

Monday, 8 July 2019

(10.05 am)

SIR BRIAN LANGSTAFF: Our first witness this morning is Maria. Her daughter may wish to say something so she will be sworn in too.

MS FRASER BUTLIN: That's correct, sir.

SIR BRIAN LANGSTAFF: Maria.

MARIA ARMOUR, affirmed

LAURA BROWN, affirmed

Questioned by MS FRASER BUTLIN

Q. Maria, you're here to talk about your infection with hepatitis C.

A. I am.

Q. In 1981, you had a miscarriage. What can you tell us about that?

A. I'd been to the doctor's a couple of days before for a blood pregnancy test, but shortly after leaving the doctor's, I started bleeding. So I was bleeding for a few days, in quite a lot of pain, but because I was used to bleeding heavy I just assumed it was my period had come. So when I went back into the doctor's, I was quite surprised when he said you were pregnant and he would need to get an ambulance and I ended up, up at the Samaritan.

Q. You ended up at the Samaritan's Women's Hospital in

1

the hospital wrote to your GP and we've got that letter -- it's 2076002, please, Paul -- and it will come up on the screen.

We can see in the first paragraph a discussion about the miscarriage, but there's no reference in the letter to you having received a blood transfusion. But your clear recollection is of waking up and finding you were having a blood transfusion?

A. Uh-huh.

Q. And then in 1983 you were admitted to the hospital again with an unknown infection?

A. Uh-huh.

Q. What happened then?

A. That was Hogmanay. I was -- I felt -- I thought it was a cold at first. My temperature went up quite high. I'd stomach pains and I got took in, admitted in, kept in for a few days.

Q. And you've said in your statement that you're not sure if they were the first signs of the hepatitis C manifesting themselves, or if they were simply other infections?

A. Uh-huh.

Q. But to you they seemed a bit strange?

A. Yes.

Q. From the time of your transfusion until you had your

3

Glasgow.

A. Uh-huh.

Q. What do you remember at about being at the hospital?

A. I don't remember much about going in because I just remember being terrified that my mum would find out.

Q. Because you were very young at the time?

A. Because nobody knew I was pregnant, nobody.

Q. And you remember the next day waking up and --

A. I had a bag of blood, and the nurse was telling me to flick it if bubbles or something came in, and that was that.

Q. Before you received that blood, were you advised about any risks of receiving it?

A. No.

Q. You had to stay in hospital after that transfusion for about a week?

A. Uh-huh.

Q. About seven days. Why was that?

A. Because the next day I took a very high temperature, and they had to give me antibiotics to try and bring it down.

Q. It was thought that you had a chest infection, but it wasn't very clear why you were unwell at that stage?

A. No.

Q. When you were discharged from hospital, the doctor at

2

two daughters, what was your physical condition like? How did you feel physically?

A. Well, I'd started to experience joint pains, skin irritations that got worse when I had my first daughter. I found I struggled to carry her, and she was quite big and it was a struggle with her, and then the joint pain just seemed to get worse from then on and the skin irritations, constant.

Q. You said in your statement you got very tired and fatigued and you had some gastro difficulties and bowel problems.

A. Yes.

Q. You were working at a residential unit for the elderly during some of that time. What happened when you were there?

A. Well, it was a dementia unit which was quite challenging. It was all like heavy lifting. There was a lot of physical work. I was not physically capable of doing it and I also had a lot of hospital appointments then. I didn't realise that you were allowed time off for hospital, so I was taking it as time off and they said it was too many absences due to ill health, and they never renewed my contract.

Q. So you lost your job at the residential unit at that point.

4

1 A. That was a week before my diagnosis.
 2 Q. In 2002 you were referred to see a gastroenterologist
 3 because you had ongoing diarrhoea and bowel problems.
 4 What happened when you went to see them?
 5 A. They just kept doing tests, every test for my stomach
 6 problems. I still tried to keep going with my work at
 7 that time, and they were testing me. I was working
 8 with adults with learning disabilities and I think it
 9 was kind of brain fog and that because I was
 10 responsible for medications and things, and I was kind
 11 of worried that I wasnae doing my job the way I could
 12 have been.
 13 Then I just kept going back to the hospital to
 14 try and find out why I was having bowel problems.
 15 Q. You had a number of blood tests during about two
 16 years, and then towards the end of those two years
 17 were you told at any point you were going to be tested
 18 for hepatitis C?
 19 A. Never.
 20 Q. And what did you worry that you might have during that
 21 time?
 22 A. Cancer.
 23 Q. Your fear was that it was some form of bowel cancer --
 24 A. Uh-huh.
 25 Q. -- that they couldn't find?

5

1 a few years back, I can remember", and then I thought
 2 I just started crying, and I went to ask him something
 3 but he wasnae looking at me. He was facing this way
 4 (*indicated*). I was sitting here, and he was just on
 5 his computer rhyming off all the blood tests to the
 6 nurse behind him, and she just said to me to come out
 7 with her, and that was the last I seen him.
 8 Q. How much information at that stage were you given
 9 about what hepatitis C was?
 10 A. He never gave me any information, but I knew because
 11 in my training, obviously.
 12 Q. So you had done some training in social and health
 13 care?
 14 A. Uh-huh.
 15 Q. So how did you find out and what did you understand
 16 hepatitis was?
 17 A. Well, when we covered it through my HNC, it was HIV
 18 and related illnesses, which was A and B. We never
 19 really touched on hep C because there wasnae much
 20 known about it then. What we got told then was it was
 21 mainly through drug addicts. They did touch upon
 22 transfusions but said it was very rare for somebody to
 23 get it like that. That's what we were taught. It was
 24 more the focus was on HIV and AIDS. But what I was
 25 worried about, because my symptoms were the same, is

7

1 A. Uh-huh.
 2 Q. Could we have document 2076007, please, dated
 3 July 2005 and it's a letter from your
 4 gastroenterologist to the GP, and in it it says:
 5 "Importantly, her hepatitis C PCR is positive
 6 suggesting that she has hepatitis C as a cause for her
 7 abnormal liver function tests."
 8 That's July 2005. Were you told at that
 9 point --
 10 A. No.
 11 Q. -- that you'd tested positive?
 12 In October 2005 you attended another appointment
 13 at the hospital. What were you expecting the
 14 appointment to be like?
 15 A. I was -- I was expecting to go in and them tell me it
 16 was just the stress, it was IBS, that's -- because
 17 what I -- I thought he was going to say, "You've no
 18 got cancer but it's IBS. It's just stress".
 19 Q. And what happened at the appointment?
 20 A. I was shouted into his office and I went in and he was
 21 sitting with a nurse and he said, "I've got good and
 22 bad news. Good news, you've no got cancer. Bad news,
 23 you're hep C positive. Any idea how you could have
 24 got it? Drug use? Partners?"
 25 I said, "No, I had a blood transfusion but ...

6

1 like the end stages of AIDS with the sores appearing
 2 in the body, diarrhoea, et cetera, all that, so that's
 3 what I was worried about. I thought I was at the end
 4 stages of that, and they were just maybe no telling
 5 me.
 6 Q. So until you had the diagnosis of hepatitis C you were
 7 worried you might have cancer?
 8 A. Uh-huh.
 9 Q. Or were you worried --
 10 A. Or have AIDS.
 11 Q. -- you might have AIDS --
 12 A. Uh-huh.
 13 Q. -- and then you were told in October 2005 it was
 14 hepatitis C.
 15 A. Uh-huh.
 16 Q. How did you feel at that point when you were given the
 17 diagnosis?
 18 A. Devastated. I knew it was end of my career.
 19 Q. I should say at this point that a response has been
 20 sought from Dr Boulton-Jones and anything that's
 21 received will be published on the website in due
 22 course.
 23 The evening after you got your diagnosis you
 24 were in such a state that you decided to phone the
 25 Samaritans and the impact on you mentally has been

8

1 quite significant since then?

2 A. Uh-huh.

3 Q. Can you tell us a little bit about that.

4 A. Well, I'd went to the doctor a couple of days later,

5 Judy and Laura was struggling, my daughters were

6 struggling, I was struggling, and within a few days

7 I was, like, thinking about people I could have

8 infected through the years, how long that -- how many

9 times I could have infected people and I was having

10 horrible dreams. The guilt I felt was terrible and

11 I was saying, "Who do I tell? Who do I don't tell?"

12 So I went to my GP and I said, "I'm no coping".

13 I says, "I need to speak to somebody. I need to ask

14 if what I'm feeling's right", and she said, "Nobody

15 will entertain you. You'll no see a counsellor. I'll

16 send you to stress management, you're just stressed,

17 and why you don't go home and find out how you caught

18 it?"

19 And I went home a couple -- she phoned me that

20 day at half 4, the doctor. She says, "Look, I've

21 checked. You got a blood transfusion in 1981. That's

22 where you got it".

23 And then a couple of days later I took

24 an overdose.

25 Q. You've said in your statement that at that stage you

9

1 I was scared in case I gave her hep C. When I seen

2 the blood, I kind of freaked out, so from then I just

3 wanted rid of it, the virus, and that was my focus.

4 Q. At that point you felt that you needed to stop

5 babysitting for the nieces and nephews --

6 A. Uh-huh.

7 Q. -- because you were very worried about infecting them.

8 The fact that you had hepatitis C did become

9 public knowledge and in your statement you've talked

10 about an occasion when you went to the pub.

11 A. Uh-huh.

12 Q. Can you tell us about that?

13 A. I was asked -- I went outside for a smoke and one

14 suddenly come out and stood with me. She says,

15 "They're speaking and they're saying they're no quite

16 happy drinking out of the same tumblers as you".

17 Q. And what happened when you went back in?

18 A. I can't tell you what I said.

19 Q. Your daughters also had difficulties at school. What

20 can you tell us about that?

21 A. Well, I think they were getting their mum's a drug

22 addict. Jade was already having problems at school,

23 bullying, so the two of them just stopped going

24 eventually. I went to their schools. I went to their

25 head teachers. I begged them for help. I says, "They

11

1 wanted to end your life.

2 A. Uh-huh.

3 Q. You wanted to go to sleep and not wake up, but your

4 daughter found you, called for an ambulance and you

5 were taken into hospital.

6 A. Uh-huh.

7 Q. Did you tell your family about the hepatitis C?

8 A. Yeah.

9 Q. What was their reaction?

10 A. They were devastated, but can I just say I never felt

11 ashamed, ever, of having it. So I wasnae scared to

12 tell anybody. I never kept it a secret, because

13 I didnae feel ashamed, ever, and I've never felt

14 ashamed about it. It wasnae my fault.

15 Q. But you did feel that it affected your relationship

16 with your nieces and nephews.

17 A. Yeah.

18 Q. Of whom there are quite a number. In what way did it

19 affect that relationship?

20 A. I couldnae kiss and cuddle them. I was scared to be

21 left alone in case they cut themselves. I had one

22 incident where I was left with my wee niece, my

23 niece's baby, and she fell, I went into pure panic.

24 She was only one. She had fell off the bed and cut

25 her lip. I didnae want to lift her or touch her.

10

1 need help. I need help." They were nae interested.

2 Q. In 2007 your long-term relationship also broke down,

3 and during this time you had started a university

4 course --

5 A. Uh-huh.

6 Q. -- in social work?

7 A. Uh-huh.

8 Q. Were you able to complete that?

9 A. No, three months in I had to give it up. I couldn't

10 cope with the physical side of it, managing in and out

11 with books, and I wasnae retaining information or

12 anything. I was struggling with the fatigue and the

13 pain, the joint pain.

14 Q. After you were told about the diagnosis of

15 hepatitis C, you were then referred to a liver

16 specialist.

17 Can we have document 2076008, please.

18 This is the referral letter in November 2006,

19 and we can see in the first paragraph that it refers

20 to you having used intravenous drugs and had partners

21 who were intravenous drug users as well.

22 Is any of that accurate?

23 A. No.

24 Q. When you obtained your records for the Skipton Fund,

25 you immediately spoke to Dr Boulton-Jones about those

12

1 notes, didn't you?

2 A. Uh-huh.

3 Q. And if we can have 2076005, we can see that you had

4 got -- this is 2018:

5 "Mrs Armour has been in touch. She has got her

6 medical records because she contracted hepatitis C

7 almost certainly through a blood transfusion."

8 And if we look at the third paragraph:

9 "She was concerned when she went through her medical

10 records to find a letter from my registrar referring her

11 to the liver service for further follow-up of

12 hepatitis C, which stated ..." and made reference to the

13 intravenous drug use:

14 "She was subsequently seen by Dr Goulding who was

15 one of our liver specialists, who also documented that

16 the hepatitis C was contracted through a blood

17 transfusion and, therefore, I do feel that this comment

18 from my registrar was simply wrong and this letter is to

19 confirm we feel that the most likely cause of this

20 lady's hepatitis C was through this blood transfusion.

21 "I've spoken to our clinical director to see if we

22 can simply remove this letter from the notes ..." but he

23 says they can't.

24 You were then provided with another letter,

25 2076006, where he says that:

13

1 was 2009, I went back and I said to her I would like

2 to just -- because she said it would take away most of

3 the symptoms that I was experiencing, so even if

4 I didnae clear the virus, there was a good chance

5 I would get back to work and finish my degree and

6 that, but --

7 Q. When treatment was first discussed with you and the

8 question was raised whether you were mentally strong

9 enough to cope with it, you were then referred to

10 perhaps a counsellor or a psychologist. You're not

11 sure which one it was.

12 A. No, that was before treatment started. That was in

13 2009, I seen the psychologist.

14 Q. And how did you find your sessions with the

15 psychologist?

16 A. It was only one session to see if I was mentally fit.

17 Q. And what was that like?

18 A. He was just asking about how I felt and I felt quite

19 strong then because I was determined that I wanted

20 this treatment.

21 Q. You were then able to start the treatment with

22 ribavirin and interferon?

23 A. Uh-huh.

24 Q. There was one occasion when you were given the needles

25 that you were required for that treatment and what did

15

1 "As discussed on the phone, I did manage to get

2 your paper records and have reviewed them. I agree

3 that the comment from Dr [X]'s letter in 2006 is

4 incorrect. As we have discussed, I have written

5 a letter to be included in your care notes to correct

6 this error and I attach a copy of that letter for your

7 information."

8 And so as soon as you saw the erroneous entry --

9 A. I phoned him.

10 Q. -- you phoned him and got it corrected.

11 A. Uh-huh.

12 Q. Now you were referred, as we saw, in November 2006.

13 When was treatment first discussed with you?

14 A. At the appointment with the liver specialist she told

15 me that the treatment they had, the interferon, that

16 she didnae think I'd be able to handle it because of

17 my mental state and I'd also lost a lot of weight and

18 that and so she said, "Your liver's not badly

19 affected. You've only got like 2%", whatever, she

20 says, "So you'll be fine for a few years, if you want

21 to wait and see something better comes out". She

22 went, "You've only got 50% of it clearing", and that

23 was when I decided to go back to you uni to try and do

24 my BA and that in social work, and when I couldnae

25 finish or complete that, I wanted the treatment, that

14

1 the nurse say to you?

2 A. Well, I took Laura with me because she was

3 an auxiliary nurse in the same hospital at the time so

4 she was currently learning to give me the injections.

5 She explained what would happen, I would be up once a

6 month collect the medication. She gave us the pills

7 and things and then she handed me the box with the

8 needles and she said, "And you know what to do with

9 them", and I was like that, "No I don't know what to

10 do with them", and she apologised. She says, "Oh, I'm

11 sorry", and she showed us how to use them.

12 Q. Because you think she believed that you were an IV

13 drug user when that had never been any --

14 A. Never been the case.

15 Q. You were warned that the side effects could be quite

16 severe.

17 A. Uh-huh.

18 Q. And if we have 2076003, please, we can see that the

19 nurse specialist wrote to your GP -- well, "to whom it

20 may concern" --

21 A. This was actually, when I was going through the

22 bankruptcy she gave me this to show them exactly that

23 I was -- the date the Disability Living Allowance

24 was --

25 Q. Which we're going to come onto very shortly but this

16

1 was the advice that you'd got at the time, wasn't it?
 2 A. Uh-huh.
 3 Q. "That the treatment is a fairly rigorous course of
 4 oral and injected medication which is associated with
 5 significant disabling side effects such as lethargy,
 6 flu-like symptoms, low mood, anaemia, anorexia and
 7 weight loss. These side effects can often impair the
 8 individual's ability to work for the duration of the
 9 therapy and for sometime afterwards."
 10 That's what you were told before the treatment
 11 as well, wasn't it?
 12 A. Uh-huh.
 13 Q. Are they the side effects you suffered from?
 14 A. Them and worse, yeah.
 15 Q. Can you tell us about that?
 16 A. For the first week I started experience severe pain,
 17 my appetite went, couldn't eat, I couldn't --
 18 I couldn't stand up without being dizzy. I was very
 19 light-headed. It was immediate, the effects of it.
 20 Instead of being at the hospital once a month, I was
 21 there every single week because the side effects were
 22 that horrific. So --
 23 Q. Sorry, go on.
 24 A. No, that's fine.
 25 Q. You underwent treatment for 72 weeks.

