

1 Tuesday, 27 September 2022

2 (10.00 am)

3 **SIR BRIAN LANGSTAFF:** Good morning, all of you. Thank you
4 for being here. Mary will invite you each to take the
5 appropriate oath before Ms Fraser Butlin begins asking
6 the questions.

7 **MR KEVIN THOMAS ROBERTS (affirmed)**

8 **MS MARLENE ELIZABETH NEVE (sworn)**

9 **MR STEPHEN JOHN TOWSEY (affirmed)**

10 **MR WAYNE GATHERCOLE (affirmed)**

11 **Questioned by MS FRASER BUTLIN**

12 **SIR BRIAN LANGSTAFF:** Yes.

13 **MS FRASER BUTLIN:** Thank you, sir. As we did yesterday, I'm
14 going to ask each witness various questions individually
15 and then we will move to a time when we discuss things
16 more thematically.

17 Kevin, if we can start with you. You have mild to
18 moderate von Willebrand's disease?

19 **MR KEVIN ROBERTS:** Yes, that's right.

20 **MS FRASER BUTLIN:** That was diagnosed in 1984?

21 **MR KEVIN ROBERTS:** Probably a little bit before. It was
22 during a tooth extraction at a primary school I was at
23 and it bled and the dentist at that time recommended
24 that I get checked, because it was quite a lot of
25 bleeding, and from that they took me to hospital, did

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1 **MR KEVIN ROBERTS:** I had cryoprecipitate for the operation.
2 I remember it vividly because of the big
3 horrible looking yellow bag. I went, "Whew". Yeah,
4 quite scared of that. And I was given that prior to the
5 operation. And found out very recently that I was given
6 three hits of Factor VIII in 24 hours after the
7 operation.

8 **MS FRASER BUTLIN:** And that's when you believe you were
9 infected with hepatitis C?

10 **MR KEVIN ROBERTS:** Yes.

11 **MS FRASER BUTLIN:** Why is that?

12 **MR KEVIN ROBERTS:** Literally between three, four weeks after
13 that operation, wow, it hit. I was bright yellow, woke
14 up bright yellow. Unbelievably weak. So weak I could
15 hardly lift my arms, walk. Bed sweats. Joint pain like
16 people putting glass into my joints. It's horrific.
17 But bright yellow, very bright yellow. Even my parents,
18 who are farmers, who are normally -- you get a cold,
19 "took" the back of your ear, "Get on with it, you'll be
20 all right" manner, they went, "Actually, we were quite
21 worried about you, you look very ill", and they took me
22 to my GP, Dr Cath. Said the doctor, sorry, "He does
23 look ill, he looks quite yellow, right, we better give
24 him some blood tests", and he said, "Come back in
25 a week's time and we will tell you the results". We

3

1 the test, and went, "Oh, by the way, you have von
2 Willebrand's", and that's how I was -- found out.
3 I believe that was '83, near the end of '83.

4 **MS FRASER BUTLIN:** That was when you were about 12?

5 **MR KEVIN ROBERTS:** Yeah, 11 probably -- I was 11 then and 12
6 in '84, so, yeah.

7 **MS FRASER BUTLIN:** At that point you were having a lot of
8 heavy nosebleeds.

9 **MR KEVIN ROBERTS:** The nosebleeds came a little bit after
10 that. I probably was nearer -- the end of '84/'85 I got
11 prolific nosebleeds, yes.

12 **MS FRASER BUTLIN:** You then needed another tooth extraction,
13 for which you were given cryoprecipitate.

14 **MR KEVIN ROBERTS:** I didn't actually need another tooth
15 extraction. I was -- after I was diagnosed with
16 von Willebrand's, I don't think it was much more than
17 a month afterwards, got a letter through: We would like
18 to let you come in to have these other two wisdom teeth
19 out. When -- it didn't hurt or nothing.

20 So, being naive farmer boys, never questioned --
21 my father never questioned, I never questioned doctors,
22 and he said, "In you go, boy, go and get these done.
23 They want you in, you go and have it".

24 **MS FRASER BUTLIN:** In order to do that tooth extraction, you
25 had cryoprecipitate before and after the operation?

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1 came back in -- I remember it so well -- and he says,
2 "Oh, Mr Roberts, your son, yeah, well, it is okay, don't
3 worry about it, he's having growing pains. Everyone
4 gets it. It's growing pains. His bones are outgrowing
5 his body, that's what the joint pain and weakness is.
6 Drink plenty of water, but especially drink lots of
7 Indian tonic water, and he will be fine".

8 Of course we left the surgery, the old man goes,
9 "Swing of the leg, boy, go on, do your chores, what's
10 the matter with you? Everyone feels like that, that's
11 normal. You've been just told by the doctor. It's
12 normal".

13 **MS FRASER BUTLIN:** In 1989 you had a tonsillectomy.

14 **MR KEVIN ROBERTS:** Yes.

15 **MS FRASER BUTLIN:** There is some uncertainty, I think, about
16 what treatment you received then, whether it was
17 Factor VIII or -- as well as DDAVP or exactly what was
18 given at that point.

19 **MR KEVIN ROBERTS:** So the tonsillectomy in July, my first
20 one, was -- look at what we found in the record -- was
21 a -- trialled -- and it's big writing, it's "Trialled
22 for DDAVP". I went, "Ooh, hang on, 'trialled', that's
23 a first time". I went, "Ooh, okay", but Factor VIII was
24 on standby in case the DDAVP doesn't work. My
25 doctors -- and haematology doctors all along have said

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1 to me, "You was never given Factor VIII". What --
 2 I obviously wasn't given DDAVP until 1989, so that left
 3 a big hole for me from '84 to '89, which is -- yeah.
 4 That's -- no, so I knew I was given Factor VIII.
 5 I always remember the little balls(?). But that kind of
 6 proved I was never lying. I knew I was right all along.
 7 And my own blood doctors didn't know better because of
 8 these missing records.
 9 **MS FRASER BUTLIN:** Can I ask you to slow slightly with your
 10 speech. We have some brilliant stenographers taking
 11 a note of everything and we just need to slow down
 12 slightly.
 13 **MR KEVIN ROBERTS:** Absolutely.
 14 **MS FRASER BUTLIN:** During your teenage years, can you tell
 15 us what your health was like?
 16 **MR KEVIN ROBERTS:** Wow, yeah. Shocking. I'm a farmer boy.
 17 My dad is very, very old school, tough, hard, and he
 18 expects you to do your chores, because he wanted his
 19 sons to be his mirror, understandably. I was weak.
 20 When I first went to comprehensive school, there's
 21 a cross country run, and out of the five years, my first
 22 year there I was the fourth fastest guy at running this
 23 cross country. The second year I did it, I was 64th,
 24 and I did everything I could to push myself. Collapsed
 25 at the end of the race, panting, breathing hard,

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1 for the bloods and -- something that I overlooked for
 2 many years. Every time I went there the nurse taking
 3 the blood would step up when they would see me coming
 4 and a new nurse would come in, to a little room, and she
 5 wore a mask, gloves, apron. PPE. I never thought about
 6 that until I talked to the other victims. And they took
 7 my bloods.
 8 And she goes, "All right, Mr Roberts, yeah?"
 9 She was always very softly spoken. Goes, "Right,
 10 here we go, ooh, I've got a few here today, 14 test
 11 tubes."
 12 I said, "14?"
 13 She said, "Yeah, here we go."
 14 I think that's nice. 14! I'm a biggish lad, so
 15 I thought I could take that.
 16 And I seen the doctor at the end, "Have any
 17 queries?"
 18 And I said, "Excuse me, Dr Kreuger" -- his name,
 19 Dr Kreuger -- and I said to him, "What are these test
 20 tubes for? I know I'm a von Willebrand's, I was
 21 a haemophiliac and I need a few test tubes for that,
 22 but 14?"
 23 He goes, "I know it seems a bit excessive, but --
 24 hang on a minute, don't you know?"
 25 "Know what?"

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1 sweating profusely, could not get enough oxygen.
 2 I remember being so, so weak. And I was pushing because
 3 this was normal, to feel this way was normal. I was
 4 told by my doctors, "This is normal, there's nothing
 5 wrong with you". I was bed wetting. I was so weak in
 6 the mornings I had to put my clothes on the floor, roll
 7 out of bed and slide my clothes on while I was on the
 8 floor and then crawl up, go down the stairs, try and eat
 9 something for breakfast, go to school dragging my feet
 10 because that is normal. That was normal. That's how
 11 everyone felt in my head. This is normal to me.
 12 Brain fog, wow. Schooling, that didn't go very
 13 well for me. Didn't go very well at all because I could
 14 not remember things. I would be given a date or a math
 15 equation and as soon as I turned my head from the paper
 16 I couldn't remember it. It just went. Reading stories,
 17 I could remember a story, I couldn't remember the names,
 18 the dates, even what the book was called. I felt thick.
 19 Very thick. And because of that I was treated thick.
 20 Again, I thought it was normal. I thought it was
 21 just me. I realised later it wasn't.
 22 **MS FRASER BUTLIN:** And how did you come to find out you had
 23 been infected with hepatitis C?
 24 **MR KEVIN ROBERTS:** I went into one of the normal
 25 three-monthly, quarterly blood tests and got pulled in

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1 "We are not only testing you about your bloods, we
 2 are testing you because we think you might have HIV."
 3 I went, "You what?"
 4 He went, "Don't worry about that". He says, "You
 5 have got hepatitis C."
 6 "What's hepatitis C?"
 7 He goes, "Oh, you really don't know, do you?"
 8 I said, "What's hepatitis C?"
 9 He said, "You've got a 50% chance of dying before
 10 the age of 25, you've got a 45% chance of curing it with
 11 this drug called interferon, and you have got a 5%
 12 chance of curing it yourself. Here's a little leaflet
 13 on hepatitis and I advise you don't drink alcohol
 14 anymore, and we will give you your HIV results in the
 15 post in a few weeks' time. Have a good day."
 16 **MS FRASER BUTLIN:** And those HIV results arrived in the
 17 post?
 18 **MR KEVIN ROBERTS:** They arrived in the post. Prior to that
 19 I got to the car and I told my father what I was told by
 20 the doctor. I said, "You know those years ago when
 21 I was really, really ill and you were told it was
 22 normal, I was in trouble, Dad". I said, "I have just
 23 been told I may not be here at 25". Dad is strong. He
 24 is not a -- he is not an emotional guy, he is not a very
 25 tactile person. He looked at me, went quiet. We drove

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1 home, the 50 minutes it took from Truro Hospital to my
2 home, and I couldn't hear a thing, I couldn't even hear
3 the car running, it was "boff", blank. Not a word was
4 said, all the way home.

