

Friday, 7 June 2019

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(10.33 am)

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

MS FRASER BUTLIN: That's correct, sir.

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

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

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

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

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

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

7 Q. It was complicated by septicaemia?

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

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

14 A. Absolutely.

15 Q. But you did.

16 A. Yes.

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

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

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

8 A. Okay.

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

11 A. Yes.

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

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

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

23 A. I did.

24 Q. Then subsequently returned to the UK?

25 A. Yes.

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

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

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

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

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

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

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

1 raised blood pressure --

2 A. Indeed.

3 Q. -- since your admission with the pneumonia?

4 A. Yes.

5 Q. You went to a GP and you were having medication for

6 that high blood pressure?

7 A. Mm-hm.

8 Q. Your GP in 1999 recommended a blood pressure research

9 project that she thought you might be interested in?

10 A. Absolutely, I was diagnosed with high blood pressure

11 when I was in Maidstone University. I think I was

12 about 25, which is pretty young to be on blood

13 pressure tablets, and my diligent GP back in south

14 London said, you know, "What is all this. Let's try

15 and get you off the drugs. There happens to be

16 a research thing going on at St George's Hospital.

17 I'd like you to get involved", so I joined it.

18 I thought that would be a interesting, let's try and

19 find out what this blood pressure's all about.

20 Q. What did that research project involve?

21 A. It involved a change of diet, lowering salt, lots and

22 lots of blood tests and a lot of investigation of you

23 know measuring and -- yes, regular visits and, you

24 know, general overall of my health, really.

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

1 test, wasn't it?

2 A. Yes.

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

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

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

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

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

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

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

7 A. Not very much actually. Not very much at all.

8 I moved from the blood pressure research department to
9 a liver specialist and I think had to wait, and you'll
10 probably have to remind me, from diagnosis I then had
11 a specific test for hep C, but from diagnosis and then
12 waiting to see a liver specialist I think took four
13 months; is that right? Does it say four months?

14 Q. You were formally diagnosed with hepatitis C on
15 22 June 1999 but not referred to the liver clinic
16 until October 1999 and then your statement indicates
17 you had the liver biopsy in February 2000.

18 A. Yes, all of that is true.

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

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

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

11 A dreadful mess and fear, just fear and frightened of
12 my mortality, actually.

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

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

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

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

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

2 MS FRASER BUTLIN: Can we stop the transmission.

3 (Pause)

4 We are fine to start the transmission again.

5 I had asked the question that part of the reason you
6 were particularly concerned was that you hadn't been
7 given a huge amount of information about the risks of
8 transmission.

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

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

25 A. Yes.

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

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

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

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

18 A. Yes.

19 Q. It was available but more expensive.

20 A. Yes.

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

23 A. Yes, absolutely, and I had to wait for that too.

24 Thanks for reminding me.

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

1 intervene.

2 A. Yes.

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

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

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

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

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

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

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

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

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

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

7 Q. What was the effect on your mental health?

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

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

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

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

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

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

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

25 Q. Your treatment lasted a year?

1 A. Yes.

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

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

11 Q. What was your reaction?

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

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

21 A. Absolutely.

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

23 A. I wanted the pegylated interferon next because that
24 was available and I knew it existed and there was
25 a better chance. I had genotype 1, which was the

1 hardest one back in the day to get rid of and when
2 I took the original interferon and ribavirin treatment
3 I think I only had about 35/40 per cent chance of
4 getting rid of it and, of course, it came back which
5 is where we are in the narrative. But I think the
6 pegylated had about a 50 per cent chance, so I thought
7 I had a -- well, if I'd sort of shifted hep C in the
8 first round of treatment, maybe the 10 per cent will,
9 you know, absolutely get rid of it. That was what
10 I wanted.

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

13 A. Absolutely.

14 Q. But there was a wait for funding again.

15 A. Again, yes.

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

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

24 Yes, you know, I also you know had to get myself
25 in the position of daring to hope that the next

1 treatment would make a difference, would make
2 a difference, really. Still determined to do it but
3 at the same time taking a little bit -- taking the
4 pressure off myself a little bit and just trying to
5 get the treatment and let it do its work really, let
6 it do its thing.