17

1 get up in the morning to going to your bed at night.
 2 As I say, I've got three young granddaughters, I'm
 3 a single parent, so taking painkillers isn't an option
 4 for me, so I just deal with the pain.
 5 I went back after a year of finishing treatment,
 6 and I says, "I don't feel I'm getting any better. The
 7 pain's no getting any better". I said, "It feels as
 8 though it's getting worse", and that's when she
 9 referred me to the rheumatologist, and I said to her
 10 you told me this would all be clearing up by now and
 11 she couldn't understand why it wasn't either.
 12 So I went back a year later and then I went to
 13 the rheumatologist and they diagnosed me with
 14 fibromyalgia. I started treatment for that. She
 15 gave me some more painkillers, physiotherapy, and then
 16 I started breaking out in big sores along my back
 17 which I knew it wasn't any of the other irritations
 18 I'd had. I knew it was something different.
 19 I googled it and it come up as lupus, immune
 20 whatever, and I was looking at the reasons, causes and
 21 it said long-term -- one of them was long-term use of
 22 interferon, so I'm back to my GP and I says think I've
 23 got lupus and they said, "I don't know what lupus is".
 24 Here's looking me and he's like that, "I think I need
 25 to get a second opinion. Do you mind if somebody else

19

1 A. Uh-huh.
 2 Q. Why was it for so long?
 3 A. I don't know.
 4 Q. What were you told --
 5 A. I was told --
 6 Q. -- at the end of the 48 weeks?
 7 A. She just said we would like you to continue for
 8 another six months. She never said why. She just
 9 said "Think about it". She gave me a couple of days
 10 to go home because I was not happy thinking that was
 11 me done my 48 weeks, so I thought of doing another six
 12 months, but I thought I've done it this far, I may as
 13 well just do it and I done it.
 14 Q. And what did the nurse say to you about the fact that
 15 you did it for 72 weeks?
 16 A. She says it's the first she ever gave anybody it for
 17 that length of time. She'd never known anybody to
 18 have it that long but she never said why I was to take
 19 it.
 20 Q. And you're still not clear now why it was for so long?
 21 A. No.
 22 Q. You completed that course and cleared the virus, but
 23 what's the ongoing physical impact been on you?
 24 A. The fatigue, the pain has got to be the worst. It's
 25 no just joint pain. It's pain everywhere. Before you

18

1 comes in?"
 2 So the next thing there were three of them
 3 behind me all pulling faces and looking, and at first
 4 I thought it was bugs had bit me, because of my --
 5 where I live, and I thought that's what they were
 6 whispering about, and I said to them, "Look, I think
 7 it might be lupus", but they were no -- they kept
 8 saying, "No, we don't know anything about lupus", so
 9 they referred me to the skin specialist, and he took
 10 tests and he agreed with me.
 11 Q. And you had the diagnosis of lupus confirmed more
 12 recently?
 13 A. Uh-huh.
 14 Q. After you left the university course and couldn't
 15 complete your degree, you then went on benefits?
 16 A. Uh-huh.
 17 Q. What happened with your Disability Living Allowance at
 18 this point?
 19 A. Because I was a -- I'd wrote in -- when I was very
 20 filling the form out, I tried to fill it myself and
 21 I wasn't like to put in it that I was feeling really
 22 bad in case they gave -- never gave me the treatment,
 23 so I said I was feeling kind of good enough to take
 24 this treatment and they took my DLA off me.
 25 Q. So you applied for the DLA just before you started the

20

1 treatment.

2 A. No, I'd been getting it. I'd been getting it for

3 a couple of year.

4 Q. You had to reapply and fill in the forms --

5 A. Uh-huh.

6 Q. -- just before you started the treatment and because

7 you were desperate for the treatment you wrote that

8 you'd weren't so bad, which meant you lost the

9 allowance?

10 A. Yeah.

11 Q. What happened after that?

12 A. I had to fight for a year to get it back, so I had to

13 go to Citizens Advice for a couple of weeks, which was

14 horrible because it was the winter. I was getting the

15 injections on the Monday. I was to go over there and

16 stand at half 8 in the morning to be guaranteed to be

17 seen that day. It was like a ticket system. There

18 was nae toilet facilities, nae tea facilities,

19 nothing.

20 Q. The toilet facilities, particularly for you were

21 really difficult because of the ongoing diarrhoea

22 issues.

23 A. Yeah, and I'd phoned them and said, "Would it be okay

24 then if I come over, could I use your staff toilets,

25 if needed?" And they were awful nice and said yes.

21

1 better physical condition but which was facing the

2 hospital, you found that very difficult?

3 A. Well, I thought it was better physical conditions to

4 I was chasing mice in there a couple of weeks ago.

5 I've only been in it ten weeks and that's got mice as

6 well.

7 Q. And the impact of being opposite the hospital, you

8 found very hard indeed?

9 A. I did, especially reading my medical records. It was

10 just -- kept bringing it back to me and it's right

11 facing the very ward, I can see the ward I was in.

12 Q. You found out about The Skipton Fund and received

13 a payment from them and then through some contacts on

14 social media you found out about the Caxton Fund.

15 A. Uh-huh.

16 Q. How did you find applying to the Caxton Fund?

17 A. An ordeal, it was terrible. It took them weeks to

18 answer you and then it took -- they would send a form,

19 you've got to fill that form in and then send it back

20 and then it would go to a panel, and then they would

21 write back. So this was what -- it would take

22 a couple of months if you asked for anything.

23 At one time they replaced my furniture due to

24 the infestations in my house and they gave me £900 in

25 Next vouchers, £10 vouchers, and I had to stand and

23

1 Q. You ended up being declared bankrupt --

2 A. Yeah.

3 Q. -- after the treatment, because financially everything

4 had gone horribly wrong?

5 A. Uh-huh. Most -- well, my benefits -- because I wasnae

6 getting money going in, there was bank charges coming

7 off, so it ended up all my benefits was just getting

8 took right away in bank charges, so I was living on

9 nothing.

10 Q. You've also had some housing difficulties.

11 A. Yeah.

12 Q. Can you tell us about those.

13 A. The whole area where I live is, for the past ten year

14 I've been campaigning daily for the infestations we're

15 dealing with. It's rife with mice, bedbugs,

16 cockroaches. This is what I'm battling to keep out my

17 home. The past four year I've had mice running about

18 my feet, sitting on my feet, trying to get in the

19 bottom of the wean's pram.

20 I got moved recently. The best offer they could

21 give me was a flat facing the hospital, where I was

22 infected, but it was either that or listening to mice

23 run through the walls in my flat, which I'd been

24 listening to for four years.

25 Q. And for you moving to a flat which was in perhaps

22

1 count them out in the shop. It was embarrassing, so

2 I never applied again, ever.

3 Q. You'd also applied for some clothes for your 50th

4 birthday?

5 A. Uh-huh.

6 Q. What happened in relation to them?

7 A. Well, my birthday was in the June and I was still

8 asking for it in I think it was September, still --

9 I ended up in tears on the phone to them.

10 Q. Those are the questions I have for you. Is there

11 anything you would like to say or I think your

12 daughter might have wanted to say something.

13 LAURA: Yes. On behalf of my mum and my family, we would

14 just like to thank yous for the opportunity for giving

15 my mum to come here today and get her story across.

16 Hopefully my mum's statement has reiterated the effect

17 that it has had on the entire family. **GRO-A**

18 **GRO-A**

19 **GRO-A** It's robbed her of everything. She lives

20 a death sentence every day and we just -- we've waited

21 14 years to get the truth and the answers she

22 deserves.

23 MS FRASER BUTLIN: I'm just going to turn round and see if

24 Mr O'Neill or Mr Dawson have anything they would like

25 to raise with you.

24

1 A. Okay. *(Pause)*
 2 Q. Just two things that they'd like me to raise with you.
 3 You had a couple of other interactions at the
 4 hospital. You had a hysterectomy in 1994 and then
 5 some bloods taken in 1998.
 6 You feel that they were opportunities that were
 7 missed?
 8 A. Uh-huh, especially '94 because I got another blood
 9 transfusion plus I had been suffering all the symptoms
 10 of hep C right up until then. When I look in my
 11 medical records, surely when they gave me more blood
 12 they would have checked and seen that I was at risk.
 13 I've never moved from the area that I live in. I'm
 14 still in the same street as the hospital. That's --
 15 so I don't see how they couldnae have found me in the
 16 look-back process.
 17 Q. So you feel the hospital missed the opportunities when
 18 you went in --
 19 A. Uh-huh.
 20 Q. -- on a couple of occasions and things were missed.
 21 They could have looked back at an earlier stage
 22 which would have picked you up earlier?
 23 A. Yeah.
 24 MS FRASER BUTLIN: Thank you.
 25 SIR BRIAN LANGSTAFF: I have no questions, but can I thank

25

1 they look like.
 2 So in each case I will make an order in the
 3 usual form. In the case of Mr T, it reads like this:
 4 I order that the name and address of witness W0123
 5 (that's Mr T to you and me) and any other identifying
 6 information, such as the witness's image or
 7 a description of their appearance cannot be disclosed
 8 or published in any form unless express permission is
 9 given by me or by the Secretary to the Inquiry acting
 10 on my behalf.
 11 Witness 0123 must be referred to only as Mr T. This
 12 order remains in force for the duration of the Inquiry
 13 and at all times thereafter unless otherwise ordered and
 14 I may vary or revoke the order by making a further order
 15 during the course of the Inquiry.
 16 On each of the occasions that I've made these
 17 orders I have asked or reminded people to be very
 18 careful in taking any photographs in and around the
 19 Inquiry, that means in and around the conference
 20 centre, just in case you inadvertently capture Mr T
 21 and the same will apply to the other witnesses we get
 22 to hear today when you take a snap. So please just
 23 take care.
 24 The press won't photograph anyone without
 25 permission. Please don't do the opposite.

27

1 you for telling us of your struggles with hepatitis C
 2 and your daughter for telling us the effects that that
 3 has had on the whole family. Thank you very much.
 4 A. Thank you.
 5 SIR BRIAN LANGSTAFF: We'll take a break until 11.10 am.
 6 Our next witnesses for the rest of the day in fact are
 7 all anonymous, so you will understand what that means,
 8 most of you. I shall tell you more about each as I am
 9 obliged to do as each comes to give evidence.
 10 11.10 am.
 11 (10.40 am)
 12 (A short break)
 13 (11.12 am)
 14 SIR BRIAN LANGSTAFF: Our next witness is Mr T.
 15 MS RICHARDS: Yes, sir. Do you want to make the
 16 restriction order before the witness is sworn in?
 17 SIR BRIAN LANGSTAFF: Yes. As I mentioned before we had
 18 the break, the next witnesses, throughout the rest of
 19 the day, will be anonymous. Now, what that means is
 20 that no one can say anything which would lead to their
 21 identity being known outside this room.
 22 Each of them will give evidence, so you will see
 23 them, but they will not be seen by the nation out
 24 there because their face will not be on any live
 25 transmission. What they say will be, but not what

26

1 MS RICHARDS: Sir, I should just say before Mr T is sworn
 2 that whilst his testimony will be live streamed on
 3 an audio-only basis, the live stream will not be
 4 functioning this afternoon. That's because of the
 5 nature of the evidence that's being given this
 6 afternoon is such that it will be unrealistic to
 7 expect the witnesses to give their evidence without
 8 mentioning names.
 9 SIR BRIAN LANGSTAFF: Yes.
 10 MS RICHARDS: And so there will be no live stream, so
 11 anyone listening presently or watching presently will
 12 not be able to follow this afternoon's proceedings,
 13 but their evidence and the audio transmission of it
 14 will be uploaded as soon as any appropriate redactions
 15 have been made.
 16 SIR BRIAN LANGSTAFF: Yes. Well, let us have Mr T.
 17 MR T, sworn
 18 Questioned by MS RICHARDS
 19 Q. You're a retired police officer having completed
 20 30 years' service.
 21 A. Yes.
 22 Q. In 1988 you sustained very serious injuries as result
 23 of a road traffic accident.
 24 A. That's correct, yes.
 25 Q. What can you tell us about what happened in terms of

28

1 your treatment.

2 A. Well, with regards to my treatment at that time, at

3 the time of the accident I had multiple fractures,

4 life-threatening. I was taken to the Glasgow Victoria

5 Infirmary after I had been cut out of my car and

6 I think it was like emergency surgeries were carried

7 out at that time. Obviously, due to the

8 circumstances, I don't really recall anything of what

9 was going on at that particular time.

10 Q. You now know you received blood transfusions. You

11 weren't in a position to be asked for your consent

12 because of the nature of your injuries, as

13 I understand it.

14 A. That's correct, yes.

15 Q. And you very candidly said in your statement that had

16 you been asked for your consent, you would have given

17 it because of the seriousness of your condition.

18 A. I think in the circumstances that's reasonable, yes.

19 Q. And we know from a recently provided witness statement

20 from the Scottish National Blood Transfusion Service

21 that their understanding is you received six units of

22 red cells and seven units of fresh frozen plasma, or

23 cryoprecipitate, on 6 April 1988, two units of red

24 cells on 11 April and four units of red cells on

25 19 April.

29

1 infected.

2 Q. The test result came back and your GP informed you

3 that you had been infected with hepatitis C.

4 A. Yeah.

5 Q. What can you recall of your reaction?

6 A. I think probably just numbness, because of the

7 occupation I knew what hepatitis C was roughly but, to

8 be honest, I was probably quite ignorant of the -- of

9 the bigger picture with regards to it, but I knew what

10 it was but didn't really know what it was going to do

11 to me. I think I did ask him, you know, "How much

12 time have I got left?"

13 Q. And you've said in your statement that you -- you were

14 in tears when you went home.

15 A. Yeah.

16 Q. Extremely emotional, in a state of turmoil?

17 A. Yeah.

18 Q. And you went on autopilot, as it were, into work?

19 A. Yeah, I just went to work that night.

20 Q. But you spoke to someone at work and actually told one

21 of the few people you ever told at work --

22 A. Yeah.

23 Q. -- what your diagnosis had been, and they told you to

24 go home.

25 A. Yeah, he did.

31

1 A. Yes, I found that out last week.

2 Q. Now you recovered from your injuries and you returned

3 to work as a police officer?

4 A. Yes.

5 Q. Some 12 years later, in 2000, you went to see your GP.

6 What prompted that?

7 A. Generally feeling unwell for a number of years,

8 probably fatigue, pains in my joints. I would liken

9 it probably a lot of the time to like flu-like

10 symptoms, so this had gone on for quite a lengthy

11 period of time and my wife eventually just said,

12 "Look, you need to go and see a doctor", because it's

13 a thing I still don't do that often, you know.

14 I won't go and see a doctor just because I'm not

15 feeling that great, so she eventually talked me into

16 going and I did.

17 Q. And you saw your GP and the GP arranged for you to be

18 tested for hepatitis C?

19 A. Yeah, that -- initially he did a blood test and he

20 initially said that he thought it could be -- I was

21 maybe just anaemic. That came back and I think at

22 that time he said, "Do you mind if I try another one

23 and test for hepatitis C?" And due to the

24 circumstances, I was quite happy with that because

25 I had obviously no reason to believe that I would be

30

1 Q. You had a great fear at that time that you might have

2 infected your wife or children.

3 A. Yes. Well, you're thinking at the time, "When did

4 this happen?" Because I obviously didn't know and

5 you're -- it's going through your mind, how did

6 I become infected? Who could I possibly then have

7 infected myself?

8 And all these scenarios are running through your

9 mind and it's probably quite -- it's quite constant in

10 that respect, that you never get that out of your mind

11 about who you have or could have infected.

12 Q. How much information was your GP able to give you

13 about the condition?

14 A. Very little at all. I think his comment in the time

15 was he said, "I believe it works on 20-year cycles of

16 kind of deterioration", he said, "but I don't really

17 know that much more about it". I think to be fair, at

18 that time, in 2000, the sort of general information

19 for GPs was apparently -- was possibly quite thin on

20 the ground.

21 Q. Your GP did refer you to a consultant, Dr Fox.

22 A. Yes.

23 Q. What can you recall about your first appointment there

24 and what you were told?

25 A. He -- he asked me a lot of questions about, you know,

32

1 is there any circumstances under whether -- under
2 which I think I may have become infected. He asked me
3 questions about, you know, was I an intravenous drug
4 user. Was -- there was all these kind of questions
5 trying to just maybe to establish where or how I'd
6 become infected, and he -- I answered to him that
7 I had no idea but I did happen to mention the road
8 accident, and described the injuries I had suffered at
9 that time and where I had been treated. And it was
10 kind of strange because at that time he said, he said,
11 "That's what it will be", and he at that time said
12 that due to the injuries I had suffered, he was quite
13 confident that I would have received a blood
14 transfusion at that time.

15 Q. You were given a leaflet at some stage.

16 We'll just have that up on screen, please, Paul,
17 it is 0123002.

18 We can see it was:

19 "How you can prevent the spread of infection to
20 others."

21 If we go over the page, we can see that there's
22 information -- some practical tips about how to avoid
23 spreading infection, and then if we go to the last
24 page, please, we can see there's a passing reference
25 to treatment:

33

1 that for weeks at a time is -- is pretty hard, you
2 know. I think with retrospect I sometimes wonder why
3 I was tested for that, because obviously the response
4 that I got last week from the Blood Transfusion
5 Service indicates that the blood was hepatitis C
6 positive but it doesn't in any way say that it was
7 HIV-positive so I'm still kind of unsure as to how
8 I got or why I was tested for HIV at the time.

9 Q. Now, Dr Fox advised that you should have a liver
10 biopsy.

11 A. Yeah.

12 Q. There was going to be quite a wait for that. How
13 long?

14 A. It was -- I think it was something like six months to
15 a year. They were saying it would probably be the
16 better part of a year before you could get one of them
17 arranged.

18 Q. So you arranged one privately?

19 A. Yes, my father offered to pay for me to go to
20 a private hospital in London.

21 Q. And the result of that -- and that was in 2001 -- was
22 that at that stage you'd suffered minimal damage to
23 your liver?

24 A. That's the way it was described to me, yes.

25 Q. And Dr Fox at that stage thought that you didn't need

35

1 "Medical treatment is available ... however it
2 is not always effective and not everyone will be
3 suitable for treatment."

4 Then it refers to complementary therapies and
5 positive living. You've described that leaflet in
6 your witness statement as somewhat basic.

7 A. Yes.

8 Q. Did you receive much more information from Dr Fox or
9 anybody else about the nature of the condition and
10 it's likely progression or treatment options?

11 A. Not really that I remember. I'm pretty positive that
12 I didn't really get much more from him at that time.
13 It was obviously described as a liver disease. It
14 could lead to cirrhosis, et cetera, but at that time
15 you're -- not being medically trained, you know,
16 you're not really sure exactly how that works or how
17 it progresses, so from the staff themselves, I don't
18 feel that I got much more information than that.

19 Q. Now, you had to be tested or you were tested for HIV.

20 A. Yeah.

21 Q. That was negative --

22 A. Yeah.

23 Q. -- but what was the wait for the test result like?

24 A. It's indescribable. You're simply just hoping that
25 it's not going to prove positive but to go through

34

1 to embark upon treatment straightaway?

2 A. No.

3 Q. And told you that the only available treatment at that
4 stage was not particularly effective?

5 A. Yes, that's correct.

6 Q. You've described in your statement how in the early
7 years after the diagnosis you -- your great anxiety
8 was that you would not be able to continue working --

9 A. Yeah.

10 Q. -- and you would not be able to support your family?

11 A. Mmm-hmm.

12 Q. Is that right?

13 A. Yes.

14 Q. And you've described in your statement feeling in
15 a state of high stress and panic?

16 A. Yes.

17 Q. What had you, whether through your work as a police
18 officer or otherwise, what kind of view had you formed
19 or understood about the nature of hepatitis C prior to
20 your own diagnosis?

21 A. I made comment in my statement about, you know, the
22 typical view at that time probably in general in
23 police officers was it was a junkie-related illness,
24 a junkie-related disease, if you want, and again
25 I think I did say in my statement that I was very

36

1 ignorant of what it was and how people would come to
 2 be infected. In the environment that I worked in, the
 3 normal way that anyone was infected was through
 4 intravenous drug use.

