance is  
19 concerned, I answer honestly so I'm financially  
20 penalised and weighted for ever even having  
21 a hepatitis test but I have declared to the best of my  
22 knowledge and belief I am clear, but I don't actually  
23 know now if that's true.

24 **Q.** Before we move on from the issue of medical records,  
25 you've also recently obtained your treatment records

1 from the UK HCDO. What did you discover in those  
2 records?

3 **A.** The records are quite short, as you'd expect, because  
4 I've only ever had three treatments. I have got maybe  
5 only four or five entries. I thought -- the first  
6 entry is 1992. When I got them I thought, "Maybe the  
7 database is a new thing", and I phoned them and they  
8 were created in 1960--something so why there's no  
9 entries before 1992 I don't know. I have an entry  
10 for 1992 for DDAVP which I was tested for in 1985 and  
11 don't respond, so it was never retested in 1992.

12 And funnily enough, I have no entry for the two  
13 treatments I had for my children. There's nothing  
14 for 1990, there's nothing for 1995.

15 When it comes to a heading for anyone treated with  
16 plasma-derived products before September 1991, it says  
17 I haven't had any. When it says have I ever tested  
18 for hepatitis C, which is another page, it says "no"  
19 and then it also says "any follow-up," and it says  
20 "no".

21 The page relating to -- sorry, mad cow disease.

22 **Q.** VCJD.

23 **A.** Thank you. Says I have never been notified of that  
24 and I have. There's a letter in my file which  
25 actually goes on -- there's another letter because

1 I actually did discuss it with someone later on. The  
2 records are completely factually incorrect. And I was  
3 surprised because clearly there's going to be  
4 haemophiliacs out there with lots of treatments, lots  
5 of entries to that. I wouldn't have thought it was  
6 difficult to get three entries correct.

7 **Q.** You mention there notification of the risk of vCJD.

8 **A.** Yes.

9 **Q.** You received that notification.

10 **A.** Yes.

11 **Q.** How has that affected you?

12 **A.** It's -- it's another thing that's hanging over your  
13 head for potential nasty death. That has been  
14 exacerbated because someone that we know not from --  
15 as far as we know not from any blood but was unwell  
16 and dead a week later, two years ago, from mad cow.  
17 It can lie latent in the body for years and years and  
18 years. It's believed his was from eating bad meat.

19 **Q.** After the birth of your son --

20 **A.** Yes.

21 **Q.** -- you developed fatigue.

22 **A.** Yes.

23 **Q.** Can you tell us about that.

24 **A.** I had fatigue and exhaustion. I work full-time.

25 I managed, I suppose but I was completely and utterly

1 exhausted. I really struggled in the mornings.

2 I would be two minutes late for work and really be  
3 very, very berated and get into a lot of trouble for  
4 that and I repeatedly at the doctors' said, "I'm  
5 exhausted", et cetera, but nothing, nothing avail.

6 **Q.** They put it down to you being a young Mum working  
7 hard?

8 **A.** Just nothing, just whatever, nothing, get out,  
9 exercise, fresh air.

10 **Q.** You've also developed severe anxiety, stress and  
11 chronic depression.

12 **A.** Yes.

13 **Q.** You've said in your statement you're not sure what  
14 caused it, but you're concerned that the hepatitis C  
15 and the trauma of being told about it may have played  
16 a part in that.

17 What can you tell us about what that's been like  
18 for you?

19 **A.** Excuse me while I read some brief notes. I had no  
20 mental health issues prior to my son being born.  
21 Date-wise that ties in. I was exhausted. I was  
22 fatigued. I had insomnia, which made the matter  
23 worse.

24 I became very stressed and very anxious, very  
25 agitated. I have completely changed my personality.

1 I am not the same person I was. It became worse and  
2 worse. I masked it for a long, long while at work by  
3 taking last-minute holidays. Subsequently, I had  
4 a period off work for maybe three weeks and then  
5 I managed several more years and I was off for seven  
6 months and a few more years later I was off for 12  
7 months and subsequently left employment.

8 I became, as I say, extremely irritable. I would  
9 say I was probably a Jekyll and Hyde. My family did  
10 not know what person was coming in the door. I used  
11 to be quite patient and tolerant. I would fly off the  
12 handle. I was never physically abusive.

13 I never swore. I swore like a trooper. I --  
14 apart from working and then when I didn't work, I --  
15 and part of this is to do with the stigma and the  
16 trauma but I stopped socialising, stopped having  
17 friends, stopped going out. I am still bordering  
18 an agoraphobic. I have not been to church in the past  
19 year, which is not me.

20 I don't see my 83-year-old mother as often as  
21 I should. She literally lives five minutes from me.  
22 The lack of socialisation, et cetera, has caused  
23 an impact clearly on my married life because I'm just  
24 not going, I can't go, I don't want to go.

25 It dawned on me one day that my children have

1 never known, and I'm going to use the word normal --  
2 who knows what normal is -- but it dawned on me one  
3 day my children have never known the normal me because  
4 this has been going on for the whole of my son's life  
5 and there's not much between him and his sister.

6 I'm worried that, you know, to do with nature and  
7 nature. Has this actually affected, the way my  
8 behaviour is, what they consider is normal behaviour?  
9 I became completely shut off, completely isolated,  
10 withdrawn. I won't answer the door. I won't answer  
11 the phone.

12 I have -- I'm totally lethargic. I've been  
13 lethargic for 24 years and even after I eventually  
14 stopped working, I'd been with the same company for 30  
15 years, it wasn't that, because I struggle with  
16 mornings.

17 Last weekend just as a little, whatever, I went to  
18 bed on Friday morning and woke up on Sunday morning  
19 and I was sleeping. I wasn't trying to sleep. I was  
20 completely sleeping. Did not get up for a drink, did  
21 not get up to the toilet and if I had the opportunity,  
22 that's what the exhaustion and the lethargy is like.  
23 I can't make myself do things or I try and set myself  
24 small tasks.

25 During this I have seen a psychiatrist. I have

1        seen various counsellors. I ended up getting a little  
2        better, when I started -- I went for mindfulness.  
3        I started doing medication and yoga. Unfortunately,  
4        I then had fibromyalgia so that hit a lot of that on  
5        the head.

6            I was despairing. I was desolate. I was  
7        emotional. I have stopped watching the news. I have  
8        stopped reading a newspaper. I won't listen to  
9        anybody talking about somebody that has died. I -- if  
10       anything else, I will watch a comedy on the  
11       television. I kind of put a bubble around myself.  
12       I'm despairing, I'm desolate, I'm alone. I got to the  
13       stage where -- and I have been several times -- where  
14       life's not worth living. I am -- everybody, my  
15       husband, my children, are better off without me.  
16       I would be better off dead. I have been suicidal  
17       several times.

18    **Q.** You've said in your statement that it's a thought  
19       pattern that becomes a very rapid --

20    **A.** It's a very rapid downward spiral and in (*unclear*)  
21       this year, I felt it happening and it's went downhill  
22       ever since. I was lucky enough after 20-odd years on  
23       antidepressants to be off them for a year and a half.  
24       I was prescribed them back in January and didn't  
25       really want to take them but six weeks ago I actually



1 was in the middle of a (*unclear*) down so I'm back on  
2 them.

3 I would describe my life, basically, I am a barely  
4 functioning, clinically diagnosed, chronic depressive,  
5 with complete anxiety and stress. I have constant  
6 palpitations. As I say, a year and a half ago I was  
7 going to a personal trainer. I was being positive.  
8 Everything was great. Then the fibromyalgia was  
9 diagnosed and it's bad. I've got chronic pain.  
10 I couldn't walk here. I had to get a taxi, so  
11 unfortunately I can't even do simple exercise.

12 Antidepressants add weight, so I'm in a Catch-22  
13 and that makes the depression worse, because you look  
14 in the mirror and you go, "Is that me?" You know,  
15 it's just -- and I can't get out of the cycle and it's  
16 like, you know, nobody loves me. I think I'll go and  
17 eat worms. It's that bad.

18 And with the best will in the world, unless you've  
19 been there, nobody understands. It must be horrendous  
20 for my family, must be.

21 **Q.** You've said in your statement that it's been very  
22 difficult in your marriage because of the struggle to  
23 understand what you're going through?

24 **A.** Yes.

25 **Q.** You've mentioned a moment ago the fibromyalgia.

1   **A.** Yes.

2   **Q.** You've also developed tension and cluster headaches.

3   **A.** Yes.

4   **Q.** And the fibromyalgia has caused environmental  
5       sensitivity to smells and sounds?

6   **A.** Yes.

7   **Q.** And, again, you're concerned about the connection or  
8       the possible connection between fibromyalgia and the  
9       hepatitis C and what's going on there but you don't  
10      really know at this stage.

11  **A.** No, no, I never thought there was a connection  
12      initially for a couple of reasons. I didn't realise  
13      that so many people with hepatitis C appear to have  
14      fibromyalgia but I have lived with the impression that  
15      I only had hepatitis C for a few years, and then  
16      I realised it was much longer than I thought, and  
17      therefore I'm thinking I only thought it was a few  
18      years.