5 I got out of the car, thought I'd better tell my
6 mum. "Mum, I've got something to tell you."

7 "What's that, love?"

8 "I have got hepatitis C. Didn't know what it was.
9 They said I might die from it." I said, "Not only that,
10 they tested me for HIV, AIDS". She waited about 10,
11 15 seconds and she looked me straight in the eye and
12 says, "If you've got AIDS, I want you to leave the
13 house. I don't want you infecting your brothers".
14 I looked at her, never said a word, went upstairs and
15 cried.

16 The envelope did arrive, about eight days, nine
17 days later. I couldn't open it for three weeks.
18 I didn't want to know, because if I did, I would have to
19 leave the house and not infect my brothers.

20 **MS FRASER BUTLIN:** You opened it and thankfully it was
21 negative.

22 **MR KEVIN ROBERTS:** I didn't understand it at first. I had
23 to read it about 50 times. What's it mean? When it
24 says O positive, I think that's my blood, I'm not sure.
25 I wasn't sure if the O positive was my blood or the

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1 clearing the virus.

2 **MR KEVIN ROBERTS:** I believe that's when -- yes, I believe
3 that as the virus was being fought I was getting better,
4 yes.

5 **MS FRASER BUTLIN:** When were you told you had cleared the
6 virus?

7 **MR KEVIN ROBERTS:** I was 23 years of age. Again, done my
8 blood testing. Doom and gloom, oh, here we go, what's
9 he going to say today? Go in to the doctor, Dr Kreuger
10 again, and he goes, "Hmm, all right, Mr Roberts, well,
11 got a bit of news for you today". I said, "Oh, have
12 you?" He goes, "I don't know how you've done it but
13 it's -- we can't find it." I said, "Find what?" He
14 said, "Your hep C. It is untreatable". He said,
15 "You'll always have the antibody in your system but,
16 well, the good news is we think you're okay, you're
17 going to be okay". I went, "Oh, okay, thank you". And
18 that was that.

19 **MS FRASER BUTLIN:** You applied to the Skipton Fund.

20 **MR KEVIN ROBERTS:** I did. I seen it in the newspapers about
21 I wasn't alone anymore. I found out about the Penrose
22 Inquiry. I read it in the newspaper. I wasn't a big
23 paper reader but this headline caught me. I don't know
24 how I ended up reading it. I went, "Hang on, there is
25 a thing called the Penrose Inquiry. There's other

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1 results. But yes, thankfully it was.

2 **MS FRASER BUTLIN:** In terms of hepatitis C, did you tell
3 anyone about the diagnosis other than your immediate
4 family?

5 **MR KEVIN ROBERTS:** Family knew. I threatened my brothers
6 that if they told anyone I'd kill them, and I never told
7 anyone. I was scared, terrified. I was 18 years old.
8 It was in the news. I knew I would be ostracised. It's
9 a small community. Everyone knows everyone. No, never
10 told no-one.

11 **MS FRASER BUTLIN:** Once you reached your twenties you
12 started to feel a bit better, a bit stronger, and things
13 started to improve.

14 **MR KEVIN ROBERTS:** I did. It was literally 17/18 years of
15 age when I was told. I started picking up a bit. But
16 by my 20s, yes, physically I was stronger. I felt
17 stronger. My memory was still poor but, yes,
18 I definitely felt stronger. I was able to do a man's
19 work. And more so, I believe. I was a strong lad. It
20 was coming back to me. And I felt very fit. I was
21 socialising a lot. I was socialising probably more than
22 I should because I didn't think I had long, so I did
23 socialise a lot more, and, yes, I did feel really,
24 really good, really good.

25 **MS FRASER BUTLIN:** You think that's probably when you were

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1 victims who were infected". I think it had a mention
2 about the Skipton Fund. I went, "Well, that's me, I was
3 infected".

4 So I think the next time I seen my doctor I asked
5 him about this Skipton Fund, and he said, "Well, no,
6 you're fine, look at you. You are fine". I said,
7 "Yeah, but I was one of those infected, wasn't I?" He
8 goes, "Well, yeah, but I don't think you'll get it".

9 "But it says I should."

10 And I didn't think I was going to get
11 an endorsement from him, that's for certain. But
12 I filled it out myself, the majority of it. I don't
13 think he did a lot to it. And we sent it off and it was
14 refused.

15 **MS FRASER BUTLIN:** The application was refused and that was
16 because you had no proof you had had hepatitis C for
17 a sufficient length of time because there weren't any
18 records available.

19 **MR KEVIN ROBERTS:** The records, yes, for some reason, I had
20 a folder in the hospital, and it was like this
21 (*indicated*). And it's gone down to that (*indicated*).
22 And I think when I got rejected I asked for my records.
23 I paid the money to get them, and when they came back
24 and I went through them, it was just missing, absolutely
25 missing. I went, "Where's it to? Where's these

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1 operations that I had? Where's the treatments I had?
 2 Where's all these tests? I was being tested every three
 3 months. There's no tests. Where are they?" But that's
 4 before I knew you could get help to look for records or
 5 how to ask officially for records. I just got sent what
 6 they decided to send me and it was not there. It was
 7 just missing.

8 **MS FRASER BUTLIN:** You have also applied to EIBSS and been
 9 refused there as well.

10 **MR KEVIN ROBERTS:** Yes, I done the Skipton twice. Got
 11 rejected. One on -- it was "You didn't have it bad
 12 enough", and one, "You didn't have it long enough", was
 13 their excuses I believe. I just remember those two
 14 bits. And then EIBSS, I only applied for EIBSS when
 15 this Inquiry started and I found out about it. And
 16 speaking to the other victims, I found out I am a victim
 17 and they said, "You're definitely eligible. You're
 18 definitely eligible", and I said, "Okay, I'll apply".

19 Again, I did the majority of the work myself,
 20 tried to get the endorsement from the blood doctors who
 21 did a terrible endorsement. Absolutely shocking.
 22 Again, sort out these missing records, including the GP,
 23 which was even worse. Massive -- like the hospital has
 24 got sporadic bits. The GP was just completely missing
 25 that period of my life. Sent it off. Thought I hit the

13

1 Marlene, in 1986/87 you needed to have
 2 a hysterectomy and you had a discussion with the surgeon
 3 before the operation about whether you would need
 4 a transfusion during the surgery.

5 What were you told by him?
 6 **MS MARLENE ELIZABETH NEVE:** Well, I offered -- I was working
 7 in health at that time as a radiographer and we were
 8 very aware of HIV. So, I asked if I could donate my own
 9 blood in case it was needed because of the surgery and
 10 the surgeon laughed at me and said "No, you haven't got
 11 enough blood for yourself, you know. This is why you
 12 need it done. However, it is highly unlikely you will
 13 need it and, if you do, the blood we have here is safe".
 14 That was it.

15 **MS FRASER BUTLIN:** You were admitted to hospital in
 16 February 1987 to have the surgery.

17 **MS MARLENE ELIZABETH NEVE:** Yes.

18 **MS FRASER BUTLIN:** But after the operation you haemorrhaged.

19 **MS MARLENE ELIZABETH NEVE:** Yes.

20 **MS FRASER BUTLIN:** What do you know about what happened
 21 next?

22 **MS MARLENE ELIZABETH NEVE:** Well, I was hemorrhaging very
 23 badly. Turns out that there was quite a large area --
 24 relatively large area that was unsutured in theatre and
 25 that's where I was hemorrhaging from and I needed

15

1 criteria because the criteria was you only had to be
 2 infected originally. And refusal. Fine. Why? How?
 3 They said they want a PCR test. A PCR test, great.
 4 Yeah, refused me. And it hurt. It hurt really badly.

5 They said, "You've got a chance of appeal", so
 6 I think I waited a bit. I think Covid happened so I had
 7 more time to put the appeal in. And this time I went
 8 for it with everything I could find. I asked for
 9 endorsements from the Hep C Trust, which was great.
 10 Again with The Haemophilia Society, again they helped.
 11 They gave me endorsements. Professor Graham Foster,
 12 I spoke to him quite a few times on the phone and email
 13 and he said, "Yes, I do believe you self cleared later
 14 than the time that EIBSS give, six months". I did
 15 American studies on mortality rates of people that
 16 self cleared, got a statement off my father under oath,
 17 and I got every single thing I could think of. And
 18 again rejected -- and this time it hurt.