5 **Q.** And you've described your own view as being
 6 ill-informed.

7 **A.** Yeah.

8 **Q.** But you nonetheless had to listen to colleagues who
 9 used phrases such as those described in your
 10 statement?

11 **A.** Yeah.

12 **Q.** Scummy, drug-infected, hep C-infected junkies and the
 13 like.

14 **A.** Yes.

15 **Q.** Whilst keeping secret the nature of your own
 16 diagnosis?

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

18 **Q.** Could we have up on screen, please, Paul, 0123003.
 19 This is a letter from September 2002, so this is
 20 nearly two years after your diagnosis, and it's
 21 a letter from Dr Fox saying:
 22 "The Blood Transfusion Service have informed me
 23 that one of the donated units of blood you received in
 24 1988 has proven in retrospect to be contaminated with
 25 hepatitis C and that this donation may be the source

37

1 you?

2 **A.** I don't think it ever leaves your mind. You're
 3 constantly thinking about it. Obviously, with the job
 4 I was doing, you have to try and remove that from your
 5 mind when you're dealing with the kind of situations
 6 that I was dealing with.

7 But when you've got downtime or there's quiet
 8 time, it's constantly in your mind. Days off, there
 9 wasn't much else went through my mind with regards to
 10 thinking, you know, "What do I do? What's the
 11 long-term prognosis for it?" You know, I need to keep
 12 working. We've got a house we've got kids. We need
 13 to pay for that.

14 You're just constantly thinking about it, as
 15 well as probably some -- the physical effects were
 16 probably still the same as well in that I was still
 17 tired a lot. As I said, constantly feeling as if you
 18 were suffering from flu-like symptoms, so ...

19 **Q.** You've described in your statement how you withdrew
 20 socially very much down to the family unit.

21 **A.** Yeah.

22 **Q.** And you would sit alone, think about the diagnosis and
 23 you felt like a dead man walking.

24 **A.** Yeah.

25 **Q.** Of the years, there were a couple of occasions when

39

1 of your infection."

2 Now, you've been critical in your statement of
 3 the use of the term, "this donation may be the source
 4 of your infection"?

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

6 **Q.** Dr Fox himself told you he was certain it was the
 7 force of your infection?

8 **A.** Yeah, he said he was 100% certain.

9 **Q.** And it's right to note that we have a statement from
 10 the current Medical Director of SNBTS which you've
 11 seen in the last few days, Dr Turner, which contains
 12 an apology to you and your family for the fact that
 13 you received the infection through a transfusion and
 14 says that the service fully accepts that you were
 15 infected as a result of the transfusion?

16 **A.** Yes, that's the one I got last week, yeah.

17 **Q.** You've talked in your statement about the stigmatising
 18 effect of hepatitis C. You felt it was a dirty
 19 disease and you were terrified your children, if
 20 people had found out, would someone be branded the
 21 children of a disgusting dad is the way you've put in
 22 your statement.

23 **A.** Yeah.

24 **Q.** In the period up until your first course of treatment,
 25 how physically and mentally did the diagnosis affect

38

1 you informed colleagues in the police force about your
 2 condition, once occupational health you informed.
 3 What was the reaction you got?

4 **A.** The occupational health sort of -- I went -- it was
 5 actually a chief inspector had said to me at the time,
 6 I had said to him that I needed to go for a medical
 7 appointment and he asked me what it was for and you
 8 don't normally get asked that, and I eventually just
 9 told him what it was with regards to.

10 He said to me, "I think you should refer
 11 yourself to occupational health", which I did, went
 12 and saw them and basically spoke to a nurse at
 13 occupational health and she kind of looked at me with
 14 a blank stare and, "Right, okay", and, "If there's
 15 anything we can do for you, get back to us", and that
 16 was it.

17 There wasn't any -- there wasn't any sort of
 18 offer of any proactive sort of assistance at all. It
 19 was basically just, "Right, okay, thank you, that's
 20 noted".

21 **Q.** And there was another occasion where you were going to
 22 be posted somewhere that would have made it difficult
 23 for you to attend medical appointments --

24 **A.** Yeah, that was more in the last sort of three to four
 25 years of my service, probably between 2012 to 2016,

40

where I was posted quite a significant distance away and there was really no need for it.

I firstly asked a superintendent, told him what the situation was, in that I still had a lot of medical appointments to attend, et cetera, felt it would be better for me if I could be posted nearer to home, which wouldn't have been a problem because there was certainly vacancies.

He said he would get it dealt with straightaway, never got back to me. I emailed him. He never got back to me. I then was posted to the area that was further away from my home, spoke to the area commander there and he was ridiculous, the guy. He actually come into my office one day, closed the door behind him and he was -- he was quite belligerent and said to me he didn't understand what I had been gibbering about, so he asked me whether I thought this was really necessary. *(Pause)*

Q. Was there any point at which you received any kind of supportive or sympathetic response from your employer?

A. No. When I said to him I thought it was -- he asked me to put it in writing to him, so I did by way of an email. What he actually did with it was he opened it; he closed it; he marked it as "unread"; and then he deleted it.

41

which would be interferon and ribavirin would have debilitating side effects and you wouldn't be able to work.

A. Yeah, I was advised that I wouldn't be able to work and that it was inadvisable to work as well.

Q. In fact, you continued to work throughout that course of treatment.

A. Yeah.

Q. You'd inject yourself with the treatment at home with your wife sitting on the stairs to warn you if the children were coming in?

A. Well, that first course of treatment I actually had to go into the hospital to get the injections all the time. The injecting myself was actually in the second course.

Q. So in --

A. Sorry.

Q. In relation to the first course of treatment you arranged your shift patterns and your hospital appointments so that you could continue working whilst still having the treatment.

A. Yeah.

Q. And what were the side effects of that treatment physically and mentally?

A. I think the tiredness got worse, certainly a lot of

43

Q. In terms of your children, you have described in your statement how both the infection and the treatment which we will discuss in a moment, how that affected your mood and your ability to communicate with your children.

A. Yeah.

Q. I think it's right that you didn't tell them for a while.

A. I didn't tell them until about three years ago.

Q. And it was an occasion where you describe you blew up at your son and that was the occasion where you said in your statement where you actually felt suicidal --

A. Yeah. It was just --

Q. -- at what you had become.

A. Yeah, it was just the anger that I reacted to him the way I reacted to him, and, you know, it's looking at yourself reacting in that way.

Q. And it was after that that you decided that you would tell the children?

A. Yeah, we basically sat them both down and told them.

Q. I need to ask you about the treatment that you received for hepatitis C. It was 2005 when you --

A. Yeah.

Q. -- I think you first had a discussion about embarking upon treatment, and you were told that the treatment

42

pain.

I think as far as your mindset was concerned, I've described it -- I think the word "befuddled" sums it up sometimes, did I do that? I can't remember if I did that, and having to double-check things.

Again, from the perspective of probably not realising what the effects of the medication could be, it was confusing in that respect. But physically whilst doing that and continuing to work shift, a shift pattern, including night shifts, it would be the end of a shift pattern, I would sometimes spend the two days off in bed just sore and tired.

Q. And you experienced, your statement describes, mood swings, panic attacks and anxiety?

A. Yeah, sleeping -- sleeping was really poor. It was ridiculous situations when you were lying at night with your hand taking your own pulse and it just was ridiculous.

Sometimes off early shift starting at 7 o'clock in the morning I would maybe get an hour's sleep before going in for 7 o'clock and starting work.

Q. Now, the hepatitis C showed signs of clearing during that first course of treatment?

A. That's correct, yes.

Q. But ultimately that treatment was unsuccessful?

44

1 A. Yes.

2 Q. What was the impact of learning that the treatment

3 hadn't worked?

4 A. It was devastating. I think -- I think that anybody

5 that's been through the treatment and its failed are

6 obviously exactly the same thing in respect of the

7 fact that you're so hopeful, you're going through it,

8 you get word through it that it's cleared and then it

9 comes back. I think it was like -- I think it was

10 about six months after it I got final confirmation

11 that it had returned, and you feel as if you've been

12 through all that pain for nothing.

13 Yeah, it's very depressing.

14 Q. If we have up on screen, please, Paul, 0123004, this

15 is a letter you then received in July of 2007 saying:

16 "Following your attendance at my clinic this

17 morning, your liver functions tests have been phoned

18 back showing a significant deterioration."

19 Then there was a reference for there to be

20 a liver ultrasound scan. What was your -- what was

21 the effect on you of receiving that letter?

22 A. Well, it was just a piece of mail that came in the

23 general post. I opened it up and I was totally and

24 utterly destroyed by it. I think I probably felt as

25 if was in a trance reading it. I cried. I was in the

45

1 whatever it was he was using at the time and realised

2 that the anaesthetic hadn't worked. He tried it

3 another couple of times. It still didn't work and he

4 basically carried it out without the anaesthetic.

5 Q. Now, 2009, early 2009, you started on a second course

6 of treatment.

7 A. Yes.

8 Q. Again, interferon and ribavirin.

9 A. Yes.

10 Q. And this course lasted for about 12 months?

11 A. That's correct, yes.

12 Q. How did you manage that at work and at home?

13 A. Well, that was the time that initially prior to

14 starting that course that they showed me how to inject

15 myself in the stomach at the time. So I was giving --

16 I was given, it was like four weeks' supply and

17 I would inject myself either at home or at work,

18 depending on the shift patterns I was on.

19 So, again, from a work perspective trying to

20 find that time to just get a couple of minutes to go

21 and inject myself was -- was quite stressful. At that

22 time I was a supervisor and you're on call all the

23 time, so to try and get an injection done outside the

24 time that something critical may be happening in the

25 street was always a major concern.

47

1 house myself that day, so you're sitting with this

2 piece of news and you just didn't know what to do with

3 it. It's one of these situations that I have said

4 since that they should certainly not be sending

5 letters with that kind of information out to people

6 that they're opening in their home. They could be

7 alone. They could be with family members when they

8 are doing it and I have actually said to my present

9 consultant that this is not good way of doing things.

10 Q. And you thought that this was terminal?

11 A. Yes. Yeah, I think that would be fair, yeah.

12 Q. You had a liver biopsy --

13 A. Yes.

14 Q. -- in the October of that year.

15 A. Yes.

16 Q. And that was a very unpleasant experience, as

17 I understand your statement.

18 A. Yeah, it wasn't good. I went in to the Brownlee

19 Centre at Gartnavel Hospital. I went down to get the

20 biopsy done, bearing in mind I had had one previously

21 so I was assuming it would be straightforward as that.

22 I went in and I got a local anesthetic, which

23 was injected in my back, and I believe that's probably

24 into the liver.

25 The doctor then started to insert the probe or

46

1 In the house when I was injecting myself within

2 the house, it was -- it was awkward from the point of

3 view of having kids around. So in general I think --

4 I think in general I usually did that in the living

5 room and my wife would basically stand guard and make

6 sure that the kids didn't happen to walk into the

7 living room while I was doing it.

8 Q. And what were the physical effects of this second

9 course of treatment?

10 A. Again, it -- it went back to exactly the same as the

11 first one, although I felt that the second time the

12 physical effects were worse and the problem for me at

13 that time was that I actually showed physical effects

14 in respect of my skin drying around about my face and

15 neck.

16 I'm no medical person but I would probably

17 describe it as severe psoriasis and people commenting

18 to me, "Are you okay", and just sort of trying to

19 laugh it off and say, "I'm fine, I'm not feeling that

20 good", you know, so that was sort of consistent for

21 that 12-month period.

22 There was -- I think it was probably about half

23 a dozen occasions when I had taken the injections. It

24 was always a Tuesday I took the injections on and at

25 least half a dozen occasions the following day a nurse

48

1 phoned me up and said to me, "This week's injection,
2 could you cut that in half?" And I remember on a few
3 occasions saying, "You know I take it on a Tuesday and
4 you're phoning me on a Wednesday". So there was,
5 I would say, about half a dozen of occasions when
6 I was phoned up after the fact and told to cut the
7 dosage.
8 Q. And what about the psychological effects of the second
9 course of treatment?
10 A. Again, it's fair to describe it as being depressed.
11 My wife describes or she describes panic attacks,
12 unable to sleep in the middle of the night. I think
13 psychologically it was very difficult, but I think
14 what keeps you going is the -- is the hope that it
15 will clear.
16 Q. And in February 2010 you were told that the
17 hepatitis C had cleared.
18 A. Yes.
19 Q. But you would need to have ongoing monitoring for the
20 state of your liver until you reached the age of 72.
21 A. Yes.
22 Q. And so you attend every six months for scans and
23 tests.
24 A. Yes, I go to -- to a specialist at Gartnavel, a liver
25 specialist, and it was him that made the comment about

49

1 I just didn't get it. I think I was absolutely --
2 I was stunned, didn't understand what she was talking
3 about. We were trying to ask questions. She would
4 talk over you. It was dreadful, absolutely dreadful.
5 Q. You've described it in your statement, in fact, as one
6 of the worst experiences of your life.
7 A. Yeah, yeah.
8 Q. You've asked for counselling --
9 A. Yeah.
10 Q. -- on a number of occasions.
11 A. Yeah.
12 Q. What's the response been?
13 A. I've never had any.
14 Q. And you say in your statement that the most useful
15 person you've spoken to was someone at the British
16 Liver Trust who you contacted.
17 A. Yeah, that was quite early on. I think because of the
18 lack of information we went online and it can be
19 a good thing, it can be a bad thing. You get a lot of
20 really bad stuff online that probably you shouldn't be
21 reading but I think it was my wife that found the
22 organisation the British Liver Trust and we contacted
23 them.
24 If I remember rightly, I think that was
25 a voluntarily organisation, a charity. They were

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1 72 and I'd asked him why and he said, "Well, we reckon
2 you've had a decent innings by the time get to 72",
3 which to be honest I thought was quite funny.
4 Q. But you get terrible anxiety at the time of the scans
5 and tests.
6 A. Yes, I still get that. I think it's -- I've actually
7 got one next week, so prior to then your stress levels
8 probably go up because you're basically going twice
9 a year to find out if it's deteriorated. So every six
10 months you get that feeling of anxiety in respect of
11 the possibility of being told it's got a lot worse.
12 Q. I wanted to ask you about your experience of
13 counselling, psychological support. You did have some
14 form of counselling at one stage --
15 A. Yeah.
16 Q. -- from an HIV counsellor. What happened?
17 A. It was initially, this was very early on in my memory
18 after being diagnosed and I was asked if I wanted to
19 speak to a counsellor and I said yes, okay, I would
20 speak to a counsellor, probably from the point of view
21 that I wanted more information.
22 When I went to the hospital, they explained to
23 me they didn't have a hepatitis C counsellor, it was
24 an HIV counsellor. All she talked about was HIV. All
25 she talked about was, "I think you may have HIV".

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1 excellent. They were really good at giving you more
2 information about prognosis, treatment, et cetera, and
3 I found them very, very good.
4 Q. And in terms of your experiences in making
5 applications to the Skipton Fund --
6 A. Yeah.
7 Q. -- you yourself have not experienced any difficulties
8 with that process. Dr Fox told you about it and
9 actually filled in the forms for you?
10 A. Yeah, I believe he did the first and second and to be
11 honest I -- to be honest, I thought The Skipton Fund
12 were fantastic any time I contacted them or any time
13 I asked for information.
14 The first time Dr Fox had filled in the forms
15 for me, I think it was just a case I signed them and
16 sent them off and then the second time when we
17 discovered I had cirrhosis, he had again, I believe,
18 my memory of it was he filled it in again and I
19 literally just signed it and sent it off.
20 Q. And you've described in your statement how in 2013 the
21 Skipton actually contacted you and made you aware of
22 your potential eligibility for a top-up payment?
23 A. Yeah, it was literally a phone call out of the blue to
24 my mobile and I literally thought it was -- it was
25 just one of the scam callers and when he said, "I'm

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1 from The Skipton Fund", I then recognised obviously
2 the name and recognised that it might not be a scam
3 call, so I spoke to him and he explained what --
4 I think it was at that time he basically said I may
5 qualify for a further payment.

6 **Q.** Although the virus cleared as a result of the second
7 course of treatment, what have been the ongoing
8 effects on you of the infection and the treatment you
9 received for it?

10 **A.** I think the ongoing effects are probably psychological
11 in the main. There's not a day goes by that I don't
12 think about it. Physically, I'm probably in a lot
13 better place. I do go to a gym. I'm there -- I might
14 not look it, but I'm there five or six days a week and
15 my way of dealing with the -- with the effects of --
16 the long-term effects are to try and stay as fit as
17 I can.

18 So that's basically what I do in that respect.
19 As I say, mentally I'm getting there, but I think it's
20 something that's always going to be there.

21 **Q.** And what about the impacts on your family?

22 **A.** It's been dreadful. I think from my wife's point of
23 view, she's had to put up with the mood swings, the
24 anger, the frustration, just not been that much fun to
25 be around. We've had a situation with regards to --

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1 an order, I make an order in her case and it reads as
2 follows in words which will be becoming increasingly
3 familiar to you. The name and address of witness
4 W0136 (that's Mrs U to you and me), the name of her
5 husband who died, the names of her daughters and the
6 name of any other member of her family and any other
7 identifying information, such as the witness's image
8 or a description of her appearance, cannot be
9 disclosed or published in any form unless express
10 permission is given by me or by the solicitor to the
11 Inquiry acting on my behalf. Witness W0136 must be
12 referred to only as Mrs U.

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

18 With that introduction, may we have Mrs U,
19 please.

20 **MRS U, sworn**

21 **Questioned by MS FRASER BUTLIN**

22 **MS FRASER BUTLIN:** Mrs U, you're here to talk about your
23 late husband and we've agreed that it's too hard for
24 you to talk about him without referring to him by
25 name. You'll be talking about the effect of his

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1 we've not really had a physical relationship for
2 19 years.

3 **Q.** And that's because of the fear?

4 **A.** Yeah. The kids -- I don't know, it's been dreadful
5 probably for them not understanding why I've been
6 acting the way I was been acting. That's something
7 that I've always regret, so that's been hard.

8 **Q.** Those the questions I have for you. Is there anything
9 further you would like to add?

10 **A.** No, I'm fine, thanks. That's okay.

11 **MS RICHARDS:** Thank you. Sir.

12 **SIR BRIAN LANGSTAFF:** Well, I have no questions, but let
13 me thank you very much, Mr T. It takes courage to
14 give evidence, particularly when you have particular
15 reasons for wishing anonymity, so thank you very much
16 indeed.