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

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

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

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

24 A. Yes, that was -- I was slight wary about both of those
25 results in the sense of it had happened to me before,

1 getting bad news. It was almost -- the further -- you
2 go clear of hep C and the further away you get from it
3 the more pressure comes on you to -- because it can
4 come back or it came back for me so, yes, even going
5 to get results was terrifying, even though my nurse
6 specialist was amazing, so supportive, and cried and
7 hugged on the nine month afterwards but then, of
8 course, you get another one a few months later and
9 then you get a two year clear one as well so it
10 carried on.

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

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

17 There weren't that many incidents I don't think
18 but I remember one in particular where we were going
19 up to town. We tried to live a kind of as normal life
20 as possible. We use London to its maximum. We are
21 out and about, rather ironically I took my last
22 injection of interferon in a toilet in a theatre in
23 North London. We kept going. You know, we were
24 trying to go out, trying to keep everything as normal
25 as possible and just taking it a bit easy, but I do

1 remember being a complete monster to her on the tube,
2 completely outside my character, certainly outside my
3 love for her, and the person that kind of knew what
4 I was going through and was closest to. You know,
5 I was a monster to her on the tube. I think we got
6 over it.

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

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

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

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

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

1 hospital, which I kind of ran with her.

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

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

12 A. I suppose I have been extraordinarily torn for
13 30 years. I'm in this limbo middle ground with it
14 because the blood has saved my life, okay, the
15 original blood with pneumonia has saved my life and
16 yet it ended up killing me. It's ended up killing me
17 again. It's ended me up here.

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

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

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

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

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

20 Please can we have on the screen document
21 0148006 and the first main paragraph which says:

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

1 receiving a blood transfusion whilst a patient in the
2 hospital. I understood from you that [Mr L] believes
3 he was transfused in 1991 at St Helier Hospital and
4 that no other risk of hepatitis C infection had been
5 identified apart from minor surgery in France in
6 1985."

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

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

12 Were you informed of that at the time?

13 A. No.

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

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

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

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

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

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

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

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

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

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

24 The lady at the end of the phone said, "Okay,
25 I'll go and have a look for them and I'll call you

1 back". She phoned me back a couple of days later and
2 said, "Actually, I have found them, Mr L. There's
3 quite a lot of them. What do you want", and I said,
4 "Actually, I'd like them all please", and she said,
5 "Well, it's £1 a copy. It's £1 for a copy and the
6 limit is £50". I said, "Well, I'll have the lot".

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

9 Q. A full lever arch of documents.

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

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

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

23 A. Absolutely, yes, and there's more of those. There's
24 160-tabs, tickets like that, that I have photocopied
25 that I have in that file. That's what came through,

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

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

14 A. Absolutely, yes.

15 Q. Dr Hewitt has responded to your statement and said
16 this in relation to the letter she had written in
17 1999. She says this:

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

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

12 How would you respond to that?

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

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

1 006.

2 MS FRASER BUTLIN: It is.

3 SIR BRIAN LANGSTAFF: That talks about a transfusion in
4 1991. You I think described to us a transfusion in
5 1990. Do you know where the 1991 might have come
6 from?

7 A. No idea whatsoever, a dreadful error.

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

10 MS FRASER BUTLIN: No, sir.

11 SIR BRIAN LANGSTAFF: Thank you.

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

14 A. Absolutely.

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

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

20 SIR BRIAN LANGSTAFF: Thank you.

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

25 A. Yes.

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

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

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

13 A. Yes.

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

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

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

25 A. Yes.

1 Q. -- that you had had.

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

5 MS FRASER BUTLIN: Thank you, sir.

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

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

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

13 A. Can I add a little bit?

14 Q. Of course. Please do.

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

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

23 "I admit to certain confusion as none of these
24 relate to September 1991", because of course they were
25 from the correct date of when you'd actually received

1 them but more importantly when we go over the page to
2 the final paragraph it says this:

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

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

9 A. Absolutely.

10 Q. "These would not October have been anti-HCV tested as
11 routine screening of blood donations was introduced
12 only in September 1991. This being the case, it's
13 possible that [Mr L's] hepatitis C infection
14 originated from unscreened blood transfused prior to
15 the onset of routine screening. We would not in this
16 situation attempt to carry out any investigation into
17 the donors, for more than 15 years has elapsed since
18 these donations were given. If any of the donors had
19 returned after the introduction of routine screening,
20 they would have been identified and a look back
21 carried out for recipients of previous donations. As
22 [Mr L] has not been identified through the hepatitis C
23 look back we can assume that if any of the donors were
24 infected with HCV they have not returned to give blood
25 and, therefore, their status remains unknown to us.