19 They rejected me and I went dark for three weeks.
 20 Didn't want to work. I didn't want to speak to anyone.
 21 I nearly quit the Inquiry. I didn't feel like a victim.
 22 I felt like a liar, a fraud. They was trying to tell me
 23 I made it all up, and that hurt. That really hurt me.
 24 I'm a big lad but that broke me.

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

14

1 further emergency surgery and I needed blood. I was
 2 being given emergency fluids under pressure but
 3 obviously still hemorrhaging very badly, my blood
 4 pressure was very, very low, and time was ticking away,
 5 so when they operated they also gave me some blood.

6 **MS FRASER BUTLIN:** Were you ever told how many units you
 7 were given?

8 **MS MARLENE ELIZABETH NEVE:** At the time, no, I wasn't.

9 **MS FRASER BUTLIN:** How did you come to find out you had been
 10 infected with hepatitis C?

11 **MS MARLENE ELIZABETH NEVE:** I got a letter from I think it
 12 was the Blood Transfusion Service informing me I had
 13 been infected by hepatitis C as a result of the blood
 14 transfusion, the transfused blood that was tested and
 15 found to be positive.

16 **MS FRASER BUTLIN:** So I think your recollection is the
 17 letter suggested that the donor who had donated the
 18 blood had now been identified as hepatitis C positive?

19 **MS MARLENE ELIZABETH NEVE:** That's right, yes.

20 **MS FRASER BUTLIN:** So it was perhaps part of the look-back
 21 exercise?

22 **MS MARLENE ELIZABETH NEVE:** Possibly, yes.

23 **MS FRASER BUTLIN:** At that point you made an appointment
 24 with your GP?

25 **MS MARLENE ELIZABETH NEVE:** Yes.

16

1 **MS FRASER BUTLIN:** And had a blood test, and what were you
2 told then?
3 **MS MARLENE ELIZABETH NEVE:** It was inclusive at that time
4 I was told and I was told I would need a liver biopsy to
5 make a final decision, which I eventually had.
6 **MS FRASER BUTLIN:** After that biopsy you were then told that
7 you had been infected but had cleared it?
8 **MS MARLENE ELIZABETH NEVE:** Yes.
9 **MS FRASER BUTLIN:** And what information were you told about
10 what that meant?
11 **MS MARLENE ELIZABETH NEVE:** Not a lot, really. Like most
12 people for most things these days I was given the
13 leaflet. They didn't really tell me any more than
14 I knew anyway. I was also told -- well, I was also
15 asked when I had had malaria and I said I hadn't. They
16 said, "You have", and I then described what I thought
17 was just a simple viral illness but I'd been very ill
18 with it. I wasn't able to get out of bed really. I was
19 fluctuating rapidly between absolutely burning up and
20 pouring sweat and being really cold, ice cold, shaking
21 with what's known as rigors and just fluctuating between
22 the two. This went on for three weeks. They just said,
23 "That's malaria". I said, "Well, I've not been to
24 a malarial area", and we talked about the areas I'd
25 holidayed. They said, "No, there's nothing there", so

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1 It is not a nice feeling. It makes you feel violated,
2 I suppose, without sounding too dramatic, yeah.
3 **MS FRASER BUTLIN:** And you had a young family at the time.
4 **MS MARLENE ELIZABETH NEVE:** Yes, I did.
5 **MS FRASER BUTLIN:** And did that cause anxiety for you?
6 **MS MARLENE ELIZABETH NEVE:** Yes, because nobody could really
7 answer the questions as to whether I would be okay or
8 not and, yeah, I had two young children. They were
9 probably, what, 6 and 13 at the time. They had a lot of
10 time that they were going to need a mum and I didn't
11 know if I was going to be there.
12 **MS FRASER BUTLIN:** And in terms of your physical health,
13 what's that been like?
14 **MS MARLENE ELIZABETH NEVE:** It deteriorated quite a lot.
15 I have been subsequently diagnosed with various
16 autoimmune conditions. The first one being
17 fibromyalgia. That's just -- that just deteriorates
18 year on year and causes a lot of problems. It is
19 a syndrome of very many symptoms, probably hundreds of
20 symptoms. I have also been diagnosed with Sjögren's
21 disease, which is another autoimmune, and more recently
22 a skin condition called pityriasis lichenoides, which is
23 a bit strange because it is a condition that in itself
24 is rare but when it does hit, it tends to hit juvenile
25 males, not somebody my age as a female.

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1 I said, "Well, where's that come from?" And he kind of
2 shook his head and said, "Well, that's another can of
3 worms, isn't it?"
4 **MS FRASER BUTLIN:** In terms of the hepatitis C, in relation
5 to the risks that the infection might pose, what were
6 you advised?
7 **MS MARLENE ELIZABETH NEVE:** I was told that I had cleared
8 it, which was brilliant, so I was okay. However, I had
9 to pretty much act as though I was hepatitis C positive,
10 so I had to inform anyone who was going to do any
11 invasive procedure on me, like taking blood, operating
12 on me, doing anything at all. I had to be cautious in
13 terms of sexual activity. I had to be -- use
14 protection, inform people.
15 **MS FRASER BUTLIN:** Did they explain to you why that was
16 necessary if you had cleared the virus? Was there any
17 discussion about that with you?
18 **MS MARLENE ELIZABETH NEVE:** They couldn't really answer
19 that. They just said just better err on the side of
20 caution.
21 **MS FRASER BUTLIN:** After the diagnosis, what was the impact
22 of that on your mental wellbeing?
23 **MS MARLENE ELIZABETH NEVE:** Not too good really to be
24 perfectly honest. I felt as though I had something
25 horrible crawling around my body. Still do at times.

18

1 Again, it's just another autoimmune thing, it is
2 quite debilitating all of it together. It's quite
3 debilitating.
4 **MS FRASER BUTLIN:** And you have spoken in your statement
5 particularly of the fatigue and the memory problems and
6 the joint pain that you have suffered?
7 **MS MARLENE ELIZABETH NEVE:** Yes. The muscle pain is -- the
8 best way I can describe it is, it is almost as if --
9 your muscles have a covering. It is almost like the
10 body's cling film. It is almost like the inside of that
11 covering is fine sand paper and every time you move, any
12 movement, it hurts. You get flares.
13 When I first started with it, I used to get
14 a flare about once a month and it would probably last
15 a day. I now tend to get one a week and they are more
16 like three days by the time they have cleared.
17 Yeah, memory problems. They call it fibro fog and
18 it is like some days you struggle to remember your own
19 name. It's ridiculous. You laugh it off but it isn't
20 funny.
21 The fatigue is absolutely crushing. You can't
22 push through it. It is a fatigue that you have to
23 experience to really understand it. It just stops you
24 doing anything. And some days, again it sounds
25 dramatic, but you have to be careful sort of what you

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1 are eating because the effort of lifting a knife and
 2 fork or a spoon is just too much. It's horrible.
 3 **MS FRASER BUTLIN:** What have you been told by the
 4 rheumatologists about the fibromyalgia and your
 5 hepatitis C?
 6 **MS MARLENE ELIZABETH NEVE:** I've moved house a few times, so
 7 I've seen various rheumatologists and one of the first
 8 questions is, "Have you been exposed to hepatitis C? Or
 9 hepatitis generally", and, yeah, hepatitis C is brought
 10 up, because there does appear to be some kind of link
 11 so I'm told, and so I've read.
 12 **MS FRASER BUTLIN:** So despite having cleared it, there is
 13 still a question, when you meet the rheumatologists, of
 14 whether there is a connection between fibromyalgia and
 15 hepatitis C?
 16 **MS MARLENE ELIZABETH NEVE:** Yes, and autoimmune conditions
 17 in general.
 18 **MS FRASER BUTLIN:** Your marriage broke down in 2004.
 19 **MS MARLENE ELIZABETH NEVE:** Mm hm.
 20 **MS FRASER BUTLIN:** What's the impact of the hepatitis C been
 21 on subsequent relationships?
 22 **MS MARLENE ELIZABETH NEVE:** Quite poor really. It has
 23 reared its head and has brought potential -- some
 24 potential relationships to an end.
 25 **MS FRASER BUTLIN:** I think in your statement you say that's

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1 then I would have a long lunch break, which meant that
 2 I would just go and get into bed, set my alarm and have
 3 a sleep so I could get through the afternoon. And then
 4 after the afternoon, it is like ready meal for tea
 5 because I couldn't have prepped and made a meal. And
 6 it's brought my -- it reduced my earning capacity. It
 7 has definitely shortened by career by a lot, so I have
 8 had to give up.
 9 **MS FRASER BUTLIN:** And in terms of the financial assistance
 10 schemes, you haven't applied to them?
 11 **MS MARLENE ELIZABETH NEVE:** I applied to the Skipton Fund
 12 when I found out about it and was turned down. And
 13 I haven't applied for anything since because when I read
 14 the criteria for application, we are just not a part of
 15 that.
 16 **MS FRASER BUTLIN:** Thank you.
 17 Steven, you have mild haemophilia A?
 18 **MR STEVEN TOWSEY:** That is correct.
 19 **MS FRASER BUTLIN:** And that was diagnosed in about 1978?
 20 **MR STEVEN TOWSEY:** Yes.
 21 **MS FRASER BUTLIN:** And at that point you were treated about
 22 four or five times a year at Lewisham Hospital,
 23 initially?
 24 **MR STEVEN TOWSEY:** That's right, yes.
 25 **MS FRASER BUTLIN:** You know you received Factor VIII in