17 **A.** Thank you.

18 **SIR BRIAN LANGSTAFF:** We will take an early lunch and that
19 means we will come back at 1.10 pm, so 1.10 pm.

20 (11.52 am)

(Luncheon adjournment)

22 (1.12 pm)

23 **SIR BRIAN LANGSTAFF:** Now, our next witness again has
24 anonymity and is to be known as Mrs U.

25 So in the same way as this morning I made

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1 illness and his death on you and your daughters, who
2 you're also going to name.

3 The people in this room will hear those names
4 but they mustn't be repeated. When the audio
5 recording goes up on the lived stream on the website,
6 the names will all be removed from the recording to
7 ensure that your anonymity is protected.

8 **A.** Yes.

9 **Q.** But you and I are going to use all of those names for
10 today. Okay.

11 We're going to be talking about your husband
12 [redacted]. When did you and [redacted] meet?

13 **A.** When we started working in the civil service. I was
14 16 and he'd just turned 17 and we started going out
15 right away.

16 He was a very gentle man and I remember his
17 ambitions were to do well at work and down the line he
18 wanted a detached house, a car and a large pedigree
19 dog and earn enough money to have a really good life,
20 and he said he was going to start saving and would
21 I like to -- would we like to get married. So that's
22 how we met.

23 **Q.** And you married in 1969.

24 **A.** That's correct.

25 **Q.** And you've given the Chair and myself a photograph of

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1 [redacted] from before he was ill, but for obvious
 2 reasons we won't put that up, but we've seen it.
 3 A. Yes.
 4 Q. You married in 1969 and then in early 1980 you moved
 5 house.
 6 A. That's correct.
 7 Q. What did you notice about [redacted] at about that
 8 time?
 9 A. Well, he'd taken time off work to help settle into our
 10 new home and he was painting the lounge and it was
 11 taking forever, and he was lethargic and very tired
 12 and I thought he should maybe go get and checked up as
 13 pernicious anaemia ran in his family so he made
 14 an appointment, went to the doctor, and he was sent
 15 straight into the Royal Infirmary and they did some
 16 tests, I think they did a bone marrow at that point,
 17 and perhaps gave him blood, and they said there was
 18 anomalies in his blood and they would keep an eye on
 19 him, and that's how it started.
 20 Q. Then about a week later, you went to your family
 21 doctor, your family GP. What happened then?
 22 A. [Redacted] had tonsillitis so we got an emergency
 23 appointment and it was the old doctor that I'd never
 24 seen before and after checking around and giving
 25 a prescription he asked if the girls could go into the

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1 times he went, I just can't remember.
 2 Q. And he ultimately had blood, platelets and some
 3 chemotherapy?
 4 A. Yes.
 5 Q. During that time, who was [redacted]'s treating
 6 doctor?
 7 A. Dr Ludlam.
 8 Q. And what was your relationship like with him?
 9 A. Well, initially, [redacted] was in a room on his own
 10 and I didn't really see Dr Ludlam very much, but
 11 [redacted] used to -- we always used to talk a lot, so
 12 when I went in to visit him in the afternoon he would
 13 tell me the last 24 hours' news and then I would tell
 14 him all my news.
 15 But as time went on, [redacted] got tired and
 16 started going into himself and I think it was the
 17 autumn of '92 that I was going along the corridor and
 18 met Dr Ludlam and he was concerned that I'd lost quite
 19 a lot of weight, so he said, "My office now", and
 20 I went along and he asked me what was going on and
 21 I said that [redacted] wasn't really telling me very
 22 much. In fact his nature had changed by then. He
 23 was -- he had gone into himself and there was a look
 24 that would come on his face that was -- when I asked
 25 him things, like, "Don't go any further, I don't want

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1 waiting area and count the fish in the fish tank. Of
 2 course, there was alarm bells going off.
 3 And when they left he said to me, they'd had
 4 a meeting that morning, a doctors' meeting, and they'd
 5 discussed my husband's case and he felt it was his
 6 duty to tell me that he had acute myeloid leukaemia
 7 and he would die but I mustn't tell him.
 8 I don't really remember going home, but
 9 [redacted] kept asking me is there something wrong.
 10 I was going no, no. But after a week, I just couldn't
 11 keep it in and I went to bits and told him and he was
 12 absolutely furious and he went into the Royal
 13 Infirmary and he was told that he had a bone marrow
 14 aberration, one in three goes into leukaemia and their
 15 advice to him was forget it and get on with your life,
 16 so I don't really know, they're just so different and
 17 I now wonder does everyone die who has acute myeloid
 18 leukaemia? It just seems quite a strange thing to
 19 have been told.
 20 Q. A little while after that, [redacted] did start
 21 treatment?
 22 A. He did. He used to go in and have his blood checked
 23 and then he used to go to a room where the
 24 haemophiliacs were given blood and he would get
 25 a top-up, as he called it. I'm not sure how many

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1 to discuss this. I'm too tired. I'm too exhausted.
 2 Tell mum and dad not to come in", and occasionally he
 3 would say, "Don't bring the girls in, I just don't
 4 want them to see me like this".
 5 And I said to Dr Ludlam, I just don't really
 6 know what's going on and I need to know what's going
 7 on because that's the only way I can cope. And he
 8 promised he would keep me abreast of what was going
 9 on. He would tell me the truth and I used to pop
 10 along to his office and he said just pop in.
 11 Actually, I called him Chris.
 12 And I would pop in and his secretary would say
 13 "Oh, he's not in at the moment. I'll make you coffee
 14 and I'll try and find him", and he would always come
 15 along and have a chat and because [redacted] was so
 16 ill, it was like a lifeline and he became a knight in
 17 shining armour, because I always knew I could just go
 18 and ask.
 19 Q. Because by then [redacted] had done some outpatient
 20 treatment and then he was now an inpatient in the
 21 hospital.
 22 A. He was an inpatient. He'd been in there for a while.
 23 Q. He was in isolation on his own for a very long time by
 24 then.
 25 A. Yes.

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1 Q. When [redacted] started having the transfusions of
2 blood and other products, was he -- are you aware of
3 whether he was ever warned about any risks involved in
4 receiving the transfusions?

5 A. I don't think he was, because I'm sure he would have
6 told me.

7 Q. And [redacted] by then was in hospital and his health
8 declined quite quickly?

9 A. Yes.

10 Q. Can you tell us a little bit about that.

11 A. Well, I remember in April 1983 when I saw the
12 contaminated blood scare in the papers. By then, he
13 was skeletal really. His skin was a strange colour
14 and also his eyes. He'd lost his hair, which was his
15 crowning glory and upset him enormously.

16 He also had oral thrush, which was horrendous,
17 and I was led to believe that was caused by
18 chemotherapy, and it was so bad they put a Hickman
19 line into his heart, I believe he was photographed and
20 put in the journals and it was quite a thing to have
21 this done.

22 He also had a cough, at one point coughing up
23 blood, because we had to wear masks. His nature had
24 changed. He was very depressed. Is that about all?
25 And with hindsight I think he actually had AIDS then.

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1 a Sunday and you do something nice with the girls",
2 because it was just living in that space all the time.
3 Q. [redacted] did come home for a short time around then.
4 Can you tell us about that.

5 A. Well, that was definitely between April '84, because
6 I passed my driving test on the 5th, and my first
7 journey on my home was into the [redacted] where he
8 went for convalescence and then a bit after that,
9 Dr Ludlam phoned me and he said he was concerned about
10 his mental health and he'd phone my GP, and Dr MacLeod
11 agreed to come in three times a day and administer the
12 drugs through his Hickman line, and was that all
13 right? And I said, yes, it will be nice to have him
14 home.

15 The first morning Alec MacLeod arrived at 7.30
16 and got everything ready and administered the drugs,
17 and when he came back at lunchtime, he said, "I want
18 you to scrub up". I said, "I don't know how to scrub
19 up". He said, "I'll talk you through it", so he did.
20 Actually, I remember after I did it I moved my sleeve
21 and I got a row and I had to start again and he talked
22 me through the procedure of what to do, and I put all
23 the stuff through but I was shaking, absolutely
24 shaking like a leaf. Then he said to me, "From now on
25 I want you to do it, because I could bring anything

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1 Q. When his skin changed colour and you saw in the press
2 about AIDS, what did you do?

3 A. I panicked, straight down to the Royal Infirmary to
4 see Dr Ludlam and when I asked him about it, he said,
5 "You don't need to worry. [redacted]'s blood been
6 irradiated and it's perfectly safe", and I believed
7 him.

8 Q. By Christmas 1983 [redacted] was really very unwell --

9 A. Yes.

10 Q. -- with the severe thrush and a horrible cough?

11 A. That's right.

12 Q. Dr Ludlam was keen for him to come home for a short
13 time.

14 A. Actually, I think at Christmas he'd actually asked me
15 to go in for a chat. I'd forgotten about a lot of
16 this because I buried it so deep, and he actually gave
17 him a 10% chance of getting through Christmas but it
18 was a terrible Christmas going in to see him coughing
19 like that, his face racked with pain.

20 I think in the evening when I went in -- I was
21 in with the girls in the afternoon. When dad and
22 I went in the evening, my dad cried like I'd never
23 seen him cry. He was just so horrified at what he was
24 going through and at that point on the way home he
25 stopped a car and he said, "From now on, I'll go in on

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1 into the house and infect him", or conversely he was
2 safeguarding his patients. I don't know which is the
3 truth.

4 But at teatime I found it really stressful. The
5 girls were watching Blue Peter. But I took my time to
6 get everything on the tray and when I started to put
7 the first lot through, [redacted] says, "You'll need
8 to do it slower because it's really cold", and I took
9 some deep breaths and really focused and I just had to
10 cope with that.

11 Q. And from then on you were, while [redacted] was at
12 home, you were administering the medication.

13 A. That's right.

14 MS FRASER BUTLIN: I should say, sir, there have been some
15 difficulties tracing Dr MacLeod but he has now been
16 asked to provide a response and anything that's
17 received will be published in due course.

18 SIR BRIAN LANGSTAFF: Thank you.

19 MS FRASER BUTLIN: Because you've had some concerns about
20 why Dr MacLeod was asking you to do the medication?

21 A. Yes, I would have thought a district nurse would have
22 been able to do that, and then I started my supply of
23 these three bottles of drugs that were kept in the
24 fridge. They were running out, so I phoned
25 Dr MacLeod. He seemed to have a flag up that if

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I phoned, I got put through, and asked him for a repeat prescription and he said he couldn't give me one because it was illegal, so I phoned the ward and spoke to the sister and she said that she couldn't give me a prescription or a supply of them.

So Dr Ludlam was spoken to. He said I would have to go in every few days and pick up a batch, and that's what I did.

Q. After a little while, [redacted] had to go back into hospital.

A. Yes.

Q. And what was the situation then?

A. Well, he'd had quite a lot of chemotherapy treatments and he'd gone into remission for short spells, and a while after that Dr Ludlam phoned me again and he said that he was concerned about [redacted] again and there was a new chemotherapy treatment in America. He'd exhausted all the ones here and there was a new one in America, and the NHS had agreed to fund it but it was experimental and he'd spoken to [redacted]. It was like his last chance, really, so he had agreed. So he wanted me to book a caravan so we could go on holiday and [redacted] could just come out and sit in the sun and go back in when he was tired.

And the school holidays were coming up, so I put

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help.

And he was so shocked at [redacted], he was crying, but we managed to get him down the stairs and into the car, because [redacted] didn't want the ambulance because it was too painful.

So I drove him to the infirmary, and you go down the brae and there's -- you're not really meant to do that and the guy came to book me and took one look at [redacted] and said, "Put your car on the pavement and I'll get the wheelchair".

So he took [redacted] up to the room, I brought his bag, and the sister asked me to go and get a coffee and come back in an hour while they did tests.

I was a bit upset going up and sitting in the cafe, and then after an hour you've got to just steel yourself and go back. But as I walked past the sister's office, she called me in and she told me that [redacted] was dying but I mustn't tell him, and that I should phone his parents and say if they want to see their son alive, they must come now but they can only come in at visiting time and they mustn't tell him he's dying. The same in relation to the girls.

I do remember walking up towards the phone boxes, there was four phone boxes and there's a low

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all that in place and the plan was when the girls came home from school on the Friday, I would take them and our large boisterous dog over mum and dad's and [redacted] could have a couple of days to recover. And then the girls were going to come home on the Sunday, and we'd have five days at home and then a week in the caravan, and then I went down to pick up [redacted].

And the sister, her last words were, "Will you keep an eye on his eyes and if they haemorrhage, you must bring him straight back in".

So when we got home [redacted] was just exhausted, so I got him up to bed and he just crashed out. The following morning when I woke up, I was lying looking at his ravaged body just thinking, you know, just -- just not really -- sorry. (Pause)

When he opened his eyes, they were both haemorrhaged and so I had to tell him, I said, "I'll need to go and phone the ward and say you're coming back in". When I phoned, the sister says, "Get him in as quickly as possible".

I got ready very quickly but I found I couldn't -- I just couldn't lift or help [redacted] to sit up. It was as if the fatigue just had floored him, so I had to go and get a neighbour to come and

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wall that all the winos used to sit on, and I went in to use the phone box to make those difficult phone calls of my life, and there was a party going on outside. And when I phoned [redacted] I think she was horrified and she said her usual retort, [redacted], and I said, "[redacted] the sister's told me to tell you I've got to go because I've got to phone the girls", you know. I phoned my mum and her response was the opposite, just keep praying and everything will be all right.

When I came out the phone boxes, all the guys sitting there obviously realised that I was in a state so they all got round me and were saying, "Are you wanting a wee drink", and, "you'll be all right".

So I went back down to [redacted]'s room and he was totally unconscious. I thought at first he was asleep and I spoke to him and I took his hand, but there was no response and I talked to him. I went and stood at the window for a while just looking out and then I went back and spoke and there was really no response.

I wondered if he was maybe in a coma and then the door opened and Dr Ludlam came in with two students and he probably asked me how I was, but I couldn't say, "Well, I'm not", but -- so [redacted]

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1 stirred at the deep male voices and he had a brief
2 chat and Dr Ludlam and the students left and
3 [redacted] looked at me and he said, "Why are you
4 here, it's not visiting time?" And I said, "Oh, the
5 girls are coming in later and I'm waiting to take them
6 home", and he kind of just laid back, shut his eyes
7 and went to sleep, but minutes later he took the
8 rigors really strongly.

9 That had happened before and I had to go and get
10 the nurse to get the tinfoil blanket but, of course,
11 when I went out they were clearing away -- all the
12 nurses were clearing away the tea, there was no nurses
13 to be seen, but Dr Ludlam was around so I ran down to
14 him and said to him -- and then I ran back to his room
15 and he was already dead. He'd had a massive brain
16 haemorrhage.

17 Q. He died at age 36. Your daughters then arrived. Can
18 you tell us about that.

19 A. The sister waylaid my Mum and Dad and said to the
20 girls, "I'll just take you in here for a moment", and
21 she brought mum and dad along to me, and then she went
22 back to her room and said to the girls, "Your daddy's
23 died and gone to heaven, you'll have to be good for
24 your mummy", and then she brought them along to the
25 room. [redacted], my youngest daughter, screamed and

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1 asked how the girls were and I said, "Well, we've all
2 gone into ourselves". We were a family that were
3 always together and talked all the time, but it was
4 just too painful. And then he asked how old they were
5 and he said, "I could arrange some family counselling
6 but I think it's been too long. It will probably
7 start surfacing in their 40s".

8 He did arrange the family counselling and it
9 just -- it just didn't happen.

10 Q. Some time after that you were visiting a gentleman in
11 the hospital. Can you tell us about that.

12 A. Yes. I went back to work about six years after
13 [redacted] died and I met [redacted] and we were both
14 on our own, we both liked the countryside, so we
15 started hillwalking and we went for some meals, and
16 then he said he was going down to see his mum in
17 Cumbria and he said it would be nice to get engaged,
18 would you like to come down and meet her?"

19 So the morning before we were going, he phoned
20 me up and said, "I'm really ill, I'm just so ill,
21 you'll just have to come now", so I rushed over and
22 yes he did look very ill, and I phoned the doctor and
23 the doctor came and said, "Oh, it's a mild heart
24 attack but I'm going to send you into the Royal
25 anyway", so I followed in the car and the usual, you

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1 ran out.

2 I can't remember any of that, [redacted] says
3 that dad was in death throes. His eyes were open and
4 his mouth was open and it was horrific. I'm afraid
5 I've blocked that out completely.

6 Q. Your mother and father-in-law arrived and then after
7 a little while you all left?

8 A. We left, uh-huh.

9 Q. [redacted]'s death certificate record that he'd died
10 of acute of myeloid leukaemia.

11 A. That's correct.

12 Q. And you are the girls were devastated.

13 A. Absolutely devastated. I mean, at that age you're
14 looking forward to going on hospital with your dad
15 who's been in hospital all that time and it's cruelly
16 taken away.

17 Q. You went to see Dr Ludlam about seven years after
18 [redacted] died. Why was that?

19 A. Well, I often reflected on the callousness of the way
20 we were treated that -- or the way, well, we were all
21 treated that day and I decided that I wanted to go and
22 share my experience with him because I felt it wasn't
23 right.

24 And I took him through that day and he said

25 I was right that things needed to change, and then he

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1 go and have coffee while they do the tests.

2 And then I went back in and we chatted, and
3 I think it was a chap that was in charge of the ward,
4 he says, "I'm sure things will be fine. You'll be
5 able to come and pick him up tomorrow and go down to
6 Cumbria". So I went home and made the tea, and then
7 I went back in, and when I was going back in I met
8 Dr Ludlam and he asked me why I was there, after we
9 had a wee chat, and when I told him, he said -- he
10 patted my arm and went, "Oh, he'll be absolutely
11 fine".

12 However, 3 o'clock the next morning my phone
13 rang and it was the ward to say that his blood
14 pressure had dropped significantly and it could be
15 indicative of a heart attack, would I like to go in?
16 I raced in.

17 When I got to the ward there was no nurses about
18 and then one came out a room and said, "Oh, he's had
19 a massive heart attack. We're trying to save him",
20 and she ran that way and got something and ran back
21 in. Shortly after that, she came out and said she was
22 sorry, he'd gone.