19            It's been at that least that many years, there  
20      could be an effect, and of course fibromyalgia has  
21      fatigue and exhaustion but with the depression that's  
22      a bit chicken and egg, but the sensitivity, the  
23      itching, all of those things as well and I'm now --  
24      yeah, I'm now starting to look back with more --  
25      having the access to my medical notes I step back and

1 start to put the dots together and the timescale, yes.

2 **Q.** In your statement you talk about the stigma of  
3 hepatitis C.

4 **A.** Mmm-hmm.

5 **Q.** If we can start by discussing your interactions with  
6 doctors over the years, what your experience been of  
7 their reaction to your previous hepatitis C?

8 **A.** After the rant by my GP, it has never ever once been  
9 discussed with any GP at the practice, it's never been  
10 mentioned whatsoever. It has never been mentioned at  
11 the haemophilia unit. The odd time I have been in  
12 hospital and it's been there, I'm either -- you get  
13 some nurses who are genuinely curious about what it is  
14 and how I believe I got it, what you also get is when  
15 you're in room and you can hear them outside the door,  
16 and you can hear them, it's not really that discreet,  
17 even though I have a hearing-aid I can still hear  
18 them, and they are clearly talking about you. It's  
19 not pleasant. They're talking as if you're some type  
20 of scum. It's not nice.

21 **Q.** You've described in to your statement a particular  
22 incident with a doctor who didn't believe you'd been  
23 infected during childbirth. What can you tell us  
24 about that?

25 **A.** That was, I think, two years ago. Routine appointment

1 at the Glasgow Royal Infirmary. Same set-up, height,  
2 weight. It was a female doctor who I hadn't seen  
3 before, but that's quite normal in the Royal,  
4 obviously you get whoever is doing the rotation, and  
5 she brought up the issue of hepatitis C which is quite  
6 normal for a new doctor up there, and when I told her,  
7 she had said, "No, that that was completely  
8 impossible. There was no way that I contracted  
9 hepatitis C at that time".

10 She asked me several times, was I quite sure that  
11 I hadn't had a bleed and been treated as a child or  
12 one thing or another, and she was starting to get  
13 a little bit irate, but she was completely adamant  
14 that couldn't possibly have happened.

15 I didn't quite realise until the journey home when  
16 I was sitting thinking in the car, and I thought,  
17 "Wait a minute. What was that about?" And I don't  
18 know what that was about. I don't know whether she  
19 was trying to deflect responsibility away from the  
20 hospital, she was quite young, she wouldn't have been  
21 there then.

22 Now I'm wondering was it the date, as late as  
23 December 1990, that she thought, no that can't have  
24 been -- being a younger doctor. I have no idea, but  
25 she was completely adamant that I had got it some

1 other way.

2 **Q.** Have you felt able to tell anyone else that you're  
3 infected?

4 **A.** Having been treated like a leper in the maternity  
5 hospital by medical professionals, I didn't quite  
6 fancy the reception from the general public.  
7 Gradually over the years I have told my immediate  
8 family. Clearly my husband [redacted] had to be  
9 tested, et cetera, at my behest, my mother, my  
10 siblings. I never told my employer. I didn't tell  
11 any of my friends, and -- until now, no.

12 **Q.** What's the effect of having to keep it within a very  
13 limited range of people? What's the effect of that  
14 been on your marriage?

15 **A.** Well, that clearly adds to the stress because you've  
16 got something in your head and even after I thought  
17 I was clear, you've still got, as I say, will it come  
18 back? Have I infected anybody else? So you've got  
19 all this constantly running throughout your head  
20 throughout the years, even though you try and push it  
21 to the back, so it adds to the stress and the  
22 agitation and the depression obviously.

23 If something's really bothering you, you want to  
24 tell people who are close to you. I'm so close to my  
25 mother and eventually did tell her, but the fear of

1 the stigma and the trauma. So you're having to keep  
2 that in yourself. You can't discuss it with anybody.  
3 You can't vent. You can't, you know, have the counsel  
4 of a friend.

5 No, sorry, my perception -- this is clearly my  
6 perception, that is how I feel in the situation.  
7 I didn't want to face rejection again. So you're  
8 having to deal with it all internally and that would  
9 lead to stress, anxiety, depression and maybe venting  
10 it, as you do, to your nearest and dearest, which  
11 would be the people I live with.

12 **Q.** You've described in your statement that very difficult  
13 time at home with the children, with your husband, and  
14 the whole conglomeration of the anxiety, the  
15 depression, the stigma and the difficulties --

16 **A.** Yes, yes.

17 **Q.** -- there.

18 **A.** Yes.

19 **Q.** Do you want to say anything more about what was  
20 happening at home or I can read a bit from your  
21 statement?

22 **A.** You can read a wee bit from my statement.

23 **Q.** You said that -- sorry, let me just take a moment.

24 *(Pause)*

25 You said:

1           "The depression particularly has severely impacted  
2           on all my relationships. My family home has been full  
3           of tension and my mood changes."

4           You realise that the children never knew the  
5           normal you and that you've struggled in -- on the  
6           impact of your children of a Mum who's unwell?

7   **A.** Yes, yes, as I said, once upon a time I was patient  
8           and tolerant, I can still on good days but less --  
9           much less tolerant with any of them, and any normal  
10          situations that appear with any children, I could have  
11          a very short fuse, a very short fuse. And if --  
12          usually obviously their father would be the butt of it  
13          and, to be fair, he was very good, but there are  
14          points when he'd had enough, so they were never  
15          physical but there could be quite heated, loud rows  
16          which they clearly heard. It wasn't particularly  
17          nice.

18   **Q.** You said that the family as a whole missed out on  
19          doing many things like nights out and holidays because  
20          you couldn't cope?

21   **A.** Yes. No, no, no.

22   **Q.** You had to give up work partly because of your  
23          depression, partly because of the fatigue.

24   **A.** Mmm-hmm.

25   **Q.** And you're now living on benefits?

1 **A.** Yes.

2 **Q.** That's had a significant impact on you financially?

3 **A.** Yes. So I left work 20 years short of a pension.

4 I wasn't able to get ill health retiro. Luckily,  
5 luckily, we had paid off our mortgage and luckily my  
6 husband works, so we're a lot better off than a lot of  
7 other people, so I'm not really complaining. But  
8 I worked with the same employer for 30 years and then  
9 all of a sudden the incomer halved and we still had  
10 two young people to rear, put through uni, whatever  
11 else.

12 We were very lucky, we really didn't have any  
13 debt, so we're lucky but it is a bit of a culture  
14 shock when all of you sudden you think let's curtail,  
15 and then, you know, we do spoil our children a little  
16 and then the realisation that you can't. You haven't  
17 got it. And, yes, I'm lucky that I get  
18 National Insurance-based ESA. I don't get any more  
19 than that because my husband works and it's  
20 means-tested but that's -- you know, it's certainly  
21 better than nothing, that's good. But all the  
22 enhanced premiums that you pay for insurance, they  
23 still have to come out of half the money.

24 **Q.** You say in your statement you've struggled to obtain  
25 insurance.



1   **A.** Yes.

2   **Q.** Can you tell us a bit more about that.

3   **A.** I've always had life assurance. I've always told the  
4 truth. I've always told about the von Willebrand's,  
5 so the premiums for that are already weighted. When  
6 you answer the question honestly about have you ever  
7 been tested for hepatitis? Which, as I say, to the  
8 best of my knowledge, I answered truly, that's  
9 weighted another 100% on top of that, but I've always  
10 had it.

11           But when it comes to all the cold calls I'm  
12 getting about reviewing your premiums and they're  
13 horrified at how much I'm paying, which is far enough,  
14 and they say, "We can give you an over the phone  
15 review". No, you can't, because when you start saying  
16 these things they have no idea what you're talking  
17 about, then you get passed on to somebody else. Then  
18 the underwriters and they're phoning you back, and  
19 either they phone you back and go, "Oh, no, no, you're  
20 better sticking where you are", or they just don't  
21 phone you back. So -- and obviously the older you  
22 get, the harder it's getting.

23           The fibromyalgia has only been since my last  
24 review so it's never going to get any easier as you  
25 get older, so you just add things to the mix.

1 Q. You applied for a Skipton Fund payment.

2 A. I did.

3 Q. But it was refused initially.

4 A. Yes.

5 Q. What happened?

6 A. I found out about Skipton from family. I applied.

7 I cannot tell you what the form was like or whatever,

8 but I applied and I was rejected because the period of

9 my diagnosis and my clearing was less than six months,

10 which clearly is not the case, but that was the

11 timescales. The words they should have used would

12 have been the timescale between my infection and

13 clearing, which was basically six months. However,

14 I didn't realise that at the time and now we know

15 that's not even accurate dates either, so I was

16 rejected and that was that.

17 I raised it several times over the years in

18 conversation when people thought I should have got it,

19 but I didn't attempt to reapply, no.

20 Q. You recently phoned the Scottish Infected Blood

21 Scheme?

22 A. I did.

23 Q. What did they say?

24 A. I have no idea why I phoned. It was straight out of

25 the blue one day and I phoned and a very nice lady

1 answered the phone, and it was general terms, this is  
2 the state of play. She couldn't believe that I wasn't  
3 already registered with Skipton. She sent me out the  
4 forms. I went through the process of having them  
5 filled in and the hospital adding their pieces and,  
6 yes, I was accepted.