23

1 because there that difficult conversation that has to be
 2 had --
 3 **MS MARLENE ELIZABETH NEVE:** Absolutely.
 4 **MS FRASER BUTLIN:** -- about the fact that although you've
 5 cleared you've been advised you have to explain.
 6 **MS MARLENE ELIZABETH NEVE:** You have to be honest with
 7 people, yeah.
 8 **MS FRASER BUTLIN:** In terms of your working life, what's the
 9 effect been on that?
 10 **MS MARLENE ELIZABETH NEVE:** It has had quite an impact. I'm
 11 the sort of person who will try to just get on with
 12 things but, yes, it's -- I changed careers from being
 13 a radiographer to a chiropodist.
 14 Chiropody I chose because at the time I retrained
 15 I realised I had the fibromyalgia, didn't know a lot
 16 about it at that time so when I chose another career,
 17 I chose one which, if I needed to, I could do from
 18 a wheelchair.
 19 I didn't realise the whole body impact of it at
 20 all. It has shortened that career dramatically and made
 21 it -- the actual working of it very difficult. For
 22 example, I would -- the last -- my last few working
 23 years up to retirement were -- I got down to two days
 24 a week and that was a struggle. And so I would work --
 25 I would do the morning and see perhaps four patients and

22

1 October 1979 to treat a particular bleed?
 2 **MR STEVEN TOWSEY:** Well, it was told to me it was a bleed at
 3 the time, yeah, 1979.
 4 **MS FRASER BUTLIN:** And it was a bleed in your left hip.
 5 **MR STEVEN TOWSEY:** That's right.
 6 **MS FRASER BUTLIN:** Otherwise I think you were unsure whether
 7 you received cryoprecipitate or when you received
 8 Factor VIII and how that balance flowed through your
 9 treatment?
 10 **MR STEVEN TOWSEY:** What, from 1978?
 11 **MS FRASER BUTLIN:** Yes.
 12 **MR STEVEN TOWSEY:** I received treatment in 1979 for the hip,
 13 I don't know if I'd had any prior to that.
 14 **MS FRASER BUTLIN:** Can you tell us what your health, your
 15 physical health was like during your teenage years?
 16 **MR STEVEN TOWSEY:** During primary school it was awkward just
 17 because of haemophilia. I was treated different, like
 18 you can't play the sports, you have to be careful in PE.
 19 In fact, the only sport they would allow me to do was
 20 swimming. It wasn't until I got to secondary school
 21 that I was tired all the time. It was -- I was coming
 22 home, I was just collapsing on the sofa and it just got
 23 to the extent that my mum thought I was on drugs because
 24 I was falling asleep all the time. I was collapsing at
 25 school. Twice this happened in secondary school and the

24

1 teachers said, "Oh, you just fainted", and I listened to
 2 them. I believed what they were telling me.
 3 There was another time I was on the train to visit
 4 me auntie in Strood and again collapsed on the train.
 5 Passengers took me off the train and left me on the
 6 platform. Again, in secondary school I wasn't allowed
 7 to do any sports at all.
 8 **MS FRASER BUTLIN:** In terms of those times when you
 9 collapsed, did you see your GP about them at all?
 10 **MR STEVEN TOWSEY:** Never seen a GP. The only time I would
 11 have seen my GP as a child was for vaccinations or
 12 unless there was something that was quite obviously
 13 wrong, like an ear infection or maybe you have got
 14 chickenpox. That's it. I never really see my GP. It
 15 was hospital, everything.
 16 **MS FRASER BUTLIN:** Did you mention the collapses to the
 17 haematologist at all?
 18 **MR STEVEN TOWSEY:** No, because I assumed they were due to
 19 faints. I'd never fainted before in my life.
 20 Throughout primary school. It wasn't until I got to
 21 secondary school that this extreme tiredness just hit me
 22 and I was collapsing.
 23 **MS FRASER BUTLIN:** How did you come to find out that you had
 24 been infected with hepatitis C?
 25 **MR STEVEN TOWSEY:** It would have been in the late '80s, and

25

1 **MS FRASER BUTLIN:** Why did you go to ask them about it at
 2 that stage?
 3 **MR STEVEN TOWSEY:** I wanted confirmation. I was with my
 4 girlfriend at the time and she didn't understand and
 5 I couldn't explain it, so we wanted confirmation.
 6 We booked to see Lewisham Hospital and what they
 7 done is they couldn't give me the confirmation, they had
 8 to test me. I think it was over a period of six to
 9 12 months, regular intervals, I had to have various
 10 different tests. I was told to use barrier methods of
 11 contraception. [Redacted]
 12 And eventually they gave me that -- well, what
 13 they told me wasn't the all clear, they said, "Yes, you
 14 have come into contact with hepatitis C, the virus is
 15 below our detectable limits". So what does that mean?
 16 Does that mean that I've got it or I haven't got it?
 17 All that meant was it is below what we can detect for
 18 and all the time it remains at that level, it is not
 19 a problem.
 20 **MS FRASER BUTLIN:** In your statement you have described the
 21 nurses as saying that you had natural immunity and that
 22 you should consider yourself very lucky?
 23 **MR STEVEN TOWSEY:** Yes, that was -- after speaking to the
 24 haematologist nurse, "Yeah, you've effectively got
 25 immunity against hepatitis A" -- I'd been vaccinated

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1 it wasn't -- we didn't just receive a letter and was
 2 told, it was more vague than that. It was, "You've" --
 3 it was -- they spoke about it when you got to the
 4 hospital but it was, "You've been infected with" -- or,
 5 "You've come into contact with hepatitis C. Now, it is
 6 not causing you any problems at the moment, it is just
 7 something you get. Something you need to deal with".
 8 And that was it. There was no information. No
 9 leaflets. Nothing at all.
 10 **MS FRASER BUTLIN:** I think your recollection is that it was
 11 in about 1992 that you got that initial letter, maybe
 12 a little bit earlier?
 13 **MR STEVEN TOWSEY:** 1992 was when I was aware -- more aware
 14 of what I'd received, yeah. Because I think I got
 15 a leaflet at that time to explain the symptoms of
 16 hepatitis C and what that actually means. But there was
 17 never any other advice, there was no support, nothing.
 18 It was just, "Oh, right", and that was it. But because
 19 I had been told that you don't worry about them things,
 20 we didn't. We just -- we got on with our lives.
 21 **MS FRASER BUTLIN:** Then in 1996 you went to ask doctors
 22 about your hepatitis?
 23 **MR STEVEN TOWSEY:** That's right.
 24 **MS FRASER BUTLIN:** And you saw a haemophilia nurse.
 25 **MR STEVEN TOWSEY:** Yes.

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1 against hepatitis A, vaccinated against hepatitis B --
 2 "You should consider yourself very lucky", and I didn't
 3 consider myself lucky.
 4 **MS FRASER BUTLIN:** And why was that?
 5 **MR STEVEN TOWSEY:** [... redacted ...]
 6 **MS FRASER BUTLIN:** After you were married you applied for
 7 some life insurance, in about 1997. What happened with
 8 those applications?
 9 **MR STEVEN TOWSEY:** I applied for life insurance and they
 10 asked me a question, if I had ever been -- if I had ever
 11 had a test for hepatitis C. And I'd never been asked
 12 that on previous occasions for any sort of insurances,
 13 it just took me back a bit. So I had to be honest,
 14 I said, "Yes, I have", and as a result they refused me
 15 my life insurance.
 16 **MS FRASER BUTLIN:** And on the application form were you able
 17 to make clear that you had cleared it?
 18 **MR STEVEN TOWSEY:** No, it was just a tick box.
 19 "Have you been infected?"
 20 Or, "Have you been tested?"
 21 Yes, I have. That was it. There was no other box
 22 for putting a reason down, it was that's it.
 23 **MS FRASER BUTLIN:** In about 2000 you moved to Cambridgeshire
 24 and transferred your care from Lewisham to
 25 Addenbrooke's.

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1 **MR STEVEN TOWSEY:** That is correct.
 2 **MS FRASER BUTLIN:** And you sought your records from Lewisham
 3 Hospital in about 2003.
 4 **MR STEVEN TOWSEY:** That's right.
 5 **MS FRASER BUTLIN:** What did you discover was missing when
 6 you obtained the records?
 7 **MR STEVEN TOWSEY:** I was missing I think it's from about
 8 1979 to 1985 all my microbiology blood results. So
 9 there was no liver function test results. No blood
 10 results, anything during that period. And being
 11 a haemophiliac under Lewisham, we were tested -- or had
 12 blood tests taken every year under the annual review.
 13 So they were all taken but none in my medical records at
 14 all.
 15 **MS FRASER BUTLIN:** In 2004 your application to the Skipton
 16 Fund was refused. Do you recall why -- what the reason
 17 for the refusal was?
 18 **MR STEVEN TOWSEY:** The first time I applied for Skipton
 19 I filled out the form, sent it off, it was refused
 20 because I didn't meet the criteria. I applied again and
 21 this time I got help from a lot of people. I went to
 22 various organisations, got letters of support. The
 23 doctor at the time from Lewisham, she wrote me letters.
 24 I had The Haemophilia Society, I had -- I want to say
 25 Contaminated Blood --