23 Q. Then a few years later, in about 1994, you were again
24 in the hospital, this time visiting your mum.

25 A. That's correct.

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1 Q. What happened then?
 2 A. I bumped into Dr Ludlam and we had a chat, and then he
 3 said, "Who are you visiting this time?" And I said,
 4 "Oh, it's mum this time", and then he said, "Oh, and
 5 how's your young man?" And I said, "Oh, he died the
 6 following morning at 3 o'clock", and he was so visibly
 7 shaken, I just -- I thought it was strange.
 8 But actually I had gone to see Dr Ludlam in
 9 January '93 because my nephew had been diagnosed with
 10 acute myeloid leukaemia, my daughter's only cousin, my
 11 only nephew. I just couldn't believe that this could
 12 happen again. And at that point acute myeloid
 13 leukaemia was the symptoms that my husband had
 14 presented and I was thinking, "Oh, God, my poor
 15 nephew", and I'm thinking, "Well, that's nine years",
 16 so I phoned Dr Ludlam up and said could I come in and
 17 have a chat? It was just to see how treatments had
 18 progressed and what was the prognosis.
 19 And I think that's important in the story
 20 further on.
 21 Q. Thank you for adding that in. So you'd spoken to him
 22 about your nephew and then in 1994 you've had the
 23 conversation when you're visiting your mum and he
 24 looked visibly shaken.
 25 A. Shaken, yeah.

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1 spree. Treat yourself to lunch and come back at
 2 4 o'clock", I can't remember if it was 4 or half past,
 3 so I don't know where I went and I definitely didn't
 4 have lunch. I didn't buy anything, and I was sitting
 5 waiting on him, his secretary always making me my
 6 coffee.
 7 Then he came in and said, "It's all right,
 8 you're clear". Then he said he'd been to court on
 9 behalf of the haemophiliacs. He said he didn't
 10 involve me because I'd been through enough, and he
 11 would do all the forms and down the line I would hear
 12 from The Macfarlane Trust or The Eileen Trust,
 13 I believe is the non-haemophiliac part of it, and
 14 I think was it August '94, the cheque -- the cheques
 15 arrived.
 16 Q. When you spoke to Dr Ludlam he also told you that
 17 vials of [redacted]'s blood had been kept.
 18 A. Yes.
 19 Q. Did he say anything more about that?
 20 A. He didn't, no.
 21 Q. Why --
 22 A. It made me feel physically sick actually to think he
 23 still had [redacted]'s blood ten years after he'd
 24 died. The whole thing was -- there's just no words to
 25 describe.

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1 Q. You were then phoned by Dr Ludlam?
 2 A. That's correct.
 3 Q. And what did he say?
 4 A. He said, "I need to talk to you", and I said, "You are
 5 talking to me, what is it? What is it now", you know.
 6 He says, "No, I need you to come in". I said, "Well,
 7 I need you to tell me now". He says, "No, come in
 8 tomorrow at 10 o'clock".
 9 So 10 o'clock the next morning I was in his
 10 office and when he came in, he said, "There's just no
 11 easy way to say this, but [redacted] contracted AIDS
 12 through a blood transfusion and I've brought you in
 13 today to ask you if at any time on [redacted]'s visits
 14 home, few visits home, and I always thought he would
 15 be too ill, did you ever make love?"
 16 And I said, "Yes, just the once", and he said,
 17 "Well, I have to test you". God, it's like the bottom
 18 falling out of your world, because all I could think
 19 of was, "Oh my God, what if I've given that to the
 20 girls or" -- and that's the only thought I had in my
 21 head and he took the blood and I said, "Does it not
 22 take about it a week?" And he said, "No, remember,
 23 I'm head of haematology. As soon as you go I will go
 24 straight and have it tested".
 25 So he said, "Go into town and have a spending

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1 Q. Did he explain to you why he told you about [redacted]
 2 contracting AIDS at that point in time?
 3 A. I think the shock was just too much for me to think on
 4 any questions, and I've never felt -- I've never felt
 5 able to go back and speak to him because of the
 6 betrayal I felt.
 7 I remember saying to the girls, "Do you know,
 8 I believe I called him Chris", and it's just so --
 9 I mean, he was my knight in shining armour. He was
 10 there for me and to be betrayed like that ten years
 11 down the line, it was just -- so I said I think we
 12 should just shut the door on that and move forward,
 13 but then you don't realise what that does to you, the
 14 fact that you're betrayed and you're shocked and it
 15 devalues you as a human being. You just lose your
 16 self-worth. What are you worth that you can be
 17 treated like that?
 18 And I believe he should have told us, he should
 19 have told [redacted] and I together, because I went in
 20 on my own in the afternoon because as a family you
 21 would have been able to cope with that and you would
 22 have been in charge of your own destiny instead of
 23 which you're robbed of that and it just -- well,
 24 you're self-esteem plummets and the girls and I have
 25 lived with the consequences of that ever since.

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1 Q. You've said in your statement you don't now know what
2 complications arose from the AIDS and what was from
3 the leukaemia?
4 A. That's right.
5 Q. And that's something you really struggle with?
6 A. Mmm-hmm, what was the reality back then? I just don't
7 know.
8 Q. Your daughters -- one of your daughters has said that
9 the question of whether her dad was used for research
10 torments her, and you've said you have a list of
11 questions you wish you'd asked Dr Ludlam at the time,
12 but you haven't been able to.
13 A. I felt unable to.
14 Q. And they are questions like when was he infected, when
15 did they know he was infected and why they didn't tell
16 you at the time.
17 A. Yes.
18 Q. Can you tell us a little bit about the impact on your
19 daughters as well.
20 A. Well, the aftermath of [redacted] dying, you're trying
21 to cope with a funeral, telling the schools, seeing to
22 all these things and then I think the girls struggled
23 with -- well, we struggled to talk about it because
24 our grief was so intense, it just couldn't be
25 verbalised.

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1 talked about it.
2 Q. All the family statements have said that many of the
3 same questions of what was happening and why and part
4 of the -- what you've tried to do since then is to get
5 some answers to your questions by applying for
6 [redacted]'s medical records.
7 What did you receive when you applied for his
8 hospital records?
9 A. There's none. There's no records, apart from I went
10 to the NHS archivist and she found something but, of
11 course, she couldn't tell me what I was and it's just
12 a test that they did on the day he died, and that's
13 the only -- but then I got a copy of all the policies
14 from the NHS starting and it would read in my mind
15 something of such medical significance would have to
16 have been kept, but they can find no trace.
17 And when I got the letter back from Darren
18 Poole, the medical records office, he had put about
19 haemophilia which freaked me out because he wasn't
20 a haemophiliac. I was thinking, oh, he's gone down
21 the wrong -- but no, they say they've researched
22 everywhere.
23 MS FRASER BUTLIN: And for the record, I should record
24 that Dr Ludlam has been asked for his response and he
25 has indicated that a response will be provided.

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1 I think to make matters worse, not long after
2 [redacted] was diagnosed with scoliosis which meant we
3 were going backward and forward to the Princess
4 Margaret Rose. My daughters were very close and
5 played together and now they were silent, and we'd
6 gotten into the habit of eating our meals watching the
7 telly and I said to them, "This is no good. We must
8 start eating at the table again and talking", and
9 there was total silence for about a month but we
10 couldn't really get through that barrier of grief.
11 And, yes, I think low self-esteem has played
12 a part and [redacted] struggled, I think you both
13 struggled.
14 Q. And once [redacted] -- once you've were told that
15 [redacted] had also contracted AIDS, you said in your
16 statement the girls have said in their statements that
17 they came to question everything and had a loss of
18 trust in doctors whenever they had to deal with
19 anything medical.
20 A. Well, this is true. I don't think I fully trusted
21 anyone since. I feel myself pulling back. That level
22 of betrayal, I don't think -- and there was never any
23 counselling offered. I think when he told me that,
24 that was the opportunity to offer counselling and
25 I think we've all worked at that in our own way and

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1 SIR BRIAN LANGSTAFF: Thank you.
2 MS FRASER BUTLIN: As you've looked back to when
3 [redacted] was ill, you've also been concerned about
4 your interactions with Dr MacLeod and the giving --
5 why you were asked to give the medication.
6 What are you now concerned about in that regard?
7 A. Well, I went to see him to say I thought under the
8 circumstances he should have never have asked me to do
9 the procedure, because I was exhausted at that point
10 and it placed an extra burden on us all. And he said,
11 "Yes, but you're nothing but a bloody stupid woman",
12 at which point I stood up and said, "Well, I haven't
13 come here to be spoken to like that", but with
14 hindsight I believe that he knew [redacted] had AIDS,
15 that he possibly had known for a long time, and he
16 thought I was stupid because I hadn't thought about
17 it, but in actual fact I had gone to Dr Ludlam and
18 asked him and clearly been lied to.
19 Q. And while [redacted] was ill, Dr MacLeod had also
20 asked to do blood tests on your daughters.
21 A. That's correct.
22 Q. And at the time, what did you think those tests were
23 for?
24 A. Well, the -- he thought they were maybe a bit anaemic,
25 but then they were always pale.

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1 Q. And what's your concern now about those blood tests?
 2 A. Well, the girls thought that we were maybe getting
 3 tested for acute myeloid leukaemia but with hindsight
 4 we now wonder it was to see if we had HIV/AIDS or
 5 hepatitis C.
 6 Q. And your concern now is that not were you not told and
 7 [redacted] not told about the AIDS but that the GP had
 8 been told --
 9 A. That's correct.
 10 Q. -- and was responding to that.
 11 A. Mmm-hmm. Because during my nephew's treatment, yes,
 12 he lost weight, he lost his hair, he was slimmer but
 13 his skin was the same and his eyes were the same, so
 14 that's one of the reasons I wondered if [redacted] had
 15 hep C.
 16 Q. After [redacted] died, what was your financial
 17 situation like?
 18 A. It wasn't good. I remember going to a solicitor
 19 because the house was in [redacted]'s name. He hadn't
 20 made a will, and I was told that I'd probably lose the
 21 house. I'd have to go to court and the thought of
 22 that was horrendous. I just kept thinking, "Oh God,
 23 we'll have to go and stay with mum and dad and it's
 24 a tiny house", but that was resolved down the line
 25 because [redacted], obviously it was insured properly.

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1 Q. You'd moved house and didn't think to tell them but
 2 equally there was no indication that you were entitled
 3 to anything else or that you should be applying for
 4 anything else?
 5 A. No, it was a one-off payment that you had to sign to
 6 say you wouldn't go to the press or whatever.
 7 Q. Then in July 2017 your daughters told you about the
 8 Scottish Infected Blood Support Scheme?
 9 A. That's right.
 10 Q. And you applied?
 11 A. That's right.
 12 Q. How did you find that process?
 13 A. It was actually quite easy. I phoned the helpline up
 14 to ask a question, I can't even remember what it was
 15 but they were very nice, very helpful.
 16 Q. And you've received payments from July 2017 --
 17 A. That's correct.
 18 Q. -- but they've not been backdated in any other way?
 19 A. No.
 20 Q. You've also had some problems with your pension. What
 21 were they?
 22 A. Well, this payment wasn't supposed to affect your --
 23 any benefits that you were getting and I have
 24 a guaranteed pension credit, so when I phoned them up
 25 and told them, obviously, I got a bit of grief about

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1 I went for a widow's pension my mum was with me.
 2 We were in a queue at the DSS and when I got to the
 3 top of the queue and said I'd come about a widow's
 4 pension. The woman says, "Oh, you're so lucky", at
 5 which point I was hysterical, absolutely hysterical.
 6 I remember two people coming and ushering mum and
 7 I into a room, bringing tea, and the reason I was
 8 lucky was Margaret Thatcher had brought in a rule that
 9 widows under 40 had to go out to work and as it was
 10 just being phased in, I would get half a widow's
 11 pension. It's like, "No, I don't want half a widow's
 12 pension, I don't want a whole widow's pension. I just
 13 want my husband back", and people are so ... (Pause)
 14 They're just not trained probably, but it's
 15 just -- I was grateful to have my house. I have to
 16 say that was quite scary, but I think we coped with
 17 what we had, so I remember a life of luxury never
 18 arrived but we just made the best of things.
 19 Q. Once you were told that [redacted] had contracted
 20 AIDS, you were then able to access some financial
 21 assistance.
 22 A. Yes, the cheques from The Macfarlane Trust.
 23 Q. After you received that initial payment, did you
 24 receive anything else?
 25 A. No.

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1 it and I said, "Well, I've got the letters here." So
 2 I read the letters out. So could I photocopy them and
 3 send them, which I did.
 4 Then I think my pension review was coming up and
 5 the lady was quite difficult, I would think, and
 6 I told her that I was getting this payment and she
 7 says, "Oh, we'll have to reduce your pension credit",
 8 and I says, "Oh, well, that's not how it reads", but
 9 in actual fact they did. It slightly went down and
 10 it's just been reviewed and it's gone down again,
 11 but ...
 12 Q. So because you received SIBSS payments your pension
 13 credit was also reduced?
 14 A. Yes, it was also ...
 15 Q. Those are the questions I have for you. Is there
 16 anything else you would like to say?
 17 A. Well, I think when -- just eight years after her dad
 18 died, [redacted] had a lump in her breast and went to
 19 the Royal, was it -- no, she went to the Western and
 20 when the consultant came in, the first thing he said
 21 was, "Are you [redacted]'s daughter?" Which I said to
 22 her, "That's a bit unusual".
 23 So I think that's one of the things that makes
 24 you think you're kind of being watched from afar and
 25 a neighbour who used to go to Dr Ludlam's clinic to

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1 have her blood checked, she used to say, "Oh,
 2 Dr Ludlam was asking after you", and at first that
 3 seemed a reasonable thing but it went on for years
 4 until I finally said to her, "That's really weird.
 5 He's got all these patients. He should be
 6 concentrating on them. It's really weird that he's
 7 still asking", so ...
 8 **MS FRASER BUTLIN:** Thank you.
 9 Sir?
 10 **SIR BRIAN LANGSTAFF:** I have no questions but I would like
 11 to thank you for that careful and compelling account
 12 which has obviously not been easy for you to give.
 13 Thank you very much indeed.
 14 **A.** Thank you.
 15 **SIR BRIAN LANGSTAFF:** Ms Fraser Butlin, we'll start again
 16 for our final witnesses at 2.30 pm.
 17 **MS FRASER BUTLIN:** Thank you.
 18 **SIR BRIAN LANGSTAFF:** 2.30 pm.
 19 (2.06 pm)
 20 (A short break)
 21 (2.35 pm)
 22 **SIR BRIAN LANGSTAFF:** The last two witnesses of today are
 23 both anonymous and will be known as Mr and Mrs V. In
 24 case there's any difficulty in hearing that, that's V
 25 for victor, which is not their name.

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1 live-streamed.
 2 In the event that you use each other's names
 3 naturally in the course of your evidence, although the
 4 name will be heard by those present, the effect of
 5 that order is that no one can repeat that information
 6 and when the transcript of your evidence and the audio
 7 transcript of your evidence is published, it will be
 8 with any names removed.
 9 **MR V:** Okay.
 10 **MRS V:** Okay.
 11 **MS RICHARDS:** So Mr V you were born in 1974.
 12 **MR V:** Yes.
 13 **MS RICHARDS:** And you have severe haemophilia A which was
 14 identified at birth.
 15 **MR V:** Yes.
 16 **MS RICHARDS:** You were under the care of
 17 Yorkhill Children's Hospital in Glasgow until you were
 18 about 15.
 19 **MR V:** That's correct.
 20 **MS RICHARDS:** And your mother's witness statement, she's
 21 also provide a statement to the Inquiry, tells us that
 22 until you were about five years old, you received
 23 largely cryoprecipitate.
 24 **MR V:** That's correct.
 25 **MS RICHARDS:** And you'd have to be taken to hospital in

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1 The names and addresses of witnesses W2243 and
 2 W2245 and any other identifying information such as
 3 the witness's image or a description of their
 4 appearance cannot be disclosed or published in any
 5 form unless expression permission is given by me or by
 6 the solicitor to the Inquiry acting on my behalf.
 7 Witnesses W2243 and W2245 must be referred to only as
 8 Mr and Mrs V.
 9 This order remains in force for the duration of
 10 the Inquiry and at all times thereafter, unless
 11 otherwise ordered. I may vary or revoke the order by
 12 making a further order during the course of the
 13 Inquiry.
 14 So that is the order, a reminder that it is
 15 a contempt of court to break that order, but with
 16 those introductory words may we have, please,
 17 Mr and Mrs V.
 18 **MR V, affirmed**
 19 **MRS V, affirmed**
 20 **Questioned by MS RICHARDS**
 21 **MS RICHARDS:** Mr and Mrs V, although I'm going to refer to
 22 you as such, you're going to be to some extent giving
 23 evidence about each other and it's very natural for
 24 you to refer to each other's names in the course of so
 25 doing, so for that reason, your evidence is not being

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1 order to receive that.
 2 **MR V:** Yes, I was there every week.
 3 Eventually my mum was taught home treatment,
 4 which limited the number of times I was at hospital
 5 but until that point we were there constantly at
 6 Yorkhill.
 7 **MS RICHARDS:** And it was about 1979, September of 1979,
 8 that the home treatment programme commenced.
 9 **MR V:** That's correct, yes.
 10 **MS RICHARDS:** And then you received Factor VIII products.
 11 **MR V:** Yes.
 12 **MS RICHARDS:** Now, there were not available treatment
 13 records from Yorkhill Hospital showing what products
 14 you received, but you've got an understanding or
 15 recollection of some of the products you received.
 16 What can you recall?
 17 **MR V:** Yes, I received four different American products.
 18 The only reason I know this was going back over 15
 19 years ago when there was legal action against the
 20 American pharma companies and I was told to contact
 21 Manchester -- there's an organisation in Manchester
 22 that kept all the haemophiliacs' details of what
 23 products they were given, so at that point I was given
 24 the names of four companies. I remember one was
 25 Baxter, one was Bayer, I can't remember other two, but

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1 the legal action that point collapsed. If it was
2 thrown out of court.

3 **MS RICHARDS:** And is it right that your mother was asked
4 to keep a record, her own records, of the treatments
5 that she gave you?

6 **MR V:** Yes, we had a book and it was divided up into
7 different columns. The batch numbers, the dates,
8 everything was written down, the type of injury I had,
9 and once the book was full we'd hand it into the
10 haemophilia unit at Yorkhill, but we've never seen any
11 of it since.

12 **MS RICHARDS:** So your mother provided that back to the
13 hospital at their request?

14 **MR V:** Yes.

15 **MS RICHARDS:** And as far as you know, the hospital,
16 whether they have been lost, destroyed, you don't
17 know, but none of those records have been made
18 available to you?

19 **MR V:** None at all.

20 **MS RICHARDS:** Do you know whether any warnings or advice
21 or information was provided to your parents about any
22 risks of infection associated with the products?