7 **Q.** So you've now been accepted by SIBBS?

8 **A.** Yes, but that, to be fair, was only a year ago, and if  
9 I hadn't done it -- and I don't know why I done it, to  
10 be honest -- I would still be sitting completely  
11 oblivious.

12 **Q.** And you've said in your statement the difficulty was  
13 for you was you hadn't been or you thought you hadn't  
14 been infected for very long but you were still being  
15 penalised for things like insurance and paying out  
16 more for those things --

17 **A.** Yes.

18 **Q.** And yet you were being told by Skipton that you  
19 weren't eligible.

20 **A.** That's right.

21 **Q.** But that's now been resolved.

22 **A.** Yes.

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

25 **A.** I have at least one comment to do with depression, and

1 it's in relation to GP records as well. One of the  
2 occasions when I went to my GP when I was suicidal,  
3 subsequently I was at the practice, at the nurse, and  
4 on the computer screen in front of her obviously were  
5 my records, and the comment when I had seen the doctor  
6 before that said that I was suicidal, not sure, I was  
7 flippant, at which point the nurse who was very nice  
8 suggested another one of the GPs in the practice who  
9 had more of a mental health background.

10 This is just an example of things that have been  
11 written in medical records. Anyone who has experience  
12 in mental health knows that quite often people with  
13 mental health, and I'm talking about suicidal, on the  
14 surface they smile and it's all going on underneath.  
15 That's just one indication of the things that are  
16 written down on records. *(Pause)*

17 One day at work before I left, I also decided to  
18 phone the hepatitis trust to ask whether they thought  
19 that the depression and the mental health issues could  
20 be related to hepatitis C, and they had told me no,  
21 which now I don't think is accurate. I couldn't get  
22 into, to be fair, a very prolonged conversation, it  
23 was lunchtime but there were people about, and as  
24 I say I didn't tell anybody at work. But again they  
25 timescale, no, but now we now know that timescales are

1           inaccurate.

2           As a slightly separate issue to this, yes, as  
3           a side issue, I don't know if this is common with all  
4           local health authorities but there is an issue with  
5           communication between certainly my local health  
6           authority and haemophilia units, and this has been  
7           going on for many, many years. They have been  
8           instructed to liaise with haemophilia units and they  
9           don't, and the recent example, as recently as earlier  
10          on this year, they decided they wanted to give me  
11          a lumbar puncture. I asked them to contact Glasgow  
12          Royal, which is normal procedure, and they came back  
13          and told me, yes, they'd spoken to their haematology  
14          unit and it was perfectly safe for me to have a lumbar  
15          puncture but it was up to me. I didn't have the  
16          lumbar puncture. I got home and phoned Glasgow Royal  
17          Infirmary to be told, which I knew, that that was  
18          potentially fatal and I was to take it further. Every  
19          time [redacted] needed something done, it appears as  
20          though they work in a silo. I completely accept that  
21          they have a very proficient haematology department.  
22          However, they are not haemophilia specialists and  
23          I have to phone the secretaries time and time again  
24          and ultimately [redacted] have had to go Yorkhill. So  
25          with an ongoing issue, I don't know whether that's

1       only North Ayrshire -- Ayrshire and Arran, sorry, but  
2       there seems to be, I don't know what it is,  
3       a miscommunication. They're not sharing the  
4       information, which has been -- obviously has serious  
5       repercussions.

6             I -- obviously, after the outrage by the GP, again  
7       no -- no next steps, but I had to then phone my  
8       husband's surgery, which is a different practice, and  
9       try and bypass the receptionist because I don't want  
10      to have that conversation and I then had to arrange to  
11      have my husband tested.

12   **Q.** And I think we should pause there. We must be careful  
13      unless your husband's given consent, if he's here.  
14      Yes, I can see him.

15   **A.** Sorry, I had to then arrange to have my husband  
16      tested, because obviously there had been several years  
17      between being infected and being told, and therefore  
18      without naming names, other family members, I had to  
19      arrange for testing as well. *(Pause)*

20             I would -- basically, I would also like to finally  
21      say that I'm really lucky. I am really, really lucky.  
22      Physically, as far as I know, I'm lucky. Mentally,  
23      not really. I don't feel really worthy of being here  
24      today because I'm lucky. I appreciate there are  
25      people who are much worse than me and who have lost

1 loved ones. However, I also realise that everybody  
2 has their own story, their own different value to  
3 their story, so I really do appreciate this  
4 opportunity. Thank you.

5 **Q.** I'm just going to turn and see if Mr O'Neill or  
6 Mr Dawson has anything they wish for me to raise.

7 There's nothing else they want me to raise.

8 **SIR BRIAN LANGSTAFF:** Well, I think far from your not  
9 justifying giving evidence, I think we have been very  
10 fortunate to have had it. Your story is unusual in  
11 many respects. You've shone a highlight on many  
12 aspects of communication, not just between doctor and  
13 patient but between doctor and doctor, and that  
14 evidence is very well worth hearing, so be assured you  
15 don't need to feel that you shouldn't be where you  
16 are.

17 **A.** Thank you.

18 **SIR BRIAN LANGSTAFF:** And, in particular, you've come to  
19 be where you are despite your mild agoraphobia or on  
20 the edge of agoraphobia and despite not having told  
21 a number of the people who you recognise may be seeing  
22 or hearing what you've been saying.

23 **A.** Yes.

24 **SIR BRIAN LANGSTAFF:** So that takes enormous courage.  
25 Thank you very much for that.

1 **A.** Thank you very much. Thank you.

2 **SIR BRIAN LANGSTAFF:** We'll take a break now until  
3 3.50 pm.

4 **MS FRASER BUTLIN:** I should say for those who are watching  
5 the live-stream that the next witness is anonymous and  
6 we will be turning off the video and the audio but it  
7 will be uploaded at a later date.

8 **SIR BRIAN LANGSTAFF:** So those who are watching will have  
9 nothing to see, unless it is any closing remarks which  
10 are made at the end of today, which they might not  
11 think are worth listening in to. We can deal now  
12 perhaps with what we are having tomorrow.

13 **MS FRASER BUTLIN:** We can, sir. There are three witnesses  
14 tomorrow and they are all anonymous.

15 **SIR BRIAN LANGSTAFF:** Thank you. 3.50 pm.

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

17 **(3.30 pm)**

18 **(A short break)**

19 **(4.12 pm)**

20 **SIR BRIAN LANGSTAFF:** I'm very sorry that you've been kept  
21 a little bit back from your tea, that is your high  
22 tea, because we were told earlier in the week it was  
23 called in this part of the world, as I well remember,  
24 actually. The reason for it, let me explain, is that  
25 there had to be a change in the restriction order.



1           The reason for that is that Mrs Z is going to give  
2 evidence alongside Mr Z and so those of who you have  
3 waited will actually see two witnesses, even though  
4 you only originally thought you were being offered  
5 one.

6           But because the order is actually -- it's a formal  
7 legal order which has serious consequences if it is  
8 broken, and so it has to be absolutely clear what it  
9 says, so that people know what they must not do and  
10 they can be held properly to account by the courts if  
11 they do what they shouldn't.

12           It has to be properly written out and because this  
13 was a late decision to accommodate Mrs Z's evidence,  
14 the restriction order has had to be changed formally  
15 and that's taken just a short while. But I'm sorry  
16 about the delay but you understand I hope why it is  
17 necessary, and it is also necessary that I therefore  
18 read out the order in what is its proper form. The  
19 press have been told and have got the order.

20           I order that the names and address of witness  
21 W2223, that's Mr Z to you and me, and witness W2311,  
22 Mrs Z, and any other identifying information such as  
23 their images or a description of their appearance  
24 cannot be disclosed or published in any form unless  
25 express permission is given by me or by the solicitor

1 to the Inquiry acting on my behalf. Witness W2223 and  
2 W2311 must be referred to only as Mr Z and Mrs Z.

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

7 After that, may we have, please, Mr and Mrs Z.

8 **MR Z, sworn**

9 **MRS Z, sworn**

10 **Questioned by MS FRASER BUTLIN**

11 **SIR BRIAN LANGSTAFF:** And there is no live-streaming  
12 either by video or by audio.

13 **MS FRASER BUTLIN:** Precisely, sir. And we've discussed  
14 and it's going to be too difficult for you to refer to  
15 each other by anything other than your names, so those  
16 present in this room will hear your names and probably  
17 also the name of your daughter, but when it goes out  
18 on the live-stream, those names will be removed and  
19 those present should not use the names outside of this  
20 room.

21 Mr Z, you have severe haemophilia A.

22 **MR Z:** Yes.

23 **MS FRASER BUTLIN:** And you were diagnosed at 11 months  
24 old.

25 **MR Z:** That's correct.

1 **MS FRASER BUTLIN:** You had your first treatment in about  
2 1972/nine turn 73?

3 **MR Z:** Yeah.

4 **MS FRASER BUTLIN:** When you were about five or six?