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1 would have undergone in the early 1980s are in his
 2 notes.
 3 "There is a period, therefore, between 1979 and
 4 1985 when it is likely that Mr Towsey had
 5 a transaminitis, but we are not in a position to prove
 6 this or indeed disprove that he had an active
 7 hepatitis C infection at the time.
 8 "Regular records of biochemical screening, in the
 9 form of a summary sheet, are not available until 1985,
 10 and have been normal since, noting that our results in
 11 Lewisham stop in 2000, when his care was transferred to
 12 Addenbrooke's. Mr Towsey was first noted to be
 13 hepatitis C antibody positive in 1992 and his first PCR
 14 result was in 1995 and negative.
 15 "In addition, and even though his hepatitis C PCR
 16 has been undetectable on the four occasions when it was
 17 tested, most recently in 1999, there is no guarantee
 18 that the 15% or so of hepatitis C patients who become
 19 PCR undetectable without undergoing any treatment will
 20 never reactivate. There is certainly evidence, however,
 21 that some 5% or so of hepatitis C positive patients who
 22 become PCR undetectable after treatment, will
 23 reactivate.
 24 "Given that Mr Towsey first became aware of his
 25 hepatitis C status in 1992, there were at least

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1 **MS FRASER BUTLIN:** It was The Hepatitis C Trust, I think.
 2 **MR STEVEN TOWSEY:** That's right, yeah, The Hepatitis C
 3 Trust. There was another one as well. But I got as
 4 many people as I could to write letters of support.
 5 I even had a solicitor fight my case for me. He felt so
 6 strongly, he done it free of charge. It was not
 7 a no win no fee, it was free of charge. And I thought,
 8 I've got this this time, great. And sent it all off.
 9 Refused. It went to appeal and again it was refused on
 10 the -- because I wasn't meeting the criteria. And again
 11 it said on the reason why I was refused that I should
 12 consider myself lucky.
 13 **MS FRASER BUTLIN:** In terms of the letter from your
 14 haematologist, I think it would be helpful to put that
 15 up so that we can look at it. The reference is
 16 COLL0000010, and I think it is page 45 that we want
 17 please.
 18 Just picking up from the third paragraph and I'm
 19 going to read quite a chunk of it out, Steven.
 20 "Mr Towsey first received Factor VIII in 1979 for
 21 seven days. This was in the context of a bleed in one
 22 of his hips.
 23 "His notes are unfortunately incomplete in that
 24 they no longer contain records of his early review
 25 visits, and that none of the biochemical screenings he

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1 three years during which he had no reassuring
 2 information in the form of negative PCR as the
 3 technology was not available. [... redacted ...].
 4 "The psychological distress caused to Mr Towsey
 5 under the circumstances has been considerable, given his
 6 knowledge of his own infection by the same or similar
 7 agent. I would therefore recommend Mr Towsey very
 8 strongly for compensation under the Skipton Fund
 9 scheme."
 10 That was the letter that was provided by the
 11 Lewisham consultant?
 12 **MR STEVEN TOWSEY:** That is correct.
 13 **MS FRASER BUTLIN:** And despite that letter your applications
 14 were still refused?
 15 **MR STEVEN TOWSEY:** Still refused.
 16 **MS FRASER BUTLIN:** Thank you.
 17 Wayne, you have severe haemophilia A.
 18 **MR WAYNE GATHERCOLE:** Yes.
 19 **MS FRASER BUTLIN:** And you were generally treated at
 20 Nottingham Hospital?
 21 **MR WAYNE GATHERCOLE:** Yes.
 22 **MS FRASER BUTLIN:** And that was with a variety of
 23 Factor VIII products and cryoprecipitate in the 1980s
 24 and 1990s.
 25 **MR WAYNE GATHERCOLE:** Yes.

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1 **MS FRASER BUTLIN:** When were you told you had contracted
 2 hepatitis C?
 3 **MR WAYNE GATHERCOLE:** I can't remember, probably 12/13 maybe
 4 14, around about that age.
 5 **MS FRASER BUTLIN:** Do you recall how you were told?
 6 **MR WAYNE GATHERCOLE:** Yes. I was -- we'd come to the
 7 hospital I think just for a routine appointment.
 8 Because I was there every, like, three months to six
 9 months, and we were waiting outside in the corridor and
 10 one of the nurses came out and I think my mum asked,
 11 "Why are we here today, because I don't think it is
 12 normal?", and she said it is, "Oh, it's because Wayne's
 13 got hep C". And we were just told in a corridor because
 14 the room -- you'd walk through one of the main corridors
 15 and there were just chairs outside and then you'd go and
 16 see the doctors into the main bit and we were sat
 17 waiting there and people walking past and a random nurse
 18 just kind of told us off the cuff. And then we went in
 19 to see the doctor. So ...
 20 **MS FRASER BUTLIN:** What was your mum's reaction to that --
 21 **MR WAYNE GATHERCOLE:** Shock, I think. For me, I didn't
 22 really understand it at the time. We went in to see the
 23 doctor. They kind of explained it more, in vague terms,
 24 but then we -- I can just remember we went -- we left,
 25 got in the car, me mum was really emotional, and then we

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1 **MR WAYNE GATHERCOLE:** I didn't either. It was one of those
 2 things we didn't tell people about or speak about. It
 3 was a small village where we lived and everything that
 4 occurred with AIDS appearing and stigma, it is like you
 5 didn't want that to come out as well, with the
 6 hepatitis C, so yeah. Didn't mention it.
 7 **MS FRASER BUTLIN:** When you were a teenager can you describe
 8 what your health was like?
 9 **MR WAYNE GATHERCOLE:** Not good. Very similar to how
 10 everybody else has been describing it. And it was
 11 probably when I was more getting into like 11/12 is when
 12 it really started. Just fatigue, not just feeling
 13 unwell. I had my haemophilia, which is, you know --
 14 I had days where I had bleeds and I was unwell. I know
 15 what that feels like. It is not nice; it's horrible.
 16 But then I would wake up and the bleed has gone, yay,
 17 but then you are just feeling horrible.
 18 The best way of describing it is I recently got
 19 Covid and I was feeling not very good from Covid,
 20 drained, and that was pretty much how it was like most
 21 days when I'd -- yeah, for those couple of years, just
 22 getting up, no energy, washed out, just hard and it was
 23 just really hard to get motivated to do anything,
 24 because I didn't have the energy because I didn't feel
 25 very well. I was jaundiced quite a lot. Younger than

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1 drove home to find my dad, because my dad was working,
 2 he was a window cleaner at the time, so he was somewhere
 3 around, so we drove around trying to find where he would
 4 be working. And then me mum went and told me dad.
 5 Yeah. And then -- so, not a nice day, but ...
 6 **MS FRASER BUTLIN:** What was your mum advised about
 7 precautions you needed to take in light of your
 8 infection?
 9 **MR WAYNE GATHERCOLE:** We needed to take -- make sure all of
 10 my toothbrushes and toiletries and stuff like that were
 11 in a second bathroom. They asked us do we have a second
 12 bathroom. We were like, yeah, we have a main bathroom
 13 and a -- me mum and dad had got an en-suite. They're
 14 like, "Well, can you separate everything from everybody
 15 else in the family, we don't want contact, toothbrushes
 16 especially", with my brothers, or anything like that,
 17 and to separate everything and keep them out the way.
 18 **MS FRASER BUTLIN:** Did anyone outside of the immediate
 19 family know that you had hepatitis C?
 20 **MR WAYNE GATHERCOLE:** No, we were told -- we told never to
 21 mention it in front of anybody. It was never mentioned
 22 really in front of my brother again for a long time and
 23 then we were told not to tell anybody. So, yeah, so we
 24 didn't because -- I didn't either.
 25 **MS FRASER BUTLIN:** Sorry, I missed that.

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1 my teenage years as well. Yeah, very similar to how
 2 everybody else has described it really.
 3 **MS FRASER BUTLIN:** I want to just look through three of your
 4 medical records and then I will ask you about them, if
 5 I may.
 6 COLL0000012, if we can start with that, please.
 7 We see the date is 27 July 1995, and if we go down
 8 to the middle of the page, we have this note:
 9 "Main complaint is of recurrent episodes fatigue,
 10 listlessness, disinterest. [Occasional] nausea, vomited
 11 once only. No major abdominal pain. Appetite
 12 maintained. [About] once [a] month. Stays in bed or
 13 around the house. No [weight] loss. Stays off school
 14 1-2 days.
 15 "- Mum more concerned about it than Wayne is.
 16 Also thinks he looks 'too pale'. At same time says
 17 prophylaxis allows him to be more active."
 18 Then if we could turn to COL0000013, please.
 19 This is a letter from the -- we can see on the top
 20 right corner that the clinic was held on 24 August 1995
 21 although the letter is dated 30 August. If we go down
 22 to the third paragraph:
 23 "Wayne's main complaint was of recurrent episodes
 24 of fatigue and listlessness. These are occasionally
 25 accompanied by nausea but no vomiting. He has no

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1 abdominal pain, his appetite is maintained and they
 2 occur approximately once a month. He does however stay
 3 off school for a day or two when they occur. I must
 4 confess I got the impression that these were concerning
 5 his mother far more than Wayne but she is obviously
 6 concerned lest it be related to his Hepatitis C status."
 7 Then COLL0000011, please. A clinic note from the
 8 22 February 1996, and if we go down to the third point:
 9 "Back to having lots of time off school. Only one
 10 full week at school since Xmas.
 11 "Due to: Fatigue, lethargy, Headaches, nausea.
 12 Appetite normal.
 13 "Non specific mid abdominal discomfort, worse when
 14 hungry."
 15 Do those notes, Wayne, accord with how you felt
 16 during your teenage years?
 17 **MR WAYNE GATHERCOLE:** Pretty much, yes.
 18 **MS FRASER BUTLIN:** In terms of the references to your mum
 19 being more concerned than you, what's your kind of
 20 perspective on that?
 21 **MR WAYNE GATHERCOLE:** Yes, my mum was worried but more than
 22 me was because my way of dealing with my entire life and
 23 my haemophilia is, I'm perfectly fine. It is like I am
 24 fine, I have got a bleed it is fine, that's just -- in
 25 my own little head it is me versus my body, my body