1 There is very little to be gained now from attempting
2 to contact such donors considering the long amount of
3 time that has elapsed since the donations were given."

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

9 A. Yes, that is right and also it's kind of clear to me
10 here when I read it, when she's it written the
11 15 years has elapsed, we have to remember the
12 time-line is four and a half or five years before that
13 I put forward that I had hepatitis C from blood
14 transfusions. So actually it's taken, you know, it's
15 taken four and a half/five years for her to write that
16 back which I would be under the 15 years elapsed
17 point, wouldn't I, it seems to me.

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

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

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

25 She says that her letter to the treating doctor

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

14 Is that an explanation you accept or agree with?

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

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

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

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

13 SIR BRIAN LANGSTAFF: Thank you.

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

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

21 **(Pause)**

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

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

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

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

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

21 A. Yes.

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

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

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

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

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

21 A. I'd to thank everybody for finally being interested.
22 It's become a part of me but at the same time it's
23 identified me, made me who I am; so that's again part
24 of the conflict. I'll thank my wife. She's been
25 extraordinary and if she hadn't said buy the

1 notes ... I just hope that I continue to listen to her
2 for the next 20 years really because she's been
3 amazing.

4 Thank you, everyone.

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

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

8 A. Wifey.

9 SIR BRIAN LANGSTAFF: We will take a break until
10 12 o'clock and at 12 o'clock we have ...?

11 MS FRASER BUTLIN: Maria Fletcher.

12 SIR BRIAN LANGSTAFF: Thank you.

13 **(11.29 am)**

14 **(A short break)**

15 **(12.12 pm)**

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

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

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

1 MS RICHARDS: Maria.

2 SIR BRIAN LANGSTAFF: Maria, please.

3 **MARIA FLETCHER, sworn**

4 **Questioned by MS RICHARDS**

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

7 A. Yes.

8 Q. Could you tell us what that is?

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

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

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

20 A. Yes.

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

23 A. Yes. I can't, as you said, I can't produce red blood
24 cells so I need -- my body -- well, I need blood
25 transfusions to help me to move around, otherwise, if

1 I don't have the blood transfusions my energy levels
2 are very low, non-existent and I would probably die.

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

6 A. Yes.

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

9 A. That's correct.

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

12 A. Yes. Basically, because blood's got a lot of iron, it
13 affects all the major organs in your body. So through
14 over the years at the age of 5 I started having
15 injections, and then from injections they were
16 24 hours long over a period of five/six days a week to
17 get rid of the excess iron in my body because, as
18 I said, it affects the heart and most of my other
19 organs.

20 Q. You've also have regular liver biopsies?

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

1 Q. You've produced a document that relates to one such
2 biopsy. We'll have it on screen, please, Paul. It's
3 1876003.

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

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

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

14 A. Yes.

15 Q. Why is that?

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

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

25 A. Yes, that's correct.

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

5 A. Yes.

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

9 A. Yes.

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

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

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

24 A. At that time, yes.

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

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

3 A. No.

4 Q. You were told of your hepatitis C diagnosis in early
5 1990, as far as you recall.

6 A. Yes.

7 Q. What can you remember about that?

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

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

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

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

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

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

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

18 That's January 1990 that that is being
19 identified.

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

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

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

5 A. Yes.

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

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

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

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

1 to happen at outcome of it.