23 **MR V:** No. She was given -- I remember in the mid '80s
24 she was given rubber gloves for -- just in case she
25 was contaminated with hep B, because I was given

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1 and Tuesdays and then also additional doses on any
2 occasion that you develop a painful swollen joint,
3 protracted bleeding or a haematoma in the head or neck
4 area.

5 So from September 1979 you were being given
6 Factor VIII treatments on a prophylactic regular basis
7 twice a week.

8 **MR V:** Yes, and that cut out the journey to Yorkhill
9 because we stayed quite far out from Yorkhill, we
10 stayed in [redacted], we lived in a police house, so
11 with my dad working shifts, my mum couldn't drive and
12 the police office was attached to the house, so my mum
13 would go into the police office and they would -- the
14 police would drive us straight into Yorkhill every
15 time I bled, but as soon as this new Factor VIII came
16 out it was being hailed as the best thing since sliced
17 bread.

18 **MS RICHARDS:** Now, your mum records in her statement that
19 as far as she can recall she was never given any
20 choices about which products to use. She was just
21 told what product would be available for her to
22 administer.

23 **MR V:** Yeah, at the end of the day they're the experts.
24 You go by what they tell you. You trust them.

25 **MS RICHARDS:** Then she has a recollection at some stage of

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1 an injection for that, to prevent hep B, but that
2 was -- nothing else.

3 **MS RICHARDS:** To start with your mum use to administer the
4 Factor VIII treatment to you at home?

5 **MR V:** Yes.

6 **MS RICHARDS:** Then from about the age of 11 you were able
7 do it yourself.

8 **MR V:** Yes, age 11 I was taught.

9 **MS RICHARDS:** The impression that your mum's statement and
10 your statement gives is that the information you were
11 given was that you this would be much easier, a more
12 straightforward treatment for you to receive because
13 you wouldn't need to go to hospital and it would be
14 life-saving?

15 **MR V:** That's correct.

16 **MS RICHARDS:** We can see a couple of documents that
17 provide us with some information about the treatment
18 you received at that time.

19 If we have up on screen, please, Paul, 2245002.
20 You'll see -- thank you -- Mr V, that here is
21 a letter. It's from Dr Willoughby to your GP and the
22 date of it is -- it's actually 25 September 1979, and
23 it refers to the training that was being given to your
24 mother, the home therapy training, and that you'll be
25 given regular twice-weekly doses, usually on Fridays

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1 there being a meeting at Yorkhill at which information
2 was provided about a product that would be
3 heat-treated.

4 **MR V:** Yeah, I can't remember what that was. I was quite
5 young at the time.

6 **MS RICHARDS:** Your medical records contain a number of
7 tests for HTLV-III, HIV as it is subsequently referred
8 to. As far as you know, were your parents asked to
9 consent to those tests or were they aware of them
10 being undertaken?

11 **MR V:** No, none of us did.

12 **MS RICHARDS:** Well, when and how did you discover that you
13 had been infected with hepatitis C?

14 **MR V:** At a routine hospital -- hospital appointment at
15 the haemophilia unit in Glasgow, the Glasgow Royal,
16 and my doctor at the time was Dr Lowe, Dr Gordon Lowe,
17 and he just told me straight, "You've tested positive
18 for hepatitis C", and I didn't know what it was.
19 I thought it was basically -- I thought it was similar
20 to HIV, so I asked him about my liver. I says,
21 "I know hepatitis involves the liver". I says, "Am
22 I going to get a liver transplant?" And he says
23 "Well, it could be three months, it could be three
24 years, it could be 30 years, we don't know".
25 And then he started to tell me, "Do not share

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1 razors, do not share razor blades and do not have anal
2 sex". I thought, "My God, I'm only 20 years old. I'm
3 just a boy getting told this by this old man", as he
4 was to me then, and he handed me a pamphlet and that
5 was it. My dad was down the stairs in the car.
6 **MS RICHARDS:** And that was in 1994.
7 **MR V:** 1994.
8 **MS RICHARDS:** And as far as you are concerned, 1994 at
9 a routine appointment was the first time you learnt
10 that you had hepatitis C?
11 **MR V:** Yes.
12 **MS RICHARDS:** And what was the immediate impact upon you
13 receiving that diagnosis.
14 **MR V:** I was gutted, because I blamed my Mum. I blamed
15 her for everything because she injected the stuff into
16 me. I mean, at the same time I was injecting it as
17 well, sick and perverse, if you've think about it,
18 because I was being reinfected constantly over and
19 over since 1979. My Mum was injecting me and then
20 from age 11 I was injecting myself. You couldn't make
21 it up.
22 **MS RICHARDS:** You've said in your statement:
23 "I was 20 years old and my future was just wiped
24 out."
25 **MR V:** Yeah, I thought I was gonna die. I mean, straight

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1 weren't told of that.
2 **MR V:** Correct, yes. What medical notes I do have, it
3 does say non-A non-B hepatitis going right back to the
4 early '80s.
5 **MS RICHARDS:** We'll look at some of those documents, Mr V.
6 Paul, could we have 2245009, please.
7 You'll see this is a letter dated 10 January
8 1989, so years before your diagnosis was communicated
9 to you. It is from Dr Pettigrew to Dr Lowe and if we
10 look at the second paragraph, first of all, it refers
11 to your most recent liver functions tests on
12 4 November 1988:
13 "Showed elevation of AST 179 units per litre
14 with an ALT of 54 units per litre. His liver function
15 tests have been slight elevated in the past, for
16 example, in September 1984 his AST was 75 and his
17 ALT81."
18 And then further references to blood counts,
19 white counts, platelet counts and neutrophil accounts.
20 Had you or your parents been told in late 1988
21 or early 1989, which is the date of this letter, that
22 your liver function tests had been elevated?
23 **MR V:** No, and you have to understand with severe
24 haemophilia you're constantly up at the hospital,
25 collecting treatment, dropping dirty needles and

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1 after I was told, I was working that day. My Dad had
2 driven me to the hospital for my appointment. He was
3 working shifts. I got into the car. I told my Dad.
4 He was absolutely fuming with Dr Lowe for telling me
5 on my own. He missed the cut off for the motorway to
6 take me to work. I went back to work somehow, managed
7 it, I was in a sort of dazed for the rest of the day.
8 I was in a daze. I went home that night, blamed my
9 Mum for it. It was just horrendous. I thought I was
10 going to die eventually.
11 **MS RICHARDS:** And you've described in your statement you
12 were on your own, as you say, you were given this
13 leaflet and you weren't offered any kind of follow-up
14 or counselling.
15 **MR V:** No, nothing at all.
16 **MS RICHARDS:** Were you aware before you went to that
17 routine appointment in 1994 that you had in fact been
18 tested for hepatitis C?
19 **MR V:** No.
20 **MS RICHARDS:** So the first you heard of it was that
21 appointment.
22 **MR V:** Yes, that's the first I heard.
23 **MS RICHARDS:** You now believe from the medical records
24 you've subsequently obtained that your infection was
25 known to doctors caring for you before 1994 but you

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1 syringes off at the hospital unit. We went back and
2 forth. Not as much as we were ten years previously
3 before the -- before the treatment started, but it's
4 an unusual relationship you have with haemophilia
5 because, you know, it's like a family, the staff.
6 It's not like going to your doctor's surgery where you
7 see them once in a blue moon. It's like a family.
8 Everyone knows everyone.
9 **MS RICHARDS:** And we'll look at another letter from
10 slightly later in 1989, Mr V.
11 Paul, it's 2245008, please. It's a letter of
12 10 May 1989 and it's from Dr Lowe to your GP and if we
13 go to the second page of the letter, please, last
14 paragraph, thank you, the last sentence says this:
15 "I note his liver functions tests have been
16 fluctuating in the past when he attended Yorkhill and
17 I assume that he might therefore have a degree of
18 chronic non-A non-B hepatitis for which at present there
19 is no specific treatment."
20 Were you told or your parents told that the
21 doctors treating you assumed that you had a degree of
22 chronic non-A non-B hepatitis in 1989?
23 **MR V:** No, we didn't know a thing.
24 **MS RICHARDS:** If we then have up on screen please, Paul,
25 document 2245007.

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We see here we are in the following year, this is a letter of 8 May 1990, again it's from Dr Lowe to your GP, and if we pick it up about halfway down the paragraph it says this:

"I note that when he attended Yorkhill Hospital he had elevations of his ALT which may represent a degree of chronic non-A non-B hepatitis."

So we're now in the middle of 1990. Were you told at that stage or your parents told that they thought you might have non-A non-B hepatitis?

MR V: No, nothing.

MS RICHARDS: Paul, can we have up on screen please 2245006.

This is a letter again from Dr Lowe to your GP. We're a year further on, 30 May 1991, and if we look at the last few lines of the first paragraph it says this:

"As you know ..."

The "you" being your GP:

"As you know from previous correspondence, he has a persistent slightly elevated serum ALT level. I note this has been present since 1988 when he was at Yorkhill Hospital. Neither [redacted] nor his father gave any history of jaundice or clinical hepatitis. I explained to [that's your father] that he has slight elevation of

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you either by your GP or Dr Lowe?

MR V: No, nothing at all.

SIR BRIAN LANGSTAFF: And the sentence before that:

"He is positive for antibody ..."

MS RICHARDS: Yes, sir, thank you for picking that up, yes:

"... positive for antibody to the recently described hepatitis C virus as shown by second generations tests, as is the case with most haemophiliacs who have received non-heat treated blood products in the past."

So a first reference there to hepatitis C but that wasn't communicated to you?

MR V: No, nothing at all, no.

MS RICHARDS: We have then later on in 1992 document 2245005, please. The last four lines, this is a letter of 23 June 1992 from Dr Lowe again to your GP:

"We are still looking into the possibility of obtaining some interferon for treatment of chronic hepatitis."

Had there been any discussion with you by then at least, June 1992, either of the belief that you had hepatitis or the possibility of treatment with interferon.

MR V: No, nothing at all.

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serum transaminase which we will keep an eye on at the clinic. This may represent a degree of chronic non-A non-B hepatitis from previous treatment with blood products."

There's clearly been some discussion with your father and a reference to keeping an eye on some test results, but were or your father, as far as you know, told that this may represent a degree of non-A non-B hepatitis?

MR V: No, never.

MS RICHARDS: Or any causal connection with previous treatment with blood products?

MR V: No, never.

MS RICHARDS: Can we have up on screen please 2245013.

This is a letter dated 7 January 1992. Again it's from Dr Lowe to your GP and if we pick it up towards the bottom of the letter, the last main paragraph, it says:

"Here his chronically abnormal liver function tests noted initially at Yorkhill and subsequently here may therefore reflect chronic hepatitis C for which there is no specific treatment at present, although studies of interferon are being conducted and this may be an option for the future should his liver disease progress."

We are now in 1992. Was this communicated to

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MS RICHARDS: And then finally, if we have up on screen please 2245003. This is a more recent document. It's an extract I think from -- whether it's your GP or other records I'm not sure, but if we go about two-thirds of the way down the page, Paul, please just below the words "past procedures" we can see the words:

"Chronic viral hepatitis C", and then the date of onset and date recorded given as 1 January 1989. Not something you had been told?

MR V: No, nothing at all.

MS RICHARDS: Your recollection is 1994 --

MR V: Yes, '94.

MS RICHARDS: -- when you learnt this information.

If we have up on screen, please, Paul, 2245012.

This is a letter of 4 November 1994 from Dr Lowe to your GP, and if we look in the second paragraph -- it is refers in the first paragraph to having reviewed you on two occasions and then it describes on the first occasion:

"I updated him on recent advances in knowledge about hepatitis C and viewed with him precautions with blood, sex and alcohol. He is known to be hepatitis C antibody positive and he is on also positive by the recently introduced HCV PCR test."

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1 Then there is a reference to you being advised
 2 about the possibility of chronic liver disease and
 3 that your serum ALTs continue to be borderline
 4 elevated.
 5 That's your understanding of the occasion when
 6 you were not updated but told for the first time that
 7 you had --
 8 **MR V:** The first time, yes.
 9 **MS RICHARDS:** -- hepatitis C.
 10 You were also concerned, your statement says,
 11 that your employers, you were a civil servant, were
 12 told about the doctor's view that you had non-A non-B
 13 or hepatitis C before you were.
 14 **MR V:** That's correct.
 15 **MS RICHARDS:** If we have up on screen, please, Paul,
 16 2245014.
 17 We can see this is a request that was sent from
 18 the Civil Service Occupational Health Service,
 19 17 March 1993, to your GP and it was -- we can see the
 20 purpose of the request in the second paragraph:
 21 "Management have expressed some doubt as to
 22 suitability on the basis of the candidate's health
 23 declaration which revealed haemophilia."
 24 Then if we have, please, Paul, document 2245005
 25 and we look at the second page, please, Paul.

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1 **MR V:** That's correct.
 2 **MS RICHARDS:** And your GP was someone who knew well.
 3 **MR V:** Yes, we lived next to door to him.
 4 **MS RICHARDS:** And that was information was never passed on
 5 to you or, whilst you were a child, your parents.
 6 **MR V:** No, nothing at all.
 7 **MS RICHARDS:** You say in your statement that you believe
 8 you have been tested without your knowledge and
 9 consent.
 10 **MR V:** Yes.
 11 **MS RICHARDS:** Is that a reference to the HIV tests and the
 12 hepatitis C tests that you weren't aware were being
 13 carried out?
 14 **MR V:** Yes.
 15 **MS RICHARDS:** And your Mum says in her statement to the
 16 Inquiry that every time she would take you as a child
 17 to Yorkhill, blood would be taken, she would ask why
 18 and she would be told it was just routine.
 19 **MR V:** Yes.
 20 **MS RICHARDS:** You received in 2001, 2002, 2004 and 2009
 21 letters about the risk of vCJD.
 22 **MR V:** That's correct.
 23 **MS RICHARDS:** What can you recall about the receipt of
 24 those letters and the steps you took?
 25 **MR V:** Just letters asking me if I would like to know if

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1 We can see your GP's response dated
 2 22 March 1993 to the Civil Service Occupational Health
 3 Service is to describe you as very independent and in
 4 charge of your own treatment for your haemophilia, and
 5 then it says:
 6 "I enclose a photocopy of his last two hospital
 7 reports which may be of some assistance to you."
 8 For the record the enclosures are those two
 9 letters from 1992 that we've looked at --
 10 **MR V:** That's right.
 11 **MS RICHARDS:** -- which refer to the suspicions about you
 12 having --
 13 **MR V:** That's correct. I only found that out back in
 14 about '96, 1996 I found out, when I was off work,
 15 I had an operation on my ankle for haemophilia, and
 16 the occupational health nurse came out to the house
 17 and handed me the file and that's when I saw
 18 hepatitis C and the date on it.
 19 **MS RICHARDS:** And your understanding from the records,
 20 therefore, is that not only did those treating you at
 21 the hospital understand and believe that you had
 22 hepatitis C for about five years before you were told
 23 but that your employers knew from 1993, so the year
 24 before you were told, and your GP knew from the
 25 communications received from Dr Lowe.

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1 I've received blood from a donor who has since died of
 2 variant CJD and it was up to myself if I wanted to
 3 know or not, so I contacted the haemophilia out in
 4 Glasgow and arranged an appointment with Dr Lowe,
 5 which I went to, and he said on this particular -- the
 6 first time I went he said on this particular instance
 7 you didn't receive the blood from the contaminated
 8 batch. You can go home and have a well-deserved pint,
 9 and I says, "Well, I can't. I've got hepatitis C",
 10 and that was it.
 11 **MS RICHARDS:** And although you were told that you hadn't
 12 received anything from an implicated batch in relation
 13 to vCJD, you've continued to receive notifications
 14 about being at risk for public health purposes.
 15 **MR V:** Yes.
 16 **MS RICHARDS:** And, as I understand it, you are not
 17 confident in any event in the information you have
 18 been given and its accuracy.
 19 **MR V:** No. I don't believe, a word Dr Lowe has told me.
 20 I think he's lied to me.
 21 **MS RICHARDS:** And does the possibility of infection with
 22 vCJD continue to concern you?
 23 **MR V:** Yes. It's constantly on my mind. I'm terrified.
 24 I mean, last year I got diagnosed with severe stress.
 25 It's just horrendous what we've had to go through.

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1 What else can they do to us? What else?
 2 **MS RICHARDS:** What, broadly, has been the impact of the
 3 hepatitis C diagnosis and infection on your physically
 4 and mentally?
 5 **MR V:** Well, going back to when I was 20, that was my life
 6 wiped out, as far as I was concerned. I didn't tell
 7 any of my colleagues in work. I kept it quiet for ten
 8 years. Only my close family and friends knew. It was
 9 living on death row. That's the only way I can
 10 describe it. Eventually after about ten years in
 11 work, I told my boss, explained what happened. He was
 12 very supportive, because at that time I attended
 13 several demonstrations, blood campaign demonstrations,
 14 and he'd let me have time off work to go and attend
 15 them. The guy was great. But I still kept it quiet
 16 from the -- my actual immediate colleagues until I had
 17 the interferon treatment.
 18 **MS RICHARDS:** Before we talk about the interferon
 19 treatment, what physically has been the symptoms or
 20 effects of the hepatitis C that you've experienced?
 21 **MR V:** Things like I developed asthma, skin conditions,
 22 really bad eczema, and when I say itching, I mean I'm
 23 clawing at myself, it's that bad. So I'm
 24 an outpatient at the dermatology department at the
 25 Glasgow Royal. I have been on and off for the past,

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1 it, I didn't tell [redacted] I had hepatitis C for the
 2 first 18 months I was seeing her. I didn't even tell
 3 her I had haemophilia. I just wanted her to think
 4 I was a normal average guy, healthy, so when I told
 5 [redacted] it was a complete bombshell.
 6 **MRS V:** Yes, I did actually approached the Sandyford
 7 Clinic in Glasgow which is -- they call it the walk-in
 8 services and someone there who was really helpful.
 9 They saw me alone and then they saw us together. They
 10 explained a lot more than [redacted] had ever had from
 11 doctors and specialists. We then took it upon
 12 ourselves to look at things like diet and supplements
 13 and things that we can do ourselves.
 14 Again, I mean, the reason why we want to be
 15 anonymous today isn't because we are ashamed in any
 16 shape or form, but the stigma attached to the illness
 17 now is the same as 20/30 years ago. People don't
 18 think that. People tend to think that information has
 19 gotten better and people's mentality is a little bit
 20 wider but it isn't.
 21 I work with young people and I am hearing loads
 22 of comments like, you know, "hep C riddled junkies",
 23 and we can instruct people and help them understand
 24 but there is still a stigma so as much as I'm
 25 definitely not ashamed of [redacted] or anything, but

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1 well, just over 20 years, since I had the first round
 2 of interferon.
 3 Psychologically, my memory's gone, my memory's
 4 terrible. Constantly tired. It's just -- it was
 5 a struggle to come here today but I was determined not
 6 to let the government get away with it, or the
 7 doctors.
 8 **MS RICHARDS:** And I will ask you in a moment specifically
 9 about the treatments but I just wanted to ask you
 10 first, Mrs V, how long have the two of you known each
 11 other?
 12 **MRS V:** 18 years.
 13 **MS RICHARDS:** And what's your impression and understanding
 14 of the effect that your husband's diagnosis has had on
 15 him?
 16 **MRS V:** Well, now, of course, I fully understand what the
 17 illness is about and the effect that it has on
 18 someone's body. When I first met [redacted] it was
 19 new to me. I had only ever heard the name and, again,
 20 it was something that was associated with drug abuse
 21 mainly.
 22 There wasn't a lot of information back then
 23 beside what [redacted] told me so we did some research
 24 after together because you were still coming to --
 25 **MR V:** The problem was, because of the stigma attached to

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1 you're still kind of worried in a work environment how
 2 the reaction is going to be, especially when you work
 3 with the public and I think they have had enough
 4 during the years when they were younger of, you know,
 5 getting bullied or getting put in corners and not
 6 being able to take part in activities, and we didn't
 7 want this drag on now in his 40s to maybe being
 8 pointed at by neighbours and colleagues and stuff.
 9 It's hard because [redacted] isn't --
 10 **MS RICHARDS:** That's fine, but --
 11 **MRS V:** -- isn't much older than me, so you would expect
 12 that when we met we would have been able to do loads
 13 of different activities but due to the way he is
 14 physically, I mean, I think fatigue has been what
 15 I thought -- because as [redacted] said, he's never
 16 said to me what was wrong with him but I did think at
 17 that stage he wouldn't come ice skating or he would be
 18 quite tired and withdrawn and he would be keener on
 19 staying in rather than going out, so -- and this has
 20 affected him up to now and always will, I guess.
 21 Memory as well. It's hard not to get frustrated
 22 because I do know that it is part of the illness, but
 23 sometimes you can't count on him for anything, you
 24 know. There might be weeks where really his memory
 25 isn't there almost at all, but yeah ...