5 **MR Z:** Yeah.

6 **MS FRASER BUTLIN:** How frequently did you require  
7 treatment when you were young?

8 **MR Z:** Probably up until I was about five or six I didn't  
9 need any treatment but after that I was a regular  
10 receiver of cryoprecipitate and Factor VIII.

11 **MS FRASER BUTLIN:** It started off as cryoprecipitate --

12 **MR Z:** It started off as cryoprecipitate, yes.

13 **MS FRASER BUTLIN:** And then gradually it became  
14 Factor VIII?

15 **MR Z:** That's correct, yeah.

16 **MS FRASER BUTLIN:** When you were receiving those products  
17 were your parents or latterly you, were they ever  
18 warned about risks involved in receiving them?

19 **MR Z:** No, I have asked my parents and they can't recall  
20 anything either.

21 **MS FRASER BUTLIN:** You're quite softly spoken, so you  
22 would mind coming slightly closer to the microphone so  
23 everyone can hear you.

24 And did you tend to receive treatment when you  
25 needed to it or were you ever put on prophylaxis?

1 **MR Z:** No, I was played a lot of football when I was  
2 young which sometimes necessitated bleeds, sometimes  
3 it didn't and I got cryoprecipitate as and when  
4 required.

5 **MS FRASER BUTLIN:** In 1976 you were admitted into the  
6 Royal Infirmary with infective hepatitis.

7 **MR Z:** Yes.

8 **MS FRASER BUTLIN:** Can you tell us about that occasion  
9 from what your parents have told you?

10 **MR Z:** Well, at the time we were told it was jaundice,  
11 turned yellow, as you do. We were actually told it  
12 had been due to a dirty needle. I was put in solitary  
13 confinement at the City Hospital. I wasn't allowed  
14 out of the room, and basically kept there for four or  
15 five weeks until I was better.

16 **MS FRASER BUTLIN:** But subsequently it's been questioned  
17 whether that was contracted through a -- from one of  
18 the factors products.

19 **MR Z:** Yeah, we did think at the time how could you get  
20 a dirty needle? But that's what we were told at the  
21 time.

22 **MS FRASER BUTLIN:** In 1985, when you were about 18, you  
23 were told you had HIV.

24 **MR Z:** That's correct, yeah.

25 **MS FRASER BUTLIN:** What can you tell us about that

1 appointment?

2 **MR Z:** I remember it quite well. I could actually take  
3 you to the room in the ward where it was at. I was  
4 told that I was HIV-positive. Certain things  
5 I couldn't do. You know, if I cut myself I had to  
6 make sure it was cleaned up, actually brushing my  
7 teeth as well it can sometimes bleed your gums, you  
8 have to be careful, and other things as well, like  
9 having partners, et cetera, but when I was that age  
10 all that meant anything to me was football.

11 **MS FRASER BUTLIN:** Please can we have document 2223009.

12 It says this:

13 "This is simply to confirm that [Mr Z's] HTLV III  
14 antibody status is positive. [Mr Z] himself knows this.  
15 I have not told his parents as this is entirely between  
16 [Mr Z] and them. I discussed the situation and some of  
17 the implications of this positive test with him when  
18 I told him the result. The immediate implication is  
19 simply that he has met this virus at some time in the  
20 past and has made antibodies to it. The fact that this  
21 test is positive does not [and it is underlined] mean  
22 that he has got AIDS. We know that a small but  
23 uncertain proportion of people with this positive  
24 antibody test do go on to develop AIDS in the future but  
25 we cannot identify those who will."

1           And if we pause there for a moment, can you tell  
2           us how you felt about being told you were  
3           HIV-positive?

4   **MR Z:**    What I remember at the time was that the  
5           television advert, where it was a grave stone and I'm  
6           sure it said AIDS at the top of it and it was just  
7           falling over, and it was quite scary at the time and  
8           there was a huge stigma at the time but at the time  
9           HIV -- I thought HIV was AIDS but obviously it's not.  
10          So, yeah, they told me I was HIV-positive but I don't  
11          think I fully understood what -- what it meant.  
12          I just knew it was scary with all the television  
13          adverts that was on.

14   **MS FRASER BUTLIN:**  And if we go back to the letter  
15          a little bit further down it says -- it discusses the  
16          risks of transmission.  It says:

17                 "However, the only way that this virus can be  
18                 transmitted is by sexual activity and I discussed this  
19                 with him."

20                 Did that concern you at the time?

21   **MR Z:**    Not at the time but obviously later in life it  
22          would have had some bearing, but it was just a case of  
23          don't have family, that was it.  There was nothing  
24          else at that time.

25   **MS FRASER BUTLIN:**  Subsequently, if we just pause on the

1 letter for a moment, subsequently, before you had your  
2 child, when you were older, when technology had moved  
3 on, were you ever advised about the possibility of  
4 sperm washing?

5 **MR Z:** We were but that was after our daughter was born.  
6 Otherwise we would have probably have taken up the  
7 offer, if you see what I mean. But we weren't aware  
8 of it beforehand, no.

9 **MS FRASER BUTLIN:** You were never proactively informed --

10 **MR Z:** No.

11 **MS FRASER BUTLIN:** -- about it, until after you'd had your  
12 daughter?

13 **MR Z:** Yeah.

14 **MS FRASER BUTLIN:** And then returning to the daughter at  
15 the last paragraph, it says this:

16 "In view of the unnecessary hysteria raised by the  
17 press about this subject, in which the infective risks  
18 were quite grossly exaggerated, I would not propose that  
19 information about HTLV III antibody positivity should be  
20 disseminated more widely than the patient, his GP,  
21 Dr Dawson and myself ..."

22 **SIR BRIAN LANGSTAFF:** Do you think we should redact  
23 Dr Dawson?

24 **MS FRASER BUTLIN:** No, sir, because it has been put to  
25 her.

1     **SIR BRIAN LANGSTAFF:** That's fine.

2     **MS FRASER BUTLIN:** "... and myself and any laboratory  
3         which requires to handle your patient's blood."

4             Do you remember again then in relation to what you  
5         were reading and who your were told you could tell  
6         about your HIV status how you felt about that at the  
7         time?

8     **MR Z:** At the time, I mean, obviously I don't think my  
9         mother and father was told, so that was left to me and  
10         of course I told them but no one, not even my sisters  
11         at the time, were told about it. That was just kept  
12         between mother and father and myself. Because, as  
13         I say, there was a huge stigma at that time about it.

14    **MS FRASER BUTLIN:** And how did you feel about that, about  
15         not being able to tell people?

16    **MR Z:** Well, I wouldn't have wanted to because it  
17         really -- I didn't want any sympathy. That's not the  
18         type of person I am, but it was just better it was  
19         kept -- we felt it was better to be kept between the  
20         three of us and other people, as we saw fit.

21    **MS FRASER BUTLIN:** In 1987, in your records there is  
22         a letter indicating that there was a meeting with you  
23         and, at that time, your girlfriend at that time, to  
24         discuss the implications of HIV and haemophilia.

25             Do you recall any such meeting?



1 **MR Z:** No. I first found that out when I met the counsel  
2 a few weeks back, and I cannot recall that meeting  
3 ever taking place. I've got a very good memory.  
4 I remember most things but that is just something  
5 I cannot recall.

6 **MS FRASER BUTLIN:** We're just going to have a look at the  
7 letter which appears to have been written at around  
8 this time. It's 2223008, and if we look at the  
9 paragraph numbered 1, it says this:

10 "The fact that all severe haemophiliac patients in  
11 Scotland should be regarded as having met the HIV virus  
12 at some stage in the past regardless of any blood  
13 test ..."

14 This is what was apparently advised at the time:

15 "Current blood tests detect only antibody to HIV and  
16 cannot detect the virus itself. The exposure of  
17 haemophiliac patients to HIV has not necessarily been  
18 the result of imported Factor VIII and, in fact, Mr Z  
19 has never had anything other than Scottish Factor VIII."

20 Do you have any reason to think that that part of  
21 the letter is incorrect, that you'd only ever received  
22 Scottish Factor VIII?

23 **MR Z:** Well, I got the HIV virus from somewhere, so  
24 that's all I can say.

25 **MS FRASER BUTLIN:** But you've got no reason to think

1           you --

2   **MR Z:**    No.

3   **MS FRASER BUTLIN:**  -- that you received other commercial  
4           products?

5   **MR Z:**    No, not at all.

6   **MS FRASER BUTLIN:**  As far as you're concerned, that's  
7           right, you only had Scottish product?

8   **MR Z:**    I certainly wasn't told where it was coming from,  
9           no.

10  **MS FRASER BUTLIN:**  Then if we go to the very end of the  
11           letter there's a handwritten note:

12                 "[Mr Z] didn't ask the result of [Mr Z's] HIV ..."

13                 Sorry:

14                 "The lady who was apparently at the appointment  
15           didn't ask the result of [Mr Z's] HIV antibody test.  
16           I didn't volunteer it as I thought she had enough to  
17           cope with.  As you'll see in (1) above I've said that  
18           all haemophilia patients should probably be taking  
19           similar precautions.  Of course, when she asks I will  
20           tell her this result."