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

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

8 A. Yes.

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

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

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

25 A. No.

1 Q. Then you have said this:

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

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

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

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

24 A. Yes. You know, I've lived with thalassaemia, I've
25 lived now with hepatitis, that I've cleared it up

1 finally, but you don't know what's around the corner
2 because there's always going to be something I fear
3 that it could be either from having a blood
4 transfusion or just something that my body needs, you
5 know, the requirements that I need to go through in
6 life, I think.

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

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

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

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

16 A. Yes.

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

20 A. Well, physically, as I said, very tired and, you know,
21 living with two conditions, thalassaemia major and
22 hepatitis, it was quite stressful for my body and the
23 treatments that I've had to go through and the effects
24 that those treatments have caused me, which were
25 terrible, and I had to give up work because of the

1 treatments, hepatitis C. You know, I had a very good
2 job with a big cosmetic company and then being
3 diagnosed with hepatitis C and then, you know, during
4 the time that I was working I had to start treatment
5 and treatment wasn't given to me straight away when
6 I was diagnosed. I waited a few years. By that time,
7 I started getting cirrhosis of the liver and the
8 treatments affected my life.

9 Q. You've undergone five courses of treatment.

10 A. Yes.

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

12 A. Yes.

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

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

1 come back. It was undetected during the treatment and
2 then three months later it had come back.

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

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

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

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

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

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

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

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

18 A. Yes.

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

21 A. Yes.

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

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

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

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

9 A. Yes.

10 Q. That treatment has cleared the virus.

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

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

6 I was checking -- keep doing my bloods and I was
7 always constantly aware that I might drop some blood
8 and infect my family. And, so, yeah, going back to --
9 yes, so basically I needed to clear up hepatitis C and
10 I went to see -- I was referred to the hepatologist in
11 Leicester and he did me a fibroscan and -- which I've
12 never had in London before and he goes, "Oh, we need
13 to check, it's not as bad as having a biopsy", which
14 I thought great, so I had a fibroscan and went back to
15 see the doctor after the scan and he goes to me,
16 "Well, I've got good news for you, your fibroscan
17 shows that your 6 and you're not 12. Anything above
18 12, that's when we consider giving treatment, would
19 give you Harvoni, but we feel that it's not needed
20 because you haven't got so much liver damage".

21 And, well, I go to him, "I don't understand that
22 because I've had a number of biopsies showing grade 1,
23 genotype 1, grade 1 hepatitis, cirrhosis of the
24 liver", and he goes, "Oh, your liver's, probably
25 because you've been doing your DESFRA, the iron

1 collation, probably because you've been doing that
2 more it's made your liver better", and I go, "Well,
3 no, because I've been diagnosed as severe cirrhosis of
4 the liver", and then I went home, looked on about
5 fibroscans and they're not as -- they're not -- the
6 results aren't as great as a liver biopsy.

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

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

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

24 A. Yes.

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

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

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

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

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

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

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

1 totally and utterly drained me."

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

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

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

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

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

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

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

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

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

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

23 A. Yes. You know, I had to be constantly making sure
24 that she doesn't use my razor blade because, you know,
25 but then now I move my razor blade so she can't touch

1 it. You know, she might accidentally get my
2 toothbrush.

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

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

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

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

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

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

3 A. *(The witness nodded)*

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

6 A. *(The witness nodded)*

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

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

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

25 So it was a struggle. I was living on my

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

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

9 A. Yes.

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

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

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

1 A. Yes.

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

7 A. Yes.

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

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

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

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

25 A. Yes. That's the requirement for them that you provide

1 a supporting letter to state that my pains, my
2 neuropathy is likely caused by hepatitis C, which
3 I believe it does, because I've never had this kind of
4 problem before and it's only since coming off Harvoni
5 that I've started to develop these problems, and
6 they're not little pains, they're quite, quite bad and
7 anyway I sent that letter and they replied back with
8 another letter saying that they want more specific
9 details.

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

12 A. Yes.

13 Q. It is 1876012, please, Paul.

14 It says this:

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

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

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

14 A. Yes.

15 Q. How does that make you feel, Maria?

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

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

1 you say you:

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

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

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

20 A. Yes.

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

24 A. Never, never.

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

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

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

13 A. Yes.

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

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

24 Q. You've also said in your statement that when you
25 attend the hospital, you feel that there are constant

1 reminders of your infected status.