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1 **MS RICHARDS:** May I ask you about the first course of
 2 treatment that you underwent which was in 1996.
 3 **MR V:** That's right.
 4 **MS RICHARDS:** You were in your early 20s and you embarked
 5 upon a course of treatment with interferon.
 6 **MR V:** That's right. Back then, I think it was three
 7 injections a week back then. It wasn't -- there was
 8 tablets involved, I can't remember how many but it was
 9 mainly three injections a week.
 10 Now, again, in work back then nobody knew I had
 11 hepatitis C so I would finish work, I worked flexitime
 12 so I would finish early, about 3 o'clock, and just go
 13 straight to my bed. I would get up back 7, have my
 14 dinner, back to bed, and that was an existence. That
 15 was all it was.
 16 Then eventually I developed a full body rash.
 17 I was like a lobster, that is the only way I can
 18 describe it, it was that bad. They admitted me to the
 19 hospital and they sent for a hospital photographer but
 20 I've got no idea where the photographs went. There's
 21 nothing in the notes. I couldn't find anything.
 22 **MS RICHARDS:** And how long were you able to tolerate that
 23 treatment?
 24 **MR V:** Eight weeks. It was horrendous. That was the
 25 first generation interferon. Completely floored me.

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1 don't know what state you are liver's going to be in.
 2 I couldn't get a biopsy because of having
 3 haemophilia. So all they were going on, they were
 4 just relying blood results -- blood and tests and
 5 a scan? That's was it. That's all they're relying
 6 on, and I would dread that scan.
 7 That's all I had up until that point and then
 8 I got this appointment through out of the blue to see
 9 Dr Forest and he asked if I would be interested in
 10 this latest treatment, the ribavirin, the pegylated
 11 interferon and I said, yes, I would try it.
 12 **MS RICHARDS:** And what was that second course of treatment
 13 like?
 14 **MR V:** It was torture. I had to still work for six
 15 months. It almost -- the actually -- to start one
 16 injection a week and 20 tablets a day, that was the
 17 course. I started it on a Monday. I was in work all
 18 week. I got to the Thursday, I almost passed out in
 19 the office. I managed to drag myself to the toilet,
 20 sat on the toilet. I then threw water on my face and
 21 then I just went straight home. I said, "I need to
 22 go". My boss said, "You can go and lie down
 23 somewhere". I says, "No, I need to go home", and that
 24 was me for six months.
 25 For six months, I had no appetite. I lost about

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1 I still needed to work every day for the eight weeks.
 2 I just climbed out of bed. It was a desk job. As
 3 I say, I slept most of the eight weeks. I made it to
 4 work during the day. I didn't have much of
 5 an appetite, but my body was eventually turned red.
 6 **MS RICHARDS:** As I understand it, you were essentially
 7 labelled as a failed responder after that.
 8 **MR V:** Yes.
 9 **MS RICHARDS:** And it was many years before you were
 10 offered treatment again.
 11 **MR V:** 2012.
 12 **MS RICHARDS:** But you were very keen in the intervening
 13 period to try and get treatment.
 14 **MR V:** Yes, because, I mean, I always attend the
 15 haemophilia meetings, and I knew about all the latest
 16 treatments, but for whatever reason the liver clinic
 17 wouldn't authorise it.
 18 **MS RICHARDS:** And how did it come about that finally in
 19 2012 you were able to go on a second course of
 20 treatment?
 21 **MR V:** At the time I was sent to see Dr Ewan Forrest at
 22 the Glasgow Royal, the liver specialist. Once
 23 a year -- I mean, from the mid-'90s onwards, once
 24 a year, I got one liver scan a year at the Royal.
 25 That was it, and I would dread that scan because you

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1 two stone. It was a horrible, horrible feeling I had.
 2 I had absolutely no energy. When you tell people, I'm
 3 tired", they think, "Ah, right". Genuinely,
 4 I couldn't lift my head off the pillow. I had
 5 a horrible taste in my mouth, horrible, horrible
 6 taste. I had no appetite but anything I did eat
 7 I would bring it up straightaway. So on Christmas
 8 Day, my Christmas dinner was brought straight back up.
 9 Six months of hell, that's all I can describe it.
 10 **MS RICHARDS:** And you've said in your statement you became
 11 depressed.
 12 **MR V:** Yeah.
 13 **MS RICHARDS:** Lethargic, and that you felt like killing
 14 yourself.
 15 **MR V:** Again it was an existence. I'm in house for six
 16 months lying on the couch or lying on my bed. I went
 17 from the couch to bed, bed to couch. That was it for
 18 six months.
 19 During that time, my wife lost her job and I was
 20 about to go onto half pay in work, so everything just
 21 sort of happened at once. The treatment screws you up
 22 mentally as well. It was horrendous -- my Mum
 23 actually said if we wanted to move in with her because
 24 we thought we can't keep up the payments for the house
 25 as I was about to go on to half pay, but it was

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1 a horrible time and then I had to go back to work
 2 sooner than I was fit for.
 3 Horrendous.
 4 **MS RICHARDS:** And what's your recollection of that time
 5 and the treatment process?
 6 **MRS V:** It was awful. For the first part I was working
 7 full-time and I was trying to swap shifts or drop
 8 shifts or take unpaid leave or whatever I could do to
 9 be at home longer because I did notice, possibly after
 10 the first three or four weeks, [redacted] was
 11 completely depressed. He wanted to stop the treatment
 12 and he was serious about stopping the treatment twice.
 13 Between me and the nurse, we begged him to go on for
 14 another little while because possibly he wouldn't have
 15 had another chance in the future if we dropped out
 16 now.
 17 But at that point I was really worried so I was
 18 having friends pop in when I was at work because I was
 19 so scared that he would do something. That was the
 20 lowest I had seen him.
 21 **MR V:** The other problem was I still had to attend the
 22 liver clinic for blood tests to see how the treatment
 23 was, if it was working or not. So I would drive
 24 myself, and I don't know how I managed it, I would
 25 drive every couple of weeks up to the Royal.

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1 **MR V:** Yes, I don't believe a word they tell me.
 2 **MS RICHARDS:** Although you have achieved the sustained
 3 viral response there recorded, have you received any
 4 follow-up on an ongoing basis in terms of the
 5 condition of your liver?
 6 **MR V:** Nothing at all. That's you signed off, cheerio.
 7 **MRS V:** We have asked. I specifically went with
 8 [redacted] to ask if he could perhaps once a year get
 9 a scan or blood test, anything to monitor that this is
 10 still the result and their words were, "That's
 11 an extremely good idea. We would suggest to do so.
 12 However, you will not get it on the NHS."
 13 **MR V:** So just now all they're relying on is blood tests
 14 that I get routinely every six months at the
 15 haemophilia unit. There's no more scans, nothing.
 16 **MS RICHARDS:** You heard evidence from a witness earlier
 17 today --
 18 **MR V:** Yes.
 19 **MS RICHARDS:** -- who was having twice-yearly scans and
 20 you're having --
 21 **MR V:** It was only one scan at a year at the Royal.
 22 **MRS V:** But that's before the treatment.
 23 **MR V:** That was before the treatment, yeah. Now there's
 24 nothing.
 25 **MS RICHARDS:** And you're having nothing in terms of any

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1 I would sit in a waiting room, surrounded by
 2 posters, which was about drug use and alcoholism and
 3 you're sitting thinking, "Do people think I'm
 4 a junkie?" It's -- it was a horrible place to be, not
 5 a nice environment at all.
 6 **MS RICHARDS:** What was the outcome of that second course
 7 of treatment?
 8 **MR V:** It did clear and I'll say that very loosely, they
 9 say it cleared the virus.
 10 **MS RICHARDS:** If we have up on screen please, Paul,
 11 2245004.
 12 We can see this is part of a clinic letter and
 13 if we just look down the bottom of the page it says
 14 this:
 15 "I saw your patient in the liver clinic. I am glad
 16 to say he is feeling well. He did struggle with his
 17 antiviral therapy but ultimately he has achieved
 18 a sustained viral response. Quite rightly, he raised
 19 questions regarding whether this could be regarded as
 20 a guaranteed cure of his condition and obviously the
 21 answers to this is no. However, it is about as close as
 22 we can get to being certain that he has cleared his
 23 infection."
 24 You're left with a residual concern or fear,
 25 anxiety that the infection may return.

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1 follow-up scans.
 2 **MR V:** No, nothing at all. It's not just myself. It's
 3 the majority --
 4 **MS RICHARDS:** Of other people that you know and --
 5 **MR V:** Yeah, people I know, yeah, and they get nothing.
 6 **MS RICHARDS:** In terms of the physical consequences that
 7 you continue to experience as a result of either the
 8 infection or the treatment, you've developed asthma.
 9 **MR V:** Yes.
 10 **MS RICHARDS:** Do you still have skin problems?
 11 **MR V:** Yes, I'm still attending the dermatology clinic.
 12 I've got very -- there's creams they give you and it's
 13 embarrassing in work. I told my close colleagues in
 14 work about the hepatitis and they were really
 15 supportive, but people are asking -- they're saying
 16 "My God, look at your hands [redacted]. Is everything
 17 okay?" I say, "It's okay, it's just psoriasis. I've
 18 been to the GP. He's given me some creams". They
 19 don't know it's hepatitis C-related, but to this day
 20 it continues.
 21 It flares up, it goes down, it flares up, but
 22 when it flares up you're clawing at yourself. It's
 23 that bad I use a disabled toilet in work. I had my
 24 ankles fused into one position. I can wiggle my toes
 25 and that's about it, so I use a disabled toilet in

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1 work and it's great.
 2 It sounds disgusting, it's that bad on my feet
 3 that there's a metal pipe in the disabled toilet,
 4 I will take my sock off, my shoe, and I will rub my
 5 foot on this metal pipe until it bleeds, and that's
 6 the other side of the problem I've got with the
 7 haemophilia. I've got to treat myself with Factor
 8 VIII so I'm clawing myself that much I'm bleeding and
 9 then treating myself with Factor VIII but in work, it
 10 was on my feet, I was rubbing my feet against a metal
 11 pipe in the toilet. That's how bad it is. When you
 12 tell people, "I'm itchy", it doesn't sound that bad.

13 **MS RICHARDS:** And your understanding is that that is
 14 consequence of the interferon treatment.

15 **MR V:** Oh, yes. I've had that on and off since the
 16 mid-'90s.

17 **MS RICHARDS:** And you've been left with the tiredness, the
 18 fatigue --

19 **MR V:** Yes.

20 **MS RICHARDS:** -- the memory problems.

21 **MR V:** I mean, in work my job is basically opening up
 22 envelopes, as ridiculous as it sounds, I do
 23 a different job from everyone else. I'm seen as
 24 a special case. My bosses are great. They've gave me
 25 simple, simple tasks to do. Simple inputs to the

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1 he wanted to interview some people, so he came to our
 2 house and he talked to me and [redacted].
 3 I had that going on in the background. I had
 4 all the campaign meetings which I attended, then I get
 5 this letter out of the blue from the DWP asking me to
 6 be reassessed. I got letters -- letters of support
 7 from all the various doctors. I had to go private for
 8 my surgeon. They had to fuse my ankle four times.
 9 Letters of support from everyone and, as bizarre as it
 10 sounds, I punched myself deliberately the night before
 11 my PIP assessment because you're dealing with someone
 12 who doesn't know who haemophilia is so I thought, "If
 13 I make myself bleed internally, they will see how bad
 14 it is", so I punched all my arms, didn't take any
 15 Factor VIII, so I had internal bleeding in both arms,
 16 I was in agony.
 17 [redacted] drove me there. We turned up. We
 18 were in the room an hour and a half. I was getting
 19 grilled for an hour and a half. It was actually worse
 20 than this and, my God, the woman who was a nurse, she
 21 doesn't know anything about haemophilia, explained all
 22 about hepatitis C, I made a point of wearing
 23 a short-sleeved top so she would see my arms, and she
 24 said -- she got to the end of the assessment. She
 25 says, "Normally, we would give you a physical

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1 computer and opening the mail. That is it. I'm
 2 getting paid the same as someone else who is dealing
 3 with soldiers dealing with their pensions, et cetera.
 4 I couldn't cope with that, taking it in
 5 mentally, I would mess it up. I know that for a fact,
 6 so I just do basic, basic inputs. I work flexitime
 7 which is good, so if I'm tired I can go home, I can
 8 finish early and go home. The conditions are great.
 9 I'm fortunate enough to have a job. That's -- I'm
 10 really lucky that way, but with the Civil Service they
 11 must employ so many people that are disabled and that
 12 was the only reason I got the job, I think, was with
 13 the haemophilia.

14 **MS RICHARDS:** What about the ongoing psychological
 15 consequences? You said in your statement that one of
 16 the worst things is the stress and anxiety that you
 17 continue to experience.

18 **MR V:** Yes, I mean it came to -- I mean, last year I got
 19 a letter out of the blue from the DWP asking me to
 20 reapply for PIP. I've had a Motability car since
 21 I was 14. That gets me to my work, I've got a Blue
 22 Badge. Everything was building up last year and
 23 Professor -- what was his name, Professor Goldberg at
 24 my house. He was doing a study into the effects of
 25 living with hepatitis C. He was writing a report, but

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1 examination but because you've got severe haemophilia
 2 we're not allowed to". I says, "That's fine". Then
 3 I got a letter a few weeks later saying I was rejected
 4 and I was absolutely gutted.

5 So I went to my boss, I says, "Look, I'm here to
 6 put in for voluntary redundancy here, because if
 7 I lose my car, I'll have to pack my job in.
 8 I physically cannot get to my work", because I work
 9 down [redacted] across from the road from [redacted].
 10 There's no way I can get to work on a bus and go home
 11 on a bus. As well as that, I've got contaminated
 12 needles and syringes which I would have to take on
 13 a bus to the Royal Infirmary. How do they expect me
 14 to live without my car? I've had it since I was 14.
 15 I would lost without it.

16 So my boss is very supportive. He said if it
 17 came to any tribunal he would come and speak on my
 18 behalf. I contacted one of my friends within the
 19 campaign group and he helped me throughout the
 20 process, reapplying again, filling out the forms.
 21 Eventually, it was awarded to me for the next 11
 22 years.

23 Meanwhile, while that was all going on, we had
 24 Professor Goldberg's report which was due out in the
 25 July, so everything was happening at the one time. So

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1 I contacted the haemophilia unit and asked to speak to
2 their psychologist, which I was mortified at.

3 I've never spoken to a psychologist or
4 psychiatrist in my life so I saw Grainne once a month
5 until December. She was great. But it is just one of
6 these things. I said, "Look, is there a tablet you
7 can give me, something to calm me down", and she
8 said -- she gave me CDs to try and -- to listen to,
9 someone speaking with a very soothing voice. I said,
10 "Look, no, that doesn't work for me", so I ended up --
11 I was going for stream rooms, swimming, stuff like
12 that, to try and de-stress but last year was
13 a horrific time.

14 **MS RICHARDS:** And that counselling which you asked for --

15 **MR V:** I asked for, yes.

16 **MS RICHARDS:** -- is the first counselling or psychological
17 support you've ever been offered?

18 **MR V:** Yes, that was the first time I was ever -- I asked
19 for. I hadn't been offered it up until then.

20 **MS RICHARDS:** What impact, if any, has either your
21 infection with hepatitis C or the risk of vCJD had on
22 dental or medical care?

23 **MR V:** Well, with the dental care, the haemophiliacs get
24 treated at the Glasgow Royal with their own dentist.
25 But going back about ten years ago, the hygienist at

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1 it wouldn't have haemophilia. If it was born female
2 it would be a carrier but this would make it male only
3 and we could choose its eye colour, hair colour, it
4 was really bizarre being told this. And we said no,
5 because, at the end of the day, I don't know what my
6 prognosis is going to be. I'm not selfish. I don't
7 want to bring a kid in and then end up dying as --

8 **MRS V:** I don't think it was an easy decision --

9 **MR V:** No, it wasn't an easy decision.

10 **MRS V:** -- to make because you are kind of brought up to
11 think that's what happens, you meet someone, you get
12 married, you have children, but after we decided and
13 it was good that we decided as a couple and we were
14 both going down that route, it wasn't more lateral,
15 the war was again after with the doctors.