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1 **MS FRASER BUTLIN:** Have you talked to your mum at all about
 2 her interactions with the clinicians at that point?
 3 **MR WAYNE GATHERCOLE:** Yes. I always felt my mum quite a lot
 4 of time was looked down upon -- talked down to.
 5 Especially, she was -- she had me young. She was
 6 only 20 when she had me, so a lot of time when she was
 7 dealing with the doctors, I -- she was still young.
 8 Younger than I am now. You are being told things by
 9 somebody who you are supposed to trust and take every
 10 that they say and a lot of the time they would be quite
 11 dismissive towards her, "There's nothing to worry about,
 12 he's fine. He is a typical teenager".
 13 My mum was like, "But I've got" -- my brother is
 14 only sixteen months older than me. She knows what
 15 a typical teenager is like. My brother is super fit.
 16 He has been in the army 22 years. He is that level of
 17 fitness. I'm not. And I would have like -- you have
 18 got -- he's just a normal teenager. He is just lazy.
 19 He is just tired. It's like, no, that's what Clinton
 20 can be like, but Wayne is another level. Yeah.
 21 **MS FRASER BUTLIN:** What was the impact on you mentally of
 22 being told that you had hepatitis C?
 23 **MR WAYNE GATHERCOLE:** Not great. I probably dealt with it
 24 and I still deal with it just literally putting
 25 everything in a box in my own little head and not

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1 versus me, so it treats me like crap, I'll treat you
 2 like crap. Best way of dealing with it as a kid was to
 3 be that way. It's -- yeah. And then not tell anybody
 4 really about it apart from being in pain, I need some
 5 treatment, and then you just deal with it and I'm fine.
 6 And I still do it to this day. If somebody asks me,
 7 "Are you okay?", "I'm fine".
 8 My wife moans at me all the time. She knows me
 9 best and she knows when I'm not and pulls me up on that,
 10 but at the time I used to do that to my mum. If I was
 11 really ill, she would know and I would tell her if I was
 12 really ill, but most of the time I would be fine. I'd
 13 go to the hospital, stuff would be wrong but I would say
 14 to them, "Are you okay?"
 15 "Yeah, yeah, I'm really good."
 16 I still do it now when I go to the hospital. "Are
 17 you okay?"
 18 "Yeah, yeah, I'm fine."
 19 I think I've done it this morning to a bunch of
 20 people.
 21 "Yeah, yeah, I'm fine."
 22 It's just my natural response. And I'm not but
 23 what's the point in moaning about it? Because it
 24 doesn't really achieve much because that stuff is still
 25 going to be there. So, yeah.

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1 dealing with it and ignoring it and going, "I'm fine,
 2 everything's fine", because what else could I do?
 3 I could not do anything about it. I could deal with my
 4 bleeds by having my factor, try and not injure myself or
 5 anything like that, but the hep C I couldn't do anything
 6 about that, so it's just try and stick it in a box and
 7 leave it there. And I've only just started to open that
 8 box lately in the last few years. So, yeah. So not
 9 great, but ...
 10 **MS FRASER BUTLIN:** And how did you come to find out that you
 11 had cleared the infection?
 12 **MR WAYNE GATHERCOLE:** I can't remember my exact age but I'd
 13 have been in my late teens, maybe 17-ish. I'd gone
 14 to -- started going to the hospital on my own and it was
 15 due to the fact that I'd got a girlfriend at the time
 16 and I -- you know, you want to be more active, so
 17 I think I'd asked them about that and then the response
 18 is, "Oh, you don't have to worry about that. You
 19 cleared that ages ago. It's fine. It's gone, you don't
 20 have to worry about it."
 21 "Oh right."
 22 "So, yeah, yeah, you're this and you're that.
 23 You're PCR positive" -- I can't remember which way round
 24 it is. I came home and mentioned it to my mum and dad
 25 and said, "They told me I'm fine with that". They were

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1 like, "Did you get any more information?" I'm like,
 2 "Maybe I need to go back". Yeah, I'm 17, I'm an idiot.
 3 If somebody tells you you've cleared it, like, yay.
 4 I didn't ask the questions that I would have asked if my
 5 mum and dad had been there, and I think I went back for
 6 another meeting with my mum and dad and we asked more
 7 questions because, as a typical teenager, you only ask
 8 certain questions.
 9 **MS FRASER BUTLIN:** Do you recall that second meeting what
 10 you were told, having cleared --
 11 **MR WAYNE GATHERCOLE:** No, I can't remember that second
 12 meeting. I don't know if we did go back for another one
 13 at all. I just remember being told and it being like,
 14 "Oh, right", something -- "You don't have to worry about
 15 that. You cleared it ages ago. Why are you whittling?"
 16 **MS FRASER BUTLIN:** You applied to the Skipton Fund?
 17 **MR WAYNE GATHERCOLE:** I never applied.
 18 **MS FRASER BUTLIN:** Apologies.
 19 **MR WAYNE GATHERCOLE:** So when I went to university I was --
 20 I transferred when I was about 21/22 to Sheffield and
 21 the -- Professor Macross there, when I first moved there
 22 and met him, he said, "Are you aware of this?" I was
 23 like, "No". So he was like, "Yeah, this is the Skipton
 24 Fund and, from looking at your notes, you should be
 25 eligible for this", so he was like, "I'll look into it."

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1 "Nope". She was like, "Would you be willing to go
 2 through that if we take you on as a test case to go
 3 through EIBSS, and we will get as much information as
 4 possible and we will see if we can get that one?" I was
 5 like, "Okay".
 6 So that took a long time. Eventually, with the
 7 help of my social worker and then Carol, one of the
 8 nurses there, and then Professor Macross, I think wrote
 9 a very strong letter saying, there are all these things
 10 that happened, these notes are missing but there is no
 11 way you would have done my liver biopsy or anything like
 12 that without having some notes -- some liver tests that
 13 were showing something wrong, so we do think like Wayne
 14 qualifies for that, so I was awarded it in
 15 December 2020.
 16 **MS FRASER BUTLIN:** Sir, I'm about to move on to a more
 17 thematic discussion but I wonder whether now is a good
 18 time to take our morning break and then we can return to
 19 those themes after our break?
 20 **SIR BRIAN LANGSTAFF:** Yes. Well, we have heard the personal
 21 stories of each and the general discussion of the type
 22 that we had yesterday can follow at 11.30, so 11.30.
 23 (11.02 am)
 24 (A short break)
 25 (11.32 am)

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1 I'll go through your notes. I'll get all the relevant
 2 stuff and then we will send off and apply for it". Then
 3 I got -- so I was quite excited. I can remember ringing
 4 my mum and dad about it because I was just about to
 5 finish uni, I thought that's a bit of money, I can put
 6 it down as a deposit on a house or a flat. I can
 7 remember getting excited and then the next time I saw
 8 them a few months later they were, "I've been through
 9 all your notes and there is not enough for you to meet
 10 the criteria so there's just no point us applying
 11 because you just don't -- there are so many medical
 12 notes missing you won't pass, so there's no point".
 13 **MS FRASER BUTLIN:** But you have applied to the EIBSS?
 14 **MR WAYNE GATHERCOLE:** So I have and I was awarded that in
 15 December ...
 16 **MS FRASER BUTLIN:** 2020.
 17 **MR WAYNE GATHERCOLE:** 2020, thank you.
 18 **MS FRASER BUTLIN:** Can you tell us how you came to apply to
 19 the EIBSS?
 20 **MR WAYNE GATHERCOLE:** Yes, so my social worker at the
 21 time -- I was applying -- reapplying for my PIP, so
 22 I had contacted my social worker at the hospital and she
 23 said, "Oh, by the way, are you aware of the Inquiry?"
 24 I was like, "I'm vaguely aware of it". She said, "Also,
 25 are you aware of the new EIBSS system?" I was like,

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1 **MS FRASER BUTLIN:** Thank you. I want to start with some
 2 discussion with you about the periods of physical ill
 3 health that all of you have described, either growing up
 4 or as an ongoing issue. What discussions have you had
 5 with doctors about any connection between those bouts of
 6 ill health and your hepatitis C?
 7 **MR WAYNE GATHERCOLE:** None really, I have had none that
 8 I can remember other than what's in my notes at the
 9 time. Since then I've had conversations about it.
 10 **MS FRASER BUTLIN:** Steven, you are shaking your head as
 11 well.
 12 **MR KEVIN ROBERTS:** Nothing at all. Nothing whatsoever from
 13 my doctors at all. Anything I ever learnt is from here,
 14 from the victims.
 15 **MS FRASER BUTLIN:** Marlene, you have obviously had some
 16 talk.
 17 **MS MARLENE ELIZABETH NEVE:** Yes, it has depended on which
 18 rheumatologist I've seen. I've had rheumatologists, as
 19 I say, who've said had there been a connection, you
 20 know. I've had other rheumatologists and other doctors
 21 who, "Well, you know, if you lost a bit of weight you
 22 wouldn't have these aches and pains", and really just
 23 brushed it aside, so some simply don't want to go there.
 24 **MS FRASER BUTLIN:** And each of you were told that you had
 25 cleared the hepatitis C in very different ways. Do you

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1 have any reflections on how you were told and perhaps
 2 how you should have been communicated with about it?
 3 **MR STEVEN TOWSEY:** It was very vague to start with. Again
 4 [... redacted ...] and we never got a sit-down chat with
 5 any of the doctors, "This has happened". I can't even
 6 give a date when it was found out that [redacted] had
 7 been infected with hepatitis C. It was only after
 8 seeking the doctors for clarification that it is
 9 confirmed, "Yes, you've got it and you've cleared it",
 10 but that's it.
 11 **MS FRASER BUTLIN:** With hindsight do you think that should
 12 have been more proactive in terms of telling you that
 13 you've cleared it.
 14 **MR STEVEN TOWSEY:** Yes, there's a lot of things in hindsight
 15 they should have done differently. [... redacted ...]
 16 were not even told what [redacted] were tested for. I
 17 to you, with the bloods that were taken. You said,
 18 what, 14 bottles?
 19 **MR KEVIN ROBERTS:** Yes 14.
 20 **MR STEVEN TOWSEY:** 19 on one occasion that was taken. 19
 21 bottles of blood. It was just annual reviews. They take
 22 blood. [Redacted] didn't know what it was for. Then
 23 you're just, "Oh, you need to go up there for the --
 24 with your hepatitis B vaccination". Again, in hindsight
 25 [redacted] didn't question this [... redacted ...].