2 A. Yes, even now.

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

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

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

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

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

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

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

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

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

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

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

21 So I feel that they're not doing that.

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

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

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

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

17 MS RICHARDS: Thank you.

18 Sir, do you have any questions for Maria?

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

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

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

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

3 SIR BRIAN LANGSTAFF: Graham Manning, 2.15.

4 **(1.07 pm)**

5 **(Luncheon Adjournment)**

6 **(2.18 pm)**

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

9 MS RICHARDS: Sir, yes, Graham Manning.

10 SIR BRIAN LANGSTAFF: Graham, please.

11 **GRAHAM MANNING, sworn**

12 **Questioned by MS RICHARDS**

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

15 A. That's correct.

16 Q. Can you tell us what happened?

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

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

21 A. I was in the playground, playing football and I fell
22 over in the playground and my knee started swelling up
23 and it started to ache and it wouldn't go down, and
24 I remember distinctly coming home from school and
25 I was limping and it just wouldn't stop. It just

1 burnt, really, really burnt and I knew there was
2 something wrong, my parents knew there was something
3 wrong.

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

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

12 A. That's correct, yes.

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

16 A. That's correct, yes.

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

19 A. Well, this was in 1978, May 1978, and the doctor,
20 [redacted], he was a very nice man, quite a young guy,
21 and I had -- my Mum had Dad had bought me a Star Wars
22 poster. I was a big Star Wars fan then, as I am now,
23 and basically they said -- well, the doctor said, "Oh,
24 great Star Wars poster. That's fantastic", [redacted]
25 said, "let's put this up on the wall here", and he put

1 it up and then he turned round and said to me,
2 "I love Star Wars", I said, "I do as well, it's
3 fantastic", and I said -- he then turned round and
4 said to me, "Well, this new medicine you have, this
5 new treatment that we're going to give you it's from
6 America". That's why I remember it.

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

11 A. Yes.

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

15 A. That's correct.

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

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

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

4 A. That's correct, yes.

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

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

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

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

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

21 A. Oh no.

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

24 A. Correct, yes, exactly, the actual Factor IX itself
25 because they thought I was deficient in Factor IX and

1 actually given me Factor IX, somehow that would be
2 dangerous because I didn't need it.

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

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

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

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

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

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

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

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

9 A. That is right, yes.

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

12 What can you recall about that?

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

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

22 A. Yes.

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

1 A. That's correct, yes.

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

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

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

10 It's 1367003, please, Paul.

11 We can see the date of that letter, Graham,
12 4 August 1992, it's addressed to you from the
13 consultant haematologist at the Lewisham Hospital
14 Haemophilia Centre and it says:

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

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

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

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

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

10 What can you recall thinking when you received
11 this letter?

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

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

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

23 A. That's correct.

24 Q. So you thought it was a standard letter?

25 A. Yes.

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

3 A. Yes.

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

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

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

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

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

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

24 "Dear patient, the accompanying bulletin
25 contains important information. Please read it

1 carefully. If there's anything you wish to discuss
2 further please contact the centre."

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

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

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

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

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

20 A. No, I haven't, no.

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

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

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

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

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

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

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

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

22 A. No.

23 Q. If we can have up on screen, please, 1367005, this is
24 an extract from your medical notes, Graham,
25 23 October 1995, it's a reference to haemophilia A,

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

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

7 A. Not at all, not at all.

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

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

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

24 Q. If we go back to that same document please, Paul,
25 1367005, the bottom of the page, we can see that it

1 there says:

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

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

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

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

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

23 A. Yes, that's right, yes.

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

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

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

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

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

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

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

10 "You, all right?"

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

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

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

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

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

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

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

17 A. No, not at all.

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

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

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

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

8 A. Yes.

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

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

1 someone was from the start. I was very, very
2 conscious of that.