16 We've always had to fight to get there and
17 that's why I think part of this designer baby
18 discussion came about, because doctors could not
19 believe that we had made that decision to
20 categorically not have children, full stop. And even
21 when you explain to doctors that it's not so much
22 because we're scared of if they're potentially born
23 ill or with the virus or with other viruses, it is for
24 after, so the fear that these children might not have
25 a dad after two/three years, which has happened to

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1 the Royal went off on maternity leave and she was off
2 for ages, meanwhile none of the haemophiliacs had been
3 seen, so I went to the local dentist in [redacted]
4 where I stayed at the time and I didn't even get as
5 far as sitting on the chair. As soon as I told him
6 I had haemophilia and had hepatitis C they wouldn't
7 touch me, so I'm only seen at the Glasgow Royal.

8 **MS RICHARDS:** I wanted to ask you about the impact of your
9 infection on your family life and on the decisions
10 that the two of you have made about family life. What
11 would you wish to say about that?

12 **MR V:** Well, we've not had children. My wife was pregnant
13 in 2006.

14 **MRS V:** 2006.

15 **MR V:** But we went to the hospital to discuss the
16 pregnancy, they said there was a slight chance that
17 the baby would have hepatitis C. I told them as well,
18 I might have variant CJD as well, so it was
19 a horrendous decision which we both decided to go
20 through with a termination, so my poor wife had to --
21 it is just one of these things, we both decided to go
22 through with it.

23 Since then -- that was 2006, maybe about six
24 years ago, the haemophilia unit offered us a designer
25 baby. It would only be male, born a male, which means

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1 loads of people that we have met.

2 So we've had that for ten years. We have asked
3 if we could get some sort of -- we were talking about
4 vasectomy but [redacted] couldn't go through with that
5 because of the --

6 **MR V:** Yeah, I would definitely bleed.

7 **MRS V:** When it came to myself we had to beg essentially
8 and it has taken until last year to get there. And
9 that was psychologically hard because you have this
10 fear of this might happen and then -- but we got
11 there.

12 **MR V:** Yes.

13 **MRS V:** And this is what has been right for us and for
14 what we believe and also we were -- we weren't sure at
15 the time if [redacted] would be here long, it's fair
16 to say, still, if he would be physically able to enjoy
17 having a child and see them growing up, but at the
18 same time we don't want anybody that has had children
19 to think that we have any opinions on them, because
20 every -- everybody is different and we admire people
21 that have had the courage to go through and have
22 children.

23 **MR V:** Still, I find it painful in work. I suppose it's
24 only natural people talk about their kids, talk about
25 their children in work. It's like a bloody knife

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1 through my heart listening to that. I had one girl --
 2 one of the girls in the office who's knows I've got
 3 hepatitis and what has happened, she had problems
 4 having a kid, she had problems conceiving and she told
 5 me she finds it difficult as well listening to other
 6 girls going on about their babies in the office.
 7 That's just life, you know. It's one of the these
 8 things, but it's still difficult to hear every day
 9 when they're gonna on about their kids.

10 **MS RICHARDS:** Let me ask about your work.
 11 **MR V:** Yes.
 12 **MS RICHARDS:** You have described the work you do that
 13 that's all you feel able to cope with.
 14 **MR V:** Yes.
 15 **MS RICHARDS:** What you've said in your statement is that
 16 the infection and the consequences of the infection
 17 essentially have held you back in terms of applying
 18 for promotion.
 19 **MR V:** Yes.
 20 **MS RICHARDS:** You haven't felt able to do that?
 21 **MR V:** No, no, definitely that. My boss said -- that is
 22 the reason I spoke -- I told my boss about my
 23 infection. He had asked me regarding applying for
 24 promotion and I told him it was wrong. The guy was
 25 devastated. He was genuinely shocked, and he advised

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1 they weren't happy at giving me a mortgage. They gave
 2 a mortgage in [redacted]'s name, not mine, and then
 3 recently we managed to secure -- we managed to secure
 4 a mortgage in my name, a joint mortgage, for the first
 5 time, aged 45. So that was a relief.

6 **MRS V:** Because they don't require life insurance
 7 apparently now, whereas 13 years ago they would have
 8 given you a mortgage but the life insurance payment
 9 was like five times the mortgage payment, so that's
 10 how we were only able to get a mortgage based on my
 11 wage, which -- amazing.

12 **MR V:** I don't have life insurance. I'd get a pension.
 13 I'd get a death benefit -- if I drop dead tomorrow,
 14 I have a death benefit through my work, but that is
 15 it.

16 **MS RICHARDS:** And what has been your experience in
 17 applying to the Skipton and any of the other funds or
 18 schemes for assistance?
 19 **MR V:** Argos vouchers, that sums it up. That's what
 20 I got, Argos vouchers. I'd took a bad bleed in my leg
 21 and my leg had -- no, that's a lie.

22 **MRS V:** You had a burst --
 23 **MR V:** It was a burst -- a burst vein in my knee.
 24 **MRS V:** Artery.
 25 **MR V:** A burst artery, so the mattress was saturated in

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1 me to tell my immediate team leader what was wrong
 2 with me, and I pleaded with him not to tell any of my
 3 colleagues. I didn't want anyone to know.

4 There'd been some -- there was some news in the
 5 papers, on the telly, about mad cow disease about 15
 6 years ago and one of the boys in the office shouted
 7 across, "Have you got mad cows disease, [redacted]"
 8 I said, "No, I don't think. I might do". It's just
 9 like black humour. You just laugh it off. That's how
 10 I cope. Otherwise I would crack up.

11 **MS RICHARDS:** The self-limiting of your career in that
 12 way --
 13 **MR V:** Yes.
 14 **MS RICHARDS:** -- has obviously had financial consequences.
 15 **MR V:** Yes.
 16 **MS RICHARDS:** You've not been able to earn more.
 17 **MR V:** Yeah.
 18 **MS RICHARDS:** You've told us about the experience in
 19 relation to the PIP application. What has been your
 20 ability to obtain a mortgage, life insurance, travel
 21 insurance and the like?
 22 **MR V:** When was that, 12 years ago?
 23 **MRS V:** Almost 13 years ago.
 24 **MR V:** Yeah, we moved in together -- well, I think it was
 25 about 12 years ago, we went to the bank, and back then

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1 blood and I got taken into hospital. So we contacted
 2 Skipton and asked if we could get help for bed linen,
 3 et cetera, and then they sent out vouchers for Argos.
 4 I thought, "Is that all I'm bloody worth after all
 5 this?" It was an insult. And also we got vouchers
 6 from Scottish Power for heating, but the humiliating
 7 thing was -- you dealt with the heating. You phoned
 8 them up. You phoned Scottish Power and they asked --
 9 there was a code on it and it came up "contaminated
 10 blood".

11 **MRS V:** Yeah, they knew.
 12 **MR V:** It came up something to do with -- no, it came up
 13 with Skipton and they asked [redacted], "What's
 14 The Skipton Fund?" So we had to tell them what it
 15 was. So it was really humiliating.

16 **MS RICHARDS:** And you've said in your statement that you
 17 found the process of applying the forms unnecessarily
 18 long.
 19 **MR V:** They want you to fail, that's the bottom line.
 20 They want you to fail. They want you to give up.
 21 They are giving forms, which I think you need to be
 22 a lawyer to understand in the first place, to a group
 23 of sick people, sick dying people, to fill out which
 24 they want you to fail. They don't want you to fill
 25 out properly. Any excuse to be rejected.

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1 **MS RICHARDS:** And that was your experience in relation to
2 the Skipton Fund. You've also described in your
3 statement the experience of making an application for
4 assistance in relation to mortgage payments to the
5 Caxton Fund.

6 **MR V:** That was -- that was when I was about to go on to
7 half pay, I contacted Caxton, and I was -- at the time
8 I was on the second generation interferon treatment,
9 and they said we'd qualify for monthly payments but
10 I must have a letter from the consultant, the liver
11 consultant. So it was jumping through hoops to try
12 and track down a liver consultant, who, as you can
13 imagine, are busy people. So, obviously, I'm off work
14 sick, ill. I had to physically go to the hospital to
15 try and track this guy down. I managed to get hold of
16 the nurse, the liver nurse, who assured me she would
17 get a letter from him. Now, the payments were only
18 for the duration of the treatment. Once the treatment
19 stopped, the payments stopped.

20 So as soon as the payment -- as soon as the
21 treatment stopped, that was it, the money stopped.
22 I went back to work. I was still ill, and I had
23 tell -- when I walked into the office people said, "My
24 God, what's happened to you?" I had to tell them the
25 story and everyone was shocked.

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1 minimum -- as a kid, it was, like, twice a week, but
2 as a kid you're running about so it is like three,
3 four, five times a week injecting, so you're
4 constantly being reinfected.

5 **MS RICHARDS:** I just wanted to take you back to your
6 childhood and ask you a couple of matters relating to
7 that.

8 First of all, you've shown a photograph -- you
9 showed me a photograph, the Chair has seen
10 a photograph of you and a number of the other boys who
11 was young haemophiliac boys treated at Yorkhill.

12 **MR V:** That's correct, yes.

13 **MS RICHARDS:** And without mentioning any names, that
14 photograph was taken you think in about 1987.

15 **MR V:** 1987, yes.

16 **MS RICHARDS:** And it shows a number of boys and you were
17 on a holiday.

18 **MR V:** Yeah, it was a venture week in Wales down in
19 Anglesey, and it was one of the parents of one of the
20 boys drove us down in a van. I think there was about
21 five or six of us, half a dozen of boys from Yorkhill.
22 Unknown to me at the time, they all had HIV. I don't
23 know if they knew they had HIV at the time, but we
24 were just daft young kids.

25 But the thing that plays on my mind, I was

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1 By this point I didn't care. I thought if
2 I lose my job, I lose my job. I've had enough. I had
3 my sandwiches -- sandwiches in the fridge. I thought,
4 "I wonder if anyone will have any objections to me
5 putting my food in the same fridge as them, the fridge
6 in the office that we all share." But everyone was
7 really supportive. Whether they talk about me behind
8 my back, I don't know, but the office is fine. But
9 the building I'm in, there's 1,500 people. It's
10 a military building, plus civilians as well. This is
11 why I went -- I didn't want anyone to know.

12 Also my Mum as well -- Mum worked for the
13 Transfusion Service. She'll have a lot of evidence.
14 I didn't want my Mum here. I said to her, "Look, it's
15 all right, me and [redacted] will come", because Mum
16 doesn't know that [redacted] had had a termination.
17 She didn't know [redacted] was pregnant. We kept all
18 this from her. We didn't want to upset my Mum, so
19 that was another reason.

20 **MS RICHARDS:** You've also said in relation to your Mum in
21 your statement that she feels guilty --

22 **MR V:** Yes, she feels guilty.

23 **MS RICHARDS:** -- because she gave you the treatments for
24 a period of time. She was administering them.

25 **MR V:** I'm the same. I was injecting myself. But the

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1 really homesick at the time and when we arrived there
2 we all got sent away into our rooms. There's myself
3 and another boy, and he asked to get put into the room
4 with another two boys, and I think that's because they
5 all had HIV. I think that was the reason.

6 **MS RICHARDS:** And again, without mentioning any names --

7 **MR V:** Yeah.

8 **MS RICHARDS:** -- you know that certainly two of the young
9 boys shown in that picture are dead of HIV.

10 **MR V:** Yes. Yeah, yeah, yes.

11 **MS RICHARDS:** The other point I wanted to ask you about
12 again arising from your statement was about
13 an experience you had of the stigma associated with
14 HIV. Although yourself were not infected with HIV,
15 you recalled when you were at school a TV programme
16 and how people reacted to that.

17 **MR V:** Yeah, there was a documentary on about HIV and
18 haemophilia and, if I remember, this is primary school
19 I was at at the time. The following morning I went to
20 school as normal. My Mum got a phone call from the
21 headmistress saying she'd seen the documentary and she
22 asked for surgical gloves, surgical masks and plastic
23 aprons for the staff.

24 The same morning, I used to sit next to the
25 school teacher's nephew and out of the blue suddenly

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1 the teacher announced that we're all getting split up,
2 and the nephew was put to the other side of the
3 classroom from me. It's just like constants.

4 But the teacher -- the teacher at the time, he's
5 now dead, but he would repeatedly ask my Mum, "Has
6 [redacted] got AIDS? Has [redacted] got AIDS?" And
7 Mum says, "No, that's between [redacted] and his
8 doctor, I'm not telling you."

9 In one instance, I banged my leg off the wooden
10 desk and I got a bit of wood stuck into my leg, so
11 they had to phone my Mum to come and collect me from
12 the school. So the teacher showed the wee piece of
13 wood with blood on it to my Mum. He said, "Look,
14 [redacted] is this okay? This is in my hand, am
15 I okay? Is this safe enough?" She's, "Oh, there's no
16 point in rubber gloves", and she says he's fake on,
17 his face just drained.

18 But the school wanted me out. They arranged
19 behind my parents' back for me to get sent to
20 a special school. They never told my parents this.
21 Their excuse was at the interval, at playtime I would
22 sit in the classroom, because if I went to the
23 playground, I may get burnt. My Mum couldn't drive to
24 take me to Yorkhill. Although we'd treatment in the
25 house, depending on the severity of the bleed, I would

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1 walk, easy for Mum to get to. But the priest was
2 annoyed. He came down to the house. He said he was
3 gonna write to the bishop because he was annoyed at me
4 getting sent to a non-denominational school. I've
5 never set foot in a chapel since. I've no time for
6 religion. I turned my back on it completely.

7 **MS RICHARDS:** You've mentioned that your Mum used to work
8 for the Blood Transfusion Service.

9 **MR V:** Yes.

10 **MS RICHARDS:** And there was just one further thing
11 I wanted to ask you which arises out of something she
12 said and I don't know whether she's ever said it to
13 you, she's put it in her statement to the Inquiry, but
14 it's about what she describes used to happen during
15 something -- I think it's called the Glasgow Fair.

16 **MR V:** Yeah, the Glasgow Fair. Yeah, I come to Glasgow
17 Fair. In the old days the factories would shut down
18 for a fortnight, so that's when the Blood Transfusion
19 Service would go into the prisons and take blood. She
20 would go in there. But the prisoners were being --
21 normally the prisoners were being bribed by the staff
22 to encourage them to give blood. They would be
23 offered sugar, which is one of the ingredients for the
24 drugs. But obviously once they gave blood, they were
25 only getting tea and coffee. So that they were -- the

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1 have to go into hospital. So I would stay in at
2 playtime. So the school used the excuse that I wasn't
3 socialising with the children, which was rubbish,
4 because the kids -- some of the kids would stay in the
5 classroom with me during the breaks. But, yeah, they
6 did it behind my parents' backs.

7 At the same time, when I attended Yorkhill,
8 there was a local clinic, a mother and baby clinic in
9 [redacted], and with the waste incinerating bins for
10 dirty needles, we used to hand them in to the clinic,
11 rather than travelling all the way to Yorkhill. And
12 out of the blue they said, "No, sorry we can't accept
13 them, they have to be taken to Yorkhill."

14 But everything seemed to happen all at the same
15 time period. But it's -- primary school was
16 a horrendous experience for me. The kids were fine,
17 they were nae -- but it was the teachers, the complete
18 ignorance of the teachers.

19 **MS RICHARDS:** And it was fear, you think, of HIV and
20 AIDS --

21 **MR V:** Yes.

22 **MS RICHARDS:** -- that drove that.

23 **MR V:** And when it came to -- when I finished primary
24 school, my parents decided to send me to
25 a non-denominational school which was a five-minute

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1 prisoners were annoyed at that.

2 **MS RICHARDS:** Those were the questions I had for you both.
3 Is there anything further that either of you would
4 like to say?

5 **MR V:** I've just made a wee statement.

6 When myself and my wife were asked to give
7 evidence to today, I'll be honest, I thought our story
8 was nothing special compared to other victims who've
9 died. I know that my friends and close colleagues
10 were certainly shocked when I told them about my
11 infection. We're both here to speak up for the dead
12 children in the photograph, which we can't show, but
13 who were murdered by the Government. We know it would
14 be -- we know it could easily have been me as the
15 Government was basically playing Russian roulette with
16 the lives of babies, children and adults. I'm lucky
17 to still be alive.

18 I passed my driving test. I got a job just
19 before I turned 19. I had a 21st birthday party and I
20 got married. Two months ago, I managed to secure
21 a joint mortgage with my wife for the first time in my
22 life. I can't say any more.

23 **MS RICHARDS:** Do you want to take a moment?

24 **MR V:** No, that's me finished.

25 **MS RICHARDS:** Are you sure?

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1 **MR V:** Yeah.
 2 **MS RICHARDS:** Is there anything you would like to say?
 3 **MRS V:** I'm just glad that I'm here with [redacted] giving
 4 evidence rather than as a widow.
 5 **MS RICHARDS:** I'm just going to ask Mr O'Neill if there's
 6 anything further he would like me to ask you.
 7 **MR V:** Okay.
 8 **MS RICHARDS:** If you just wait a moment.
 9 There isn't.
 10 **MR V:** Okay.
 11 **MS RICHARDS:** Thank you.
 12 Sir.
 13 **SIR BRIAN LANGSTAFF:** You've said what a struggle it was
 14 to be here today. You have shown us that you have
 15 struggled at the end, but in the middle and throughout
 16 your testimony you have given us a very clear account.
 17 Thank you very much. And thank you, Mrs V, for your
 18 joining Mr V in what he's said.
 19 **MRS V:** Thank you for giving us this opportunity.
 20 **MR V:** Yeah, thanks for listening to us.
 21 **SIR BRIAN LANGSTAFF:** Thank you both.
 22 There was a surname used during the course of
 23 that testimony as well which will need to be redacted.
 24 **MS RICHARDS:** All of the identifying information that was
 25 given during the course of the evidence is going to be

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1 redacted.
 2 **SIR BRIAN LANGSTAFF:** But the transcript will be gone
 3 through carefully, I have no doubt.
 4 **MS RICHARDS:** It will be gone through very carefully word
 5 by word.
 6 **SIR BRIAN LANGSTAFF:** Tomorrow, 10 o'clock.
 7 **MS RICHARDS:** We have three witnesses. The first is
 8 anonymous. The second witness is Christine Norval.
 9 And the third is not anonymous. I'm going to
 10 double-check, I don't believe the third witness is
 11 anonymous but I don't want to make the mistake of
 12 saying their name and discovering I am wrong about
 13 that. So we have three witnesses tomorrow in any
 14 event, sir.
 15 **SIR BRIAN LANGSTAFF:** Let us leave it there, then, for
 16 this evening. 10 o'clock tomorrow.
 17 (3.45 pm)
 18 (Adjourned until 10.00 am the following day)
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