21                 What's your reaction to that?

22  **MR Z:**    Staggering.  I mean, he would have needed my  
23           authority to disclose information like that, and we  
24           had already agreed to keep it to the three of us, so  
25           why we would tell somebody that I knew I wouldn't land

1           up marrying, why would I do that?

2   **MS FRASER BUTLIN:** You met your wife in about 1988.

3   **MR Z:** Yeah.

4   **MS FRASER BUTLIN:** And you told her about your HIV.

5   **MR Z:** I did, yes.

6   **MS FRASER BUTLIN:** Can we have 2223012, please. It's

7           a letter from 8 January 1992 to your GP, saying that

8           you had got antibodies to hepatitis C.

9           Were you told at that time --

10   **MR Z:** No, I wasn't.

11   **MS FRASER BUTLIN:** -- about the hepatitis C?

12   **MR Z:** No.

13   **MS FRASER BUTLIN:** And then if we can have 2223014,

14           7 September 1995, the last paragraph indicates that

15           your hepatitis phenotype, et cetera, had been checked:

16           "... but obviously with his HIV there would probably

17           be little question of interferon. We will, however,

18           keep him on our hep C positive register."

19           At this point were you told about your

20           hepatitis C?

21   **MR Z:** The first time I knew -- no, certainly not then,

22           I didn't know about the hepatitis C and certainly

23           I didn't know about any positive register.

24   **MS FRASER BUTLIN:** So from that, I take it you didn't

25           consent to being put on a hep C positive register?

1   **MR Z:**    No.

2   **MS FRASER BUTLIN:**  Subsequently have you been told  
3           anything about what the register is?

4   **MR Z:**    No, nobody has ever actually told me.

5   **MS FRASER BUTLIN:**  Then if we can go to 2223013,  
6           28 November 1995, in the third line -- it talks about  
7           your liver functions tests and in the third line:  
8                 "He has of course positive hepatitis C."  
9           Were you told that your liver functions tests had  
10          risen?

11   **MR Z:**    No, no.

12   **MS FRASER BUTLIN:**  And were you told at this point that  
13          you had hepatitis C?

14   **MR Z:**    No.

15   **MS FRASER BUTLIN:**  2223015, August 1995.  Your hepatitis C  
16          phenotype is identified and it says that it's one for  
17          which interferon is satisfactory:  
18                 "... which I understand means he would be suitable  
19          for interferon therapy."  
20          Were you told then about the fact that you had  
21          hepatitis C?

22   **MR Z:**    No, never told and never told about any,  
23          obviously, treatment that there was.

24   **MS FRASER BUTLIN:**  And what's your concern about that  
25          reference to interferon treatment then?

1 **MR Z:** Well, that was 1995. Why did I not get it until  
2 2005? As bad it was, that's ten years between  
3 mentioning it and actually giving it to me.

4 **MS FRASER BUTLIN:** Then if we go to 2223019, it's a letter  
5 from 1996 and it says that the implications of  
6 hepatitis C were discussed. We'll come back to that  
7 in one moment.

8 Towards the end of the letter it also discussed  
9 that you've agreed to undergo an endoscopy. Did you  
10 agree to undergo an endoscopy?

11 **MR Z:** No.

12 **MS FRASER BUTLIN:** And did one happen?

13 **MR Z:** No.

14 **MS FRASER BUTLIN:** In 1996 was there any discussion about  
15 you having hepatitis C, in March 1996?

16 **MR Z:** Not to my knowledge, no.

17 **MS FRASER BUTLIN:** And why are you so clear that at that  
18 time you did not know you had hepatitis C?

19 **MR Z:** As I said, I had told my wife that I was  
20 HIV-positive. When she fell pregnant, which would  
21 have been September '96 we obviously went to  
22 a haematology unit to get [redacted] tested for HIV  
23 and to make sure that my daughter was okay, and we  
24 obviously didn't ask to be tested for hepatitis C at  
25 that time, because we didn't -- didn't know about it.

1 **MS FRASER BUTLIN:** Your wife was clear for the HIV.

2 **MR Z:** Yes, she was.

3 **MS FRASER BUTLIN:** But she'd also, you discovered later,  
4 she had actually also been tested for hepatitis C.

5 **MR Z:** Yes.

6 **MS FRASER BUTLIN:** And that was clear?

7 **MR Z:** Yes.

8 **MS FRASER BUTLIN:** But were you told she'd been tested for  
9 hepatitis C?

10 **MR Z:** No, we had no idea at the time and we just came  
11 across it. When I had the liver transplant, we were  
12 looking through our medical notes and came across the  
13 test results. At no time were we aware of hep C being  
14 tested for.

15 **MS FRASER BUTLIN:** You simply were told the HIV results --

16 **MR Z:** Yes.

17 **MS FRASER BUTLIN:** -- but nothing about the hepatitis C?

18 **MR Z:** No.

19 **MS FRASER BUTLIN:** So in 1996 you were still not aware  
20 that you had hepatitis C?

21 **MR Z:** No.

22 **MS FRASER BUTLIN:** When were you told?

23 **MR Z:** I can't quite recall when it was. Early 2000s,  
24 maybe, but it basically came -- the new consultant was  
25 obviously looking after me and he happened to mention

1           that, "I'm more concerned now about your hep C than  
2           your HIV", and I says, "I don't have a clue what  
3           you're talking about. Can you please explain it to  
4           me", and that is the first I was aware of -- I didn't  
5           even know what hepatitis C was at that time.

6   **MS FRASER BUTLIN:** In your statement you've placed it  
7           around about 1997/1998 but it would be at least the  
8           late '90s, sometime then?

9   **MR Z:** Yes, I honestly can't recall the date but, yes, it  
10          could be then, yes.

11   **MS FRASER BUTLIN:** Now you've wanted to make clear that  
12          you have no criticisms of Dr Watson.

13   **MR Z:** No, absolutely none whatsoever.

14   **MS FRASER BUTLIN:** And I must put on record that Mr Z's  
15          statement has been provided to Dr Dawson and she said  
16          she will be responding and that response will be  
17          published in due course.

18                 Going back to that point in time when you were  
19          told you had hepatitis C, what were you told then  
20          about it?

21   **MR Z:** I think very little. I think to be fair to  
22          Dr Watson, if you were reading through my file, and  
23          you were showing some of the letters there, he would  
24          have just assumed that I'd been told, but I hadn't.

25                 I can't recall at the time -- I mean, I was

1           certainly given no leaflets or anything like that. It  
2           wasn't until later on that I discovered how serious  
3           this could be and, again, I can't give you a date  
4           because I don't know.

5   **MS FRASER BUTLIN:** Before you were told about your  
6           hepatitis C diagnosis, what was your physical health  
7           like?

8   **MR Z:** I was 6 feet 3, 14 and a half stone, muscly.  
9           I wasn't quite the perfect specimen but I thought  
10          I was!

11 **MS FRASER BUTLIN:** And in terms of your HIV, you've been  
12          on treatment for it over the years with some AZT in  
13          you think about 1992 --

14 **MR Z:** Yeah.

15 **MS FRASER BUTLIN:** -- but with limited side effects?

16 **MR Z:** Yeah.

17 **MS FRASER BUTLIN:** Since then, since about 2005/2006 you  
18          have been on Kaletra?

19 **MR Z:** Yeah.

20 **MS FRASER BUTLIN:** What side effects has the HIV  
21          medication caused for you?

22 **MR Z:** Very little. That -- I would have to say there  
23          hasn't been any, that I certainly noticed anyway.  
24          Maybe medical tests will show something different, but  
25          physically, mentally, it's had no effect on me.



1 **MS FRASER BUTLIN:** In terms of treatment for your  
2 hepatitis C, if we can have --

3 **MR Z:** Yeah.

4 **MS FRASER BUTLIN:** -- 2223021, please, and if we look at  
5 the second paragraph, it's March 2000, it says:

6 "Today I have had a fairly frank discussion with him  
7 again about the role of antiviral therapy in his case.  
8 At the moment, I do not think there is any indication at  
9 all to change from AZT monotherapy to a combination  
10 treatment. Today I have also discussed with him the  
11 potential for considering treatment of his hepatitis C  
12 with interferon and ribavirin."

13 Then towards the end, through that paragraph,  
14 there's some concern about progression of HCV in the  
15 context of HIV and at the end of the paragraph:

16 "When further studies of the use of combination  
17 therapy for HCV in the context of HIV therapy are  
18 published, then we could reconsider the situation with  
19 regards to his liver which, at the end of the day, may  
20 prove to hold the key to his eventual outcomes."

21 You were introduced to the idea in about 2000 that  
22 you may need some treatment for the hepatitis C.

23 **MR Z:** Mmm-hmm.

24 **MS FRASER BUTLIN:** And then if we go to 2223020, and we  
25 look, this is a letter from 2004, and we look at the

1 second paragraph it says:

2 "I spent some time discussing with him the fact that  
3 there is now increasing evidence that the hepatitis C  
4 co-infection should be treated in patients with HIV.  
5 The hepatitis C is now the major cause of death in these  
6 patients who are co-infected. There have been three  
7 large trials published recently which have revealed  
8 viral (HCV) clearance rate in the order of between 25%  
9 and 60%, depending on the genotype or the virus  
10 encountered. [Mr Z] when last tested had genotype 3A  
11 virus which is one of the more favourable genotypes for  
12 treatment. I would have to caution this however in that  
13 if he had cirrhosis as well as HIV infection his chances  
14 of viral eradication would be much lower. I have made  
15 him aware of all of this."