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

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

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

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

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

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

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

5 A. Yes.

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

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

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

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

25 "Every single day I would think about having

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

3 A. Every day.

4 Q. You couldn't tell anyone at work.

5 A. No.

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

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

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

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

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

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

23 A. Yes, it was like that. I'd go along for another liver
24 function test. It was a blood test. You'd go along,
25 you have this test, go on to the next one, you have

1 the other test and it was like that, like you were
2 being herded through a systems, and sometimes they
3 actually went, "Oh, what are you here for again?"

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

6 "Liver function test."

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

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

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

24 A. Yes, because you felt you were on your own. You felt
25 you were on your own. You didn't think that anyone

1 else had been tarnished with this and, it's
2 interesting, I used to go that thought in my mind when
3 you used to see people sitting in the waiting room,
4 I used to think to myself, "I wonder if they have got
5 hepatitis C", because it was a Haemophilia Centre so
6 people went there for all sorts of things and so that
7 was, yeah, that was something I used to think of
8 a lot.

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

11 A. That's right.

12 Q. In the autumn of 1996 you underwent treatment?

13 A. Yes.

14 Q. What can you tell us about that?

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

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

1 Q. You weren't responding?

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

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

5 A. Yes, yes.

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

11 A. That's okay.

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

23 The last six months of that treatment was the
24 hardest thing I have ever done in my entire life.
25 I was holding on to the fact that the virus itself had

1 gone but it was so awful. I had scabs on my head, my
2 mood swings were terrible. I turned into this
3 monster. The flu-like symptoms, and when I say
4 flu-like symptoms, it was like a raging torrent of you
5 feel ill all the time. I'd find that getting worse
6 actually in the afternoons after I had something to
7 eat. I would be at work. I'd feel absolutely
8 terrible. I was sitting at my desk feeling absolutely
9 lousy and, of course, no-one knows what's wrong with
10 me.

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

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

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

1 well done".

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

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

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

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

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

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

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

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

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

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

25 Q. Graham, you started taking medication for your

1 depression in about 2008?

2 A. Yes, that's right, yes.

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

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

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

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

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

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

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

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

1 resulted in your gallbladder having to be removed.

2 A. That's right, yes.

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

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

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

8 A. Yes.

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

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

20 I can't remember seeing the second letter but
21 I looked at my notes and it's from, not sure,
22 2008/2009, not sure, but that's when my marriage was
23 falling to pieces anyway, so if I had seen it or it
24 had been -- I wasn't in a right place, again, to even
25 look at that.

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

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

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

1 that I think it was 2001, I think, I might be wrong,
2 2001 I think it is, and that does he know and it says
3 no.

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

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

9 A. Yes.

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

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

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

1 clearing the virus.

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

5 "What's that?"

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

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

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

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

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

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

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

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

14 Q. How was it?

15 A. The actual treatment itself was tablets, Zepatier, so
16 you take one tablet a day and it went on for 12 weeks.
17 The side effects were, how can I put it? Nothing like
18 interferon, absolutely like interferon at all.

19 I would have like -- you could tell between the
20 flu-like symptoms I'd been having for years and when
21 I was actually on the Zepatier treatment. It was
22 different in that respect but the only biggest thing
23 I noticed was the heart problems I had.

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

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

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

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

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

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

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

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

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

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

7 A. That's right.

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

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

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

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

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

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

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

22 Q. You mentioned you had had some counselling?

23 A. Yes.

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

1 the help of local mental health services?

2 A. Yes.

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

4 A. Yes.

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

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

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

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

23 A. Yes.

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

25 A. It's just a long-winded, laborious process which is

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

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

16 A. Yes.

17 Q. That's how you felt about it.

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

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

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

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

8 A. Yes, if I may.

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

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

25 When you look at how we got infected and you

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

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

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

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

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

20 It's also the pharmaceutical companies. 1970s,
21 1980s Cutter was the biggest producers of Factor VIII
22 and Factor IX in the world. Bayer, as I know now,
23 basically took over Cutter. They have
24 a responsibility, as well as the other pharmaceutical
25 companies, as well as the Government, to do something

1 now.

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

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

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

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

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

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

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

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

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

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

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

1 That's all I wanted to say.

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

4 Thank you, there's nothing.

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

8 A. Thank you, sir. Thank you.

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

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

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

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

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

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

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

12 **(3.40 pm)**

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

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