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1 "I'm not that lucky", in my head I was like, "I can't be
 2 that lucky". In my head I was going to die from this.
 3 I'm not that lucky. I have never been offered the
 4 treatment so I wouldn't want to get through it that way.
 5 It look a long time, months if not a year, to actually
 6 think, "I'm going to be okay". It took that long.
 7 **MS FRASER BUTLIN:** Reflecting on how it should have been
 8 communicated?
 9 **MS MARLENE ELIZABETH NEVE:** I found that I was told after
 10 the biopsy by my GP, "Brilliant, you've cleared it", the
 11 same thing, "You are really lucky", you know, and blah,
 12 blah, blah.
 13 So I was then asking questions about does that
 14 mean it is definitely gone? "Well, you know, who can
 15 say absolutely a 100 per cent but you are fine, you are
 16 fine". I was concerned about potentially passing it on
 17 to my children and I had just become a grandma for the
 18 first time as well then and it was like, "Well, what
 19 about dealing with my grandchild, you know, that's just
 20 come along?" Because I had him a lot. "Well, you know,
 21 if you have any little cuts or anything then you will
 22 have gloves around, won't you", because they knew what
 23 I did for a living. So I said, "Well, I treat
 24 everything like barrier nursing, basically". They said,
 25 "Well, it's the safest option I suppose, but you're

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1 What does that mean? What's a carrier? {... redacted
 2 ...} Again, unnecessary, [redacted] was treated with
 3 more cryoprecipitate for the vaccinations, ten bags,
 4 five bags for the first dose and the another five bags
 5 the second dose, and [... redacted ...]. It was
 6 unnecessary.
 7 **MS FRASER BUTLIN:** Just thinking back to that conversation
 8 about having cleared the hepatitis C, do others have any
 9 reflections on how that was done, how it could have been
 10 done?
 11 **MR WAYNE GATHERCOLE:** I can remember -- I can always
 12 remember at one point being told you have cleared it and
 13 you are one of the really lucky ones because the chance
 14 of clearing it are like 0.01%. Now, it's like -- it
 15 seems to be a lot higher than that. So you should think
 16 yourself really lucky. I was like, "Yay ... but no".
 17 It was kind of like, "Yeah, you should be really
 18 grateful", and I was and I am but it was like, "Yeah,
 19 well done. You've cleared it but -- yeah, your chances
 20 of doing that were really slim so you are a special one,
 21 well done". I can always kind of remember that and then
 22 virtually most of the things you've just said that, the
 23 reply -- the hep B stuff as well --
 24 **MR KEVIN ROBERTS:** You're dead right, when I was told
 25 I didn't jump around. I didn't do a dance. I went,

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1 fine, you're fine, you're really lucky". Again, this
 2 "You're really lucky. You are one of a very, very few",
 3 but there is a lot of us.
 4 **MS FRASER BUTLIN:** What would you have wanted to happen in
 5 that communication about clearing?
 6 **MR WAYNE GATHERCOLE:** It would have been nice if I'd had,
 7 like, a proper formal -- like, gone in and said, "By the
 8 way, we have tested you now and it is showing that you
 9 did have it, but you have cleared it and you are now
 10 negative", and then explained what that meant and what
 11 that would mean for the future, anything like that.
 12 I have never had that. I have never really had anybody
 13 really explain to me what it would mean for my future.
 14 Will it mean ongoing health problems going forward? It
 15 is just that I got told, "You've -- pretty much you've
 16 have cleared it, that's it, going forward you don't have
 17 to worry about ever again. That thing you used to have
 18 that could kill you, you don't have to worry about it
 19 now, well done". It was, like, that's pretty much the
 20 information I got given in a really blasé kind of way,
 21 like off the cuff. "Why are you worrying about that?
 22 You cleared it ages ago". Never got, like, a nice
 23 meeting, coming in -- yeah.
 24 **MS FRASER BUTLIN:** So you would have preferred a more
 25 structured discussion about what's happened and what the

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1 future looks like --

2 **MR WAYNE GATHERCOLE:** Yes, even if it was just one in my

3 regular, like, quarterly or six-monthly meetings, of,

4 like, "By the way, we are going to set aside

5 five minutes and, here we go, we are going to go over

6 this thing that you had and go over it in a lot of

7 detail". I can never remember that happening at all.

8 **MS FRASER BUTLIN:** What about others?

9 **MR STEVEN TOWSEY:** I would like to -- them to have been more

10 open. If they sat me down and spoke to me, "Right,

11 you've picked this up, this is where we think you have

12 picked this up", what's the chances of anything else

13 happening in the future. But there was nothing.

14 I would have liked that. I would have liked the doctor

15 to have sat down and explained it all to me. As I say,

16 it took till well into the '90s before I could get

17 confirmation. Even still it wasn't like -- "It's okay,

18 it is fine, there is no risk left whatsoever". Even now

19 I have got that over my head that it may come back. If

20 my immune system takes a knock, it may rear its head

21 again.

22 **MR KEVIN ROBERTS:** I completely agree with that. It -- what

23 he should have said, and took more time to do it, was,

24 "Right, we don't know how you've done it, you have self

25 cleared, now we are going to monitor you to make sure it

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1 get better if they don't?" They would choose no

2 treatment if it's over you could catch something that

3 could potentially kill you.

4 **MS FRASER BUTLIN:** In terms of that ongoing conversation

5 about hepatitis C, have any of you had any ongoing

6 follow up with a hepatologist or about the condition of

7 your liver?

8 **MR WAYNE GATHERCOLE:** No, none. None that I can remember.

9 **MR STEVEN TOWSEY:** I have yearly annual reviews with a -- to

10 check my liver function tests.

11 **MR WAYNE GATHERCOLE:** I think they may do that without --

12 they may do it. I'm going to ask next time I'm there to

13 see if they do do that. But I'm ... yeah.

14 **MS FRASER BUTLIN:** Kevin, I think you've had a bit more

15 input?

16 **MR KEVIN ROBERTS:** Yes, I had a -- asked when I first come

17 up and the victims told me what I should be asking for

18 to my haematology doctor.

19 **MS FRASER BUTLIN:** So you attended the Inquiry and then went

20 back to your hospital?

21 **MR KEVIN ROBERTS:** Because I'm naive. I did not have a clue

22 about anything, apart from that one pamphlet that I had.

23 And I learnt from the other victims. They said, "Hang

24 on, mate, do you have any FibroScans?"

25 "What's a FibroScan?"

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1 doesn't come back, and we are going to monitor you later

2 to make sure you're not going to have any" -- none of

3 that. He was just like, "Don't know how you've done it,

4 Mr Roberts, but you seem to have cured it". And that

5 was that. No followup.

6 **MS MARLENE ELIZABETH NEVE:** I think for me it was more --

7 I think because of the job I was doing, I recognised

8 that they didn't actually know themselves, my GP

9 particularly, so I thought -- and as was pointed out to

10 me, I asked awkward questions to which they just didn't

11 have the answers. You know? I think if they would have

12 been probably allowed to be a bit more open and say,

13 look, we really don't know what we are dealing with

14 here, I think that could have been accepted a bit more.

15 But I think we have all had the brush off basically. We

16 are all telling a similar story. We have all had this,

17 "You're fine, it's okay, go away".

18 **MR STEVEN TOWSEY:** The further risk should have been spoken

19 about. They should have said, "Look, if you continue

20 this treatment there are these risks". But -- I have

21 done better than everyone else but I was never informed

22 of the risks. And I can't imagine for one second that

23 my mum and dad had any idea about the risk it involved

24 having this treatment, because any parent, they'd --

25 "Is it life saving they have this treatment or will it

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1 "Oh, it's a liver test. You had a liver function

2 test?"

3 "I don't think so."

4 "Why not?"

5 I said, "I just don't".

6 And from this I went back to my haematology

7 doctor, rang him up, and I said, "We need a meeting".

8 "What's this about? You know, you've got your

9 six-monthly meeting, you can wait for that."

10 I said, "No, no, I need a meeting", I needed one

11 now.

12 He says, "Why is this?"

13 "Well, I've been to the Blood Inquiry, I'm

14 a Core Participant."

15 "You are? Why is that?"

16 "Well, I was infected with hep C, you know that."

17 He said, "Oh, the Blood Inquiry?"

18 I said, "Yes, I'm with the Blood Inquiry, and

19 I have been told what I should be asking for."

20 "Oh. What do you want?"