16 Re-reading that do you remember how you felt when  
17 you were told that news?

18 **MR Z:** Well, the positive I took it from it is genotype 3  
19 was one that could be cured, so that's what  
20 I basically held on to. I can remember it, I can  
21 remember him telling side effects as well of what  
22 might happen, but certainly I went away thinking, "Oh,  
23 well, genotype 3 I've got a good chance of survival",  
24 compared to where I was later on life, 60% was  
25 a fairly high number.

1 **MS FRASER BUTLIN:** You started treatment for the  
2 hepatitis C in 2005 with pegylated interferon and  
3 ribavirin.

4 Can you tell us what the effect of the treatment  
5 was on you?

6 **MR Z:** It was just horrendous. I wouldn't have wished  
7 that treatment on my worst enemy. Not that I have  
8 any. So bad that obviously I cleared the virus but it  
9 came back, I don't think I would have done it again  
10 and I remember sitting there, it was one Friday night  
11 and we had this pain and I was ready to inject it into  
12 my stomach and I thought, "I've got no idea what this  
13 is going to do to me", but we went ahead and I had  
14 every single side effect. I had thinning of my hair,  
15 my hair, sore heads, tired all the time, couldn't  
16 sleep, itchiness in the skin, nosebleeds, cramp -- the  
17 worst thing was cramp. I was getting cramp in bits of  
18 my body I didn't even know it was possible to have  
19 cramp in, and I do remember one day I had cramp in my  
20 fingers, arms, legs, toes at the same time and I was  
21 screaming in pain. There's not a cure for cramp, and  
22 it was just horrendous. I don't think I would have  
23 taken it again.

24 **MS FRASER BUTLIN:** You'd cleared virus by about halfway  
25 through the treatment?

1     **MR Z:**     Yeah.

2     **MS FRASER BUTLIN:**   That's what the blood tests seemed to  
3         be showing?

4     **MR Z:**     Yeah.

5     **MS FRASER BUTLIN:**   But you had to stop the treatment after  
6         37 weeks.

7     **MR Z:**     Yes, that's correct.

8     **MS FRASER BUTLIN:**   Why was that?

9     **MR Z:**     I basically fell seriously ill. My gullet --  
10        obviously the liver wasn't working and doing what it  
11        needed to do and my gullet burst in various places and  
12        I started spewing blood. I was rushed into Aberdeen  
13        and that was on 17 December -- 15 December 2005 and  
14        I don't remember much after that until Boxing Day.  
15        I was out of it and, basically, my wife had been  
16        prepared that the chances of survival was low. My  
17        organs were beginning to close down and my body was  
18        basically -- I think the words they used were shutting  
19        down from the inside out.

20        But I knew nothing about it. I remember going  
21        into hospital, but after, you know, after that  
22        I remember nothing until Boxing Day.

23     **MS FRASER BUTLIN:**   Mrs Z, can you tell us what it was like  
24        for you?

25     **MRS Z:**     I had an ambulance journey in, it was a blue-light

1 journey in. I stupidly thought it was because there's  
2 was lots of traffic on the road but [redacted] was --  
3 as he said, was having a variceal bleed at that point,  
4 so they took him in, did investigation, did a brain  
5 scan, because they were scared in case, because of the  
6 haemophilia, there was a bleed on the brain.

7 He basically, as he said, fell asleep and didn't  
8 waken until Boxing Day. We were prepared -- the staff  
9 on the wards were amazing, the doctors were amazing,  
10 but I remember being taken into a relatives' room and  
11 being told that maybe we needed to start thinking  
12 about other plans because his organs were shutting  
13 down from the inside out.

14 So they would have a re-look at the medicine that  
15 they had him on at that point, and they changed  
16 everything and thankfully he started to turn a corner  
17 and pick up a bit, but it was -- it was horrendous.  
18 Our little girl was just nine at that -- 2005 -- seven  
19 at that point, so I couldn't even take her in to see  
20 her daddy, because he was just -- he was no  
21 [redacted], sorry.

22 So he did pick up thankfully, as I say, and he got  
23 home. We had a long stay in hospital. It wasn't  
24 until February he got home. So we got home, we had  
25 Christmas, but it wasn't long again until he landed

1 back in hospital and that started the spiral to what  
2 was to come.

3 **MS FRASER BUTLIN:** Before we talk about that spiral, after  
4 the treatment you were also diagnosed with type 2  
5 diabetes.

6 **MR Z:** Yes.

7 **MS FRASER BUTLIN:** That's now -- you've still got it, it's  
8 controlled by insulin.

9 **MR Z:** Yeah, apparently -- sorry, I forgot to say a side  
10 effect as well, I had a huge scab on my stomach where  
11 I was taking all the injections. That was quite  
12 unsightly.

13 Sorry, I forgot your question.

14 **MS FRASER BUTLIN:** I was asking you about the type 2  
15 diabetes.

16 **MR Z:** Yes. Later on it transpired that I was told that  
17 a side effect of interferon is diabetes, so they did  
18 tests and, yes, I am now a diabetic and remain so.

19 **MS FRASER BUTLIN:** Can you tell us what happened. You got  
20 home -- you turned a corner, you'd got home but then  
21 everything went downhill. Can you tell us about that?

22 **MR Z:** It was just encephalopathy, because your liver  
23 wasn't working to clean the toxins, basically I would  
24 become unconscious, rushed into hospital, but the  
25 worst thing, my daughter used to go to bed, I was fine

1 and she'd wake up in the morning and I wasn't there.  
2 It always seemed to happen at night, I don't know why.

3 I could be speaking away like this and within two  
4 seconds that was me for anything up to a week,  
5 I think, when I woke up, didn't know what day it was,  
6 what time it was. This -- this just happened  
7 periodically.

8 Obviously, I used to get ascites in my stomach and  
9 I remember that the first time, was it 17 litres of  
10 fluid they drained from my stomach, which I always put  
11 down to eight bottles of 2-litre Coke, and when you  
12 think of it in those terms you think "Wow". I was  
13 just huge.

14 It was painful. It got sore and it came to the  
15 times that, yeah, I had the various escapades,  
16 encephalopathy but every Sunday I used to go in and  
17 get my stomach drained and that would have been  
18 10/12 litres every week, and life was just put on  
19 hold. It had to stop.

20 **MS FRASER BUTLIN:** You were put on a list for a liver  
21 transplant in June 2006?

22 **MR Z:** Yeah.

23 **MS FRASER BUTLIN:** And you got the call in February 2007.

24 **MR Z:** Yes.

25 **MS FRASER BUTLIN:** What can you tell us about that?

1 **MR Z:** It got to the stage that I just wanted the liver  
2 transplant. I mean, being a haemophiliac and having  
3 a huge operation like that it's quite daunting but  
4 I was just so ill. I had no quality of life. As  
5 I say, I went from a guy playing football, squash,  
6 badminton, you name it I did it sport-wise, to being  
7 in a wheelchair, not able to go to the toilet on my  
8 own and my life was just rubbish and I just wanted the  
9 transplant because that would have been the saviour  
10 for everything.

11 And on the 1st --

12 **MRS Z:** 1 February.

13 **MR Z:** 1 February, I was taken down, got various tests  
14 and because of the ascites I think there was  
15 a question mark of whether I had an infection or not  
16 and I thought, "Great, we've come all this way down  
17 here", but luckily it was clear and I received my  
18 liver transplant.

19 **MS FRASER BUTLIN:** You've provided me with some  
20 photographs, and I've passed them to the Chair, of you  
21 after your liver transplant.

22 **MR Z:** Yeah.

23 **MS FRASER BUTLIN:** For obvious reasons, we won't put them  
24 up, but they show you in a very different state to the  
25 man we see now.



1 **MR Z:** Yeah.

2 **MS FRASER BUTLIN:** After you'd had the transplant, you  
3 didn't particularly pick up, though, did you? What  
4 happened then?

5 **MR Z:** No, well, the first few days I felt great, but  
6 I just started that I couldn't breathe properly and  
7 just didn't feel as -- how I thought I was going to  
8 feel. I knew there was still something wrong and  
9 that's when they discovered that probably during the  
10 time of the interferon -- remind me of the word.

11 **MRS Z:** Septicaemia.

12 **MR Z:** Septicaemia had been attached to one of my heart  
13 valves and my heart was now failing.

14 **MS FRASER BUTLIN:** So you underwent a replacement of your  
15 aortic valve --

16 **MR Z:** Yes.

17 **MS FRASER BUTLIN:** -- in about April 2007?

18 **MR Z:** That's --

19 **MRS Z:** 26 April 2007.

20 **MR Z:** Yes, aye, 2007, that's correct, yeah.

21 **MS FRASER BUTLIN:** You remained in hospital almost  
22 continuously from February 2007 until July 2007.

23 **MR Z:** That's -- yes.

24 **MS FRASER BUTLIN:** Can you tell us what the impact of that  
25 has been on your mental well-being?

1   **MR Z:**    I'm a very positive person and I think to get  
2            through what I got through you had to be.  Mentally,  
3            it's a case of, you know, I had a young daughter.  She  
4            meant everything to me, and what kept me going was  
5            being able to walk her down the aisle and I'm glad to  
6            say on [redacted] I will.  Sorry.

7            So that's the only thing I could think of.  That's  
8            what I focused on and luckily it got me through.

9   **MS FRASER BUTLIN:**  Mrs Z, can you tell us how it affected  
10           you throughout that time?

11   **MRS Z:**  It was -- it was so hard, so, so hard.  Basically  
12            [redacted] was in hospital in Edinburgh, our daughter  
13            was at home in [redacted].  She would come down every  
14            weekend but we didnae have a normal family life, we  
15            couldnae do normal things.  We spent her ninth  
16            birthday in the canteen in the hospital having her  
17            birthday there.

18            He just -- as [redacted] says his life was on  
19            hold.  You couldn't plan anything.  You couldn't --  
20            you couldn't think past that day, and to see the  
21            person that you loved just be so helpless, he could do  
22            basically nothing on his own.  And, as he said, he'd  
23            gone from this big strapping person down to just  
24            a shadow, and it was -- it was so tough, so tough to  
25            watch that and not be able to -- to do anything.  You

1 just felt helpless to be able to try and (unclear).

2 At the times of the operations, at the liver  
3 transplant one, that was -- you did feel almost  
4 a peace just that he was just getting the operation,  
5 that the answer had come that we had prayed so long  
6 for. But then he didn't recover as we thought he  
7 would and we got to the heart and to get at that  
8 point, just before [redacted] had the operation we  
9 were -- we were actually planning to take him home for  
10 palliative care because he was so poor. They told us  
11 that we should really enjoy the weekend with our  
12 family, because that's the stage that we were at.

13 Thankfully, the surgeon agreed to do the  
14 operation, and when he came to speak to us about the  
15 operation he said that [redacted] really had a less  
16 than 1% chance of coming through that operation. But  
17 at that stage, as [redacted] says with [redacted], we  
18 had to tell her that daddy might not be there much  
19 longer, but we knew we'd have tried absolutely  
20 everything. That there was no stone left unturned.  
21 That we could look at [redacted] and say, "We've tried  
22 everything, we've done it".

23 So we got to go down to the -- to the pre-op room  
24 with [redacted] before that operation, and even at  
25 that point he was thinking about us because we

1 standing at his bedside and he looked at us and he  
2 said, "Don't you worry, whatever happens in this  
3 operation, I'm going to be okay". So we had that to  
4 hold on to and thankfully, through prayer and so much  
5 amazing medical staff, he's still here, we have him,  
6 and we're thankful for that every single day.

7 **MR Z:** I think we should maybe say that because of my  
8 poor state of health, the first two heart surgeons  
9 refused to do the operation that was required, and  
10 thankfully the third surgeon said yes. And he said  
11 yes on the basis that I was young and had a young  
12 family and he was prepared to give it a go.  
13 Otherwise, I wouldn't be here today.

14 But at the time we didn't really understand why  
15 two surgeons were saying no, but the normal heart  
16 operation is you get the cut down here and they break  
17 a rib and go on. I wouldn't have survived that. But  
18 the third surgeon pioneered a new method of doing the  
19 operation required and I have a wee scar across my  
20 chest here, I don't know, maybe 3 inches. My heart  
21 was never on bypass and thankfully I'm still here  
22 today.

23 **MS FRASER BUTLIN:** What's the impact been on your  
24 daughter? Because throughout this time she was living  
25 with her grandparents --

1     **MRS Z:** Yeah.

2     **MS FRASER BUTLIN:** -- coming down when she could.

3     **MRS Z:** She was amazing. She kept us going, but there

4         was, as I say, at that point -- we had tried to

5         protect her. We had tried to -- we never lied to her,

6         we never told her lies, but we maybe didnae just put

7         everything right in front of her. But with the heart

8         surgery, we knew that we had to tell her. So I think

9         that was the hardest -- hardest night of our lives to

10        take her into that room and to explain to her what was

11        happening, that daddy might not be here. She's been

12        really strong. She absolutely adores her Dad, just

13        dotes on him. And she's -- she's been our rock.

14        She's kept it -- kept us going, but she has been

15        deprived to a certain extent of a normal family life,

16        because we didnae -- for that two-year period where

17        [redacted] was basically in hospital all the time, we

18        couldn't do anything as a family. As [redacted] says,

19        he would -- she would go to bed, she would wake into

20        a ambulance at the door having to wave daddy goodbye

21        in an ambulance. And so it's been really, really

22        tough on her but she's -- she's done amazing.

23     **MS FRASER BUTLIN:** Mr Z, you said in your statement that

24        it's is very upsetting and so you don't particularly

25        talk about it at home.

1 **MR Z:** I -- I don't talk about it. Maybe my wife does,  
2 but, no. It's gone. It's finished. It's in the  
3 past. You -- you move forward.

4 **MS FRASER BUTLIN:** Mrs Z, you stayed with Mr Z throughout  
5 and cared pretty continuously for him during that  
6 period, and you decided to leave your job to be able  
7 to do that.

8 **MRS Z:** I took a week -- a week? -- a year off work as  
9 I had parental leave that I could use. I used that.  
10 I used -- maxed out on my holidays, did everything,  
11 and then I asked to take time unpaid, so, yes, that  
12 was what I did.

13 **MS FRASER BUTLIN:** And at that point you also applied for  
14 carers' allowance.

15 **MRS Z:** Yes.

16 **MS FRASER BUTLIN:** Can you tell us what happened.

17 **MRS Z:** Well, there'd been -- so many people had said to  
18 us -- it was not something we'd thought about, but so  
19 many people had said to us, "You should apply for  
20 carers' allowance. You'll get it." So I went and got  
21 the forms.

22 And I went down to the -- I think it was the --  
23 well, it was the Citizens' Advice Bureau, completed  
24 the forms and said everything, and the lady looked at  
25 them and said, "You need to make the dark days

1 darker". And I said, "If this is not enough, then  
2 I won't have your carers leave" because I couldn't  
3 lie -- I couldn't make it any worse, I couldnae, and  
4 I certainly wasnae going to lie on forms to get carers  
5 leave, so we didn't get it.

6 **MS FRASER BUTLIN:** Mr Z, you'd kept your hepatitis C  
7 diagnosis a secret until you became seriously unwell.

8 **MR Z:** Yes.

9 **A.** Why was that?

10 **MR Z:** It's just I think, you know, I can handle this on  
11 my own. Almost made it but didn't quite. And we just  
12 wanted to keep it within the family. As I say,  
13 [redacted] was quite young and, again, hep C was  
14 supposedly restricted to, you know, certain types of  
15 individuals. We didn't want my daughter to get hassle  
16 at school and stuff like that, so we just said,  
17 "Right, we'll tell no one." But obviously when I fell  
18 ill, we had to own up, shall we say.

19 **MS FRASER BUTLIN:** And you've still not told very many  
20 people about your HIV.

21 **MR Z:** No. We've got friends here today and I thought  
22 I better tell them before they come in. So my best  
23 pal has only found out about two years ago that I'm  
24 HIV-positive.

25 **MS FRASER BUTLIN:** And again what stopped you telling

1 people?

2 **MR Z:** Again, just the stigma. I didn't want the  
3 sympathy of, "Oh, look at [redacted]". It's just not  
4 the type of person I am, so I'd rather just get on  
5 with life and survive.

6 **MS FRASER BUTLIN:** So you'd had to tell people because you  
7 got very unwell. You had the transplant. You had the  
8 heart operation.

9 **MR Z:** Mmm-hmm.

10 **MS FRASER BUTLIN:** What was your physical health like from  
11 that point until about 2008?

12 **MR Z:** Well, as I said, during the -- 2005, when I was  
13 first admitted to hospital, I think I probably should  
14 have got physio in my legs, because my right knee was  
15 stuck in the foetal position. So I was in  
16 a wheelchair or crutches. Eventually, in 2009, I got  
17 a right knee replacement. But also because of my  
18 mobility, I have arthritis in my left ankle now, plus  
19 I still had to build myself up. I'm 6 feet 3 and 5  
20 and a half stone, I just shouldn't -- shouldn't be  
21 there -- I shouldn't be here today. But I was  
22 determined. I had a lot to live for. I had to learn  
23 to walk again. But we got there, just through  
24 perseverance and my positive attitude to things.

25 **MS FRASER BUTLIN:** In 2008 you were told that the



1 hepatitis C had returned.

2 **MR Z:** Yeah.

3 **MS FRASER BUTLIN:** How did you feel when you were told  
4 that?

5 **MR Z:** I think we had a fairly good idea it was going to  
6 return anyway, simply because I hadn't completed the  
7 full 48 weeks of treatment. And it was kept under  
8 check. I mean, I can't complain about the NHS and the  
9 doctors, you know, from that point in. They were  
10 great. Kept a check on it. As I say, I don't think  
11 I would have taken interferon again. I just --  
12 there's no way I could have put myself through that  
13 again.