21 I said, "I would like liver function tests."

22 "Well, you are cleared, you don't need it."

23 "And I would like a FibroScan."

24 "What's -- I'm not sure you want one of those."

25 I said, "No, I want a FibroScan, I want peace of

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1 mind."
 2 "Oh, well, we better have you in."
 3 And got a phone call a couple of days later.
 4 "Oh, by the way we booked you in for this come in
 5 for Wednesday afternoon. Oh, hope you don't mind, we
 6 would like to bring a legal representative to be there
 7 with us."
 8 "Really? Why do you need one of those for?"
 9 "Just for us."
 10 "Do what you like."
 11 And I went there and he said -- and I said, look,
 12 it's for my peace of mind."
 13 And said, "Well, we have not done FibroScans much,
 14 we don't know much about it", he said, "but we will book
 15 you in one."
 16 "That's all I'm asking. And, you know, when I do
 17 my blood tests, can you do a liver function test for
 18 me?"
 19 Because ...
 20 "Yes, yes, we will do that for you as well.
 21 Lovely."
 22 "Okay, great."
 23 Popped in again about a week later and I said,
 24 "How are things going?"
 25 And he says, "Well, Mr Roberts, it has been

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1 slipped out, and I said fair enough, but yes, when
 2 I come back from here, I shall be back on it again.
 3 **MS FRASER BUTLIN:** Marlene, what has your experience been?
 4 **MS MARLENE ELIZABETH NEVE:** Yeah, I was monitored annually,
 5 liver function tests and saw a haematologist in
 6 outpatients. Up to about 15 years ago. And they just
 7 said, "There is no point doing them anymore, but if you
 8 have any problems let us know". And that was it really.
 9 Heard nothing since at all.
 10 I was then contacted probably ten years ago by
 11 a research group based in Cambridge who were looking at
 12 people like us, who had self cleared, and they wanted to
 13 do -- have bloods to try and find out why we had self
 14 cleared, with a view to helping perhaps a vaccine or
 15 whatever be produced. And that went on for probably
 16 about 18 months, I think, and then they just suddenly
 17 dropped out of the picture. They are not contactable.
 18 Don't really know what happened to that information.
 19 But that's it.
 20 **MS FRASER BUTLIN:** All of you have spoken about the impact
 21 on your mental wellbeing of knowing that you had the
 22 infection and that you have cleared it. Has there been
 23 any recognition of this by clinicians with whom you
 24 continued to engage?
 25 **MS MARLENE ELIZABETH NEVE:** No, nothing. Nothing at all.

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1 interesting because we had" -- my doctor, Dr Kreuger
 2 said, "Oh, we -- after we had the visit with you, I had
 3 a meeting at the -- haematology meeting in Wales where
 4 all the doctors got together, and, at the end of the
 5 meeting, as they said, 'Any questions?', I said, 'I've
 6 got a patient of mine who managed to self clear and he
 7 brought up a very valid point, he said to me, he has
 8 come from the Inquiry, he said he would like a FibroScan
 9 and a liver function test'. And he says, 'It is
 10 actually he is very right, it is very valid. Is there
 11 anything out there to bring in people who cleared with
 12 interferon or self cleared on their own, to give them
 13 these tests?' And everyone looked at each other and
 14 said no, there's nothing in writing about it. It is
 15 a very valid point. And from that meeting they sent
 16 a letter out to try to pick up these people who have
 17 been -- slipped the net, to bring them back in and offer
 18 them a chance to have these tests to check their future
 19 health."

20 And that made me feel really good. Really good.

21 **MS FRASER BUTLIN:** So you will now have -- or have had
 22 a FibroScan to check your liver?

23 **MR KEVIN ROBERTS:** I did until Covid, and I've been slipped
 24 out the net again, so I have to rattle some cages and
 25 get back on it again. But yes, since Covid I have

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1 **MR KEVIN ROBERTS:** Never been asked.
 2 **MS FRASER BUTLIN:** Do you think there should have been?
 3 **MR KEVIN ROBERTS:** Yes, most definitely, yeah.
 4 **MS FRASER BUTLIN:** What would that look like for you?
 5 **MR WAYNE GATHERCOLE:** I don't know. For me personally,
 6 after -- my plan was to try to get a bit of therapy
 7 because I've (inaudible) -- but my plan was to get today
 8 out of the way and then I'm on that. And my wife is
 9 probably going to kick my butt until I go and do it.
 10 But, yeah, that had been something.

11 I kind of feel like I was told at a very young age
 12 that I had got something that was probably going to kill
 13 me. I had seen on the news and grew up with people
 14 around me contracting and dying of AIDS, and had known
 15 about that, that I'd got something quite similar to
 16 that, at a young age knew I have got something that's
 17 probably going to kill me, probably has altered the way
 18 I have lived most of my life, if I'm honest. Yeah, and
 19 dealt with it by bottling stuff up and putting it away
 20 and trying not to deal with certain things because,
 21 yeah, it is the easiest option. It is probably not the
 22 best thing for me but it has been an easier option.

23 **MS FRASER BUTLIN:** Marlene, you are nodding to that.

24 **MS MARLENE ELIZABETH NEVE:** I recognise the bottling it up
 25 and putting it in little boxes in your head thing, and

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1 I think a lot of that comes from the attitudes that we
2 have had from the medical profession in terms of, "Well,
3 you've cleared it, you're lucky, it's not that bad, you
4 lot can go away, we have poorly people to deal with".
5 But it is only recently that I have actually managed to
6 sort of put it in my head in that, okay, we haven't lost
7 our lives, we are still here, but we have lost the lives
8 we expected to have through no fault of our own. You
9 know, you can have an accident which can change the
10 course of your life. You can develop an illness that
11 can shorten your life, can change your life. But this
12 has been done to us. And I think to have had that
13 recognised would have been a big step. And yeah,
14 perhaps some support in terms of, I don't know,
15 counselling, whatever, to actually help you to get your
16 head round that and to work out, you know, where you are
17 going, really. But yeah, we have just been brushed
18 aside and left to get on with it.

19 **MR KEVIN ROBERTS:** Same, vague. Growing up I was never told
20 about help groups -- and it would have helped -- The
21 Hepatitis C Trust, The Haematology -- Haemophilia
22 Society. I was on my own. I never talked to anybody
23 about it, not even my own family, my own mum and dad, my
24 own brothers. Just never talked to anyone about it.
25 Fear, shame. I thought I was the only one. The doctors

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1 other than that nobody knows because I have never really
2 told anybody about it. Because I was told to do that.

3 **MS FRASER BUTLIN:** A very different theme. Some of you also
4 had problems obtaining insurance. Can you tell us how
5 that felt and what effect it has had on your lives?
6 Steven, do you want to start?

7 **MR STEVEN TOWSEY:** Okay. I -- it's going back nearly
8 25 years. I got life insurance because I had a mortgage
9 and I wasn't asked any questions about hepatitis C. Got
10 the insurance no problems whatsoever. Now, I consider
11 myself fortunate on that side of things, because that
12 has still got a couple of years left to run, that
13 insurance, but it wasn't very competitive.

14 The insurance I went for, when I met my wife now,
15 I was refused. And that was because they specifically
16 asked me questions about hepatitis C. As a result of
17 that, any further insurance I have to now tell them,
18 yes, I have had insurance refused. I did appeal it.
19 I did get it -- I still got the insurance accepted but
20 they increased my premium, so I have special conditions
21 attached, so every time I go for any more insurance now
22 I have to say that, that in turn increases my premiums.
23 When my current insurance runs out in a couple of years,
24 that's it, it is not even worth me getting any more
25 insurance.

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1 should have acknowledged this; they knew the stigma
2 attached and they could have helped.

3 **MR STEVEN TOWSEY:** There was no professional support given
4 whatsoever. The only support I have ever had throughout
5 my life has been through my family, that's it. There
6 has been nothing. Even now I have had no professional
7 support at all. And it is something we have had to deal
8 with -- well, I've had to deal with from a child.

9 I agree with all these guys. It's -- you bottle it up,
10 you don't talk about it, anyone asks, "Yeah, I'm good".

11 **MR WAYNE GATHERCOLE:** I think that stems as well from being
12 told by the doctors don't tell people, don't -- don't --
13 because they knew -- they can imagine in a way the
14 stigma that would be attached to it, so, "Don't go
15 mentioning this to people".

16 It's like, today I still haven't mentioned to most
17 of my friends -- they don't know I'm here. Only my
18 wife, my mum and my dad know I'm here today. My brother
19 knew I was coming but he is currently away with work so
20 he doesn't know exactly that I'm here today because
21 I haven't spoken to him for a couple of weeks, but other
22 than that nobody else knows I'm actually here today
23 because it is something I don't talk about. A couple of
24 my friends, close friends, for a long time knew about my
25 hepatitis C, because I have now told them about it, but

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1 **MS FRASER BUTLIN:** How does that make you feel?

2 **MR STEVEN TOWSEY:** Frustrated, angry. It is something
3 that's -- it is not my fault. This is something that
4 I haven't done to myself and I'm just being refused the
5 same level of insurance anyone else would be entitled
6 to. It is frustrating. I'm just everything, annoyed,
7 hurt, everything. It should never have happened.

8 **MS FRASER BUTLIN:** Kevin, have you had any experience of
9 this?

10 **MR KEVIN ROBERTS:** To be fair, I don't even have a pension.
11 Never planned a future. So therefore I've never even
12 tried. I didn't think I would get accepted anyway, so
13 for me -- starting to