14 Not only that, because I was half the person I was  
15 as well, so I wouldn't have had the strength probably  
16 to -- to go through that again. But luckily there was  
17 a new treatment came out which I -- I went on and  
18 successfully now hep C negative.

19 **MS FRASER BUTLIN:** You had Harvoni treatment --

20 **MR Z:** Yes.

21 **MS FRASER BUTLIN:** -- in 2014?

22 **MR Z:** Yes.

23 **MS FRASER BUTLIN:** And what was that like?

24 **MR Z:** Compared to interferon, it was just night and day.  
25 The only real side effect I had was no energy --

1           apparently, I think, is it white blood cells that can  
2           reduce? So I had very little energy. So continued to  
3           work full-time throughout. How I managed that I have  
4           no idea. But it was difficult. I just had no energy  
5           to do anything. So, you know, I wasn't able to play  
6           sports or anything like that. And, I mean, I probably  
7           wasn't strong enough at that time -- I might have  
8           been, but, you know, that was out of the question  
9           because I couldn't walk to the bottom of my driveway,  
10          and it's not a long driveway, without being out of  
11          breath, shattered. No, it wasn't good health, but it  
12          was certainly better than the interferon.

13       **MS FRASER BUTLIN:** And can you tell us what your physical  
14          health is like now?

15       **MR Z:** Physical health now, it's probably as good as it's  
16          going to get. My knee now, we just got confirmation  
17          from the consultant about a month ago, due to various  
18          periods of inability, of not being able to walk,  
19          et cetera, there's a lot of scar tissue behind my  
20          patella and I only have now 8% movement in my right  
21          knee. I used to coach under-12s football and play  
22          football with them, but I've had to stop that because  
23          it's just too difficult.

24       **MS FRASER BUTLIN:** You'd actually returned to coaching the  
25          under-12s --

1 **MR Z:** Yes.

2 **MS FRASER BUTLIN:** -- just a few weeks after finishing the  
3 Harvoni treatment?

4 **MR Z:** Yes. I love my football. As I say, I played  
5 every sport apart from rugby. That's the only sport  
6 I didn't play. But had to give up the football  
7 coaching just in the last two/three months. But  
8 that's maybe an age thing as well, I don't know.

9 **MS FRASER BUTLIN:** You've talked about keeping a positive  
10 attitude.

11 **MR Z:** Yes.

12 **MS FRASER BUTLIN:** A positive mindset. Have you been able  
13 to do that since?

14 **MR Z:** You had to, yes. I'm a very positive person.  
15 I had a goal. I'll soon achieve that goal. That was  
16 the set of cards I've been dealt with, and you just  
17 had to get used to it and do the best you could.

18 **MS FRASER BUTLIN:** When we spoke earlier you talked about  
19 importance of your faith.

20 **MR Z:** Yes. People use the word "religious", I don't  
21 like that word. We have a faith and I believe I was  
22 in control of a higher authority than any doctor or  
23 consultant. And prayer is a very powerful thing and  
24 we certainly believe highly in it. When I was told  
25 I only had a few days to live, my wife texted everyone

1 in her mobile to say, "Please pray for [redacted]",  
2 and we find out that that text were being forwarded on  
3 to people in Russia, New Zealand, around the whole  
4 world. And if you've got the whole world praying for  
5 you, you've got a good chance of surviving.

6 **MS FRASER BUTLIN:** You've talked about work. Throughout  
7 this time until August 2018 you've tried to keep  
8 working.

9 **MR Z:** Yeah.

10 **MS FRASER BUTLIN:** And in fact you returned to work within  
11 weeks of being discharged from hospital after your  
12 transplant.

13 **MR Z:** I had my heart operation on 26 April and I was  
14 back at work in the end of July of 2007.

15 **MS FRASER BUTLIN:** But can you tell us a little bit about  
16 the impact all of this has had on your career.

17 **MR Z:** Yes. Just before I fell ill, I was up for  
18 promotion. I applied for one job but didn't get that  
19 one, but it was just a matter of time. I was being  
20 put forward by my bosses. But after that one attempt,  
21 I fell ill so I never, ever got the opportunity to get  
22 promotion.

23 When I did return in July, all the people that  
24 were below me were now either at the same level as me  
25 or higher and I -- you know, obviously when I went

1 back in 2007 and 2008, that's when the whole world  
2 sort of collapsed, so I never, ever got that promotion  
3 because the whole system was just flatlined. So  
4 I never, ever got that promotion. Although I got the  
5 title at the end of the day, I never got the financial  
6 reward for it.

7 **MS FRASER BUTLIN:** In August 2018 you were medically  
8 retired.

9 **MR Z:** Yeah.

10 **MS FRASER BUTLIN:** What happened?

11 **MR Z:** I was basically working ten/12 hours a day, seven  
12 days a week, and I just felt I couldn't do it any  
13 more. I wanted to be able to retire and enjoy it and  
14 do things, rather than waiting till something happens  
15 and retire and not be able to do anything. That's not  
16 really what I saw myself doing. I want to enjoy my  
17 retirement because [redacted] had worked 34 years and  
18 thought I deserved something.

19 **MS FRASER BUTLIN:** But financially your illnesses have had  
20 a significant effect on you.

21 **MR Z:** Yes. It's just things like, you know, when you  
22 fall ill -- I was in hospital for 364 days and, you  
23 know, if you take loss of bonuses, car parking, my  
24 wife had to move to Edinburgh for seven months, never,  
25 ever getting that promotion, just simple things like

1           that. Pension, you know -- I was on a fixed sum  
2           pension and that was capped by the time I -- so didn't  
3           get the benefit of certain pension rights as well, and  
4           that's not just on one year, that's for the rest of my  
5           life.

6           And financially it's just -- it's been a disaster.  
7           But we've coped. We've got a superb family network on  
8           both sides, and we've survived and will continue to  
9           survive but it's had a huge financial implication.

10       **MS FRASER BUTLIN:** You applied for financial assistance  
11       from The Macfarlane Trust.

12       **MR Z:** Yes.

13       **MS FRASER BUTLIN:** And at that time you have said in your  
14       statement that you had to sign something.

15       **MR Z:** Yes.

16       **MS FRASER BUTLIN:** What were your thoughts about that and  
17       what was it that you signed?

18       **MR Z:** Well, it was a disclaimer basically saying  
19       I wouldn't take any action against the NHS. Now, when  
20       you're 17/18, it's not -- you know, you don't really  
21       understand what you're signing and there was a sum of  
22       money being dangled out there, so you just took it  
23       because at that time, you know, HIV was huge. You  
24       didn't know if you're going to be still alive the next  
25       day or two days after or what. So I signed the

1 disclaimer and put it off and, yes, I got the sum of  
2 money.

3 **MS FRASER BUTLIN:** You've also had some financial  
4 assistance from The Skipton Fund.

5 **MR Z:** Yeah.

6 **MS FRASER BUTLIN:** What are your views of that process?

7 **MR Z:** It was -- I mean, the people before, you know,  
8 they've had difficulties. I basically filled in the  
9 form, gave it to my doctor, and it came back and it  
10 was given. But I don't think you could have argued  
11 how I landed up where I landed up. So, you know,  
12 whether he was asked to produce anything else --  
13 I mean, it was all relatively short-term and went away  
14 and it came back, but it's the only way I could have  
15 had what I had was through infected blood.

16 **MS FRASER BUTLIN:** Those are the questions I have for you.  
17 Is there anything else you'd like to say?

18 **MR Z:** I think I'd like to say this is not about money.  
19 The NHS has been fantastic for me but it also gave me  
20 a very, very deadly disease, not once, not twice, but  
21 possibly a third time with the variant CJD. So my  
22 wish is that someone just sits in front of me and  
23 says, "We're sorry. It's our fault. We made a huge  
24 mistake and I'm sorry, and it will never, ever happen  
25 again."

1           That's all I would want, just someone to take  
2           ownership that somebody made a huge cock-up, for want  
3           of a better word, somehow and it shouldn't happen.  
4           Nobody should have to go through -- I always say I'm  
5           one of the lucky ones; I'm still here. There's  
6           hundreds not here, and that's why it's so important  
7           that this never happens again.

8   **MS FRASER BUTLIN:** I'm just going to turn and see if  
9           Mr O'Neill has anything he'd like me to raise with  
10          you.

11          No, there's nothing further.

12   **SIR BRIAN LANGSTAFF:** I feel very glad that you will be  
13          here in August, at the end of August.

14   **MR Z:** Thank you.

15   **SIR BRIAN LANGSTAFF:** Your resilience is amazing and thank  
16          you for being here, both of you, to give the evidence  
17          that you have.

18   **MR Z:** Thank you.

19   **SIR BRIAN LANGSTAFF:** Thank you.

20   **MR Z:** Thank you.

21   **SIR BRIAN LANGSTAFF:** 10 o'clock tomorrow.

22   **MS FRASER BUTLIN:** Thank you, sir.

23   **(5.08 pm)**

24           **(Adjourned until 10.00 am the following day)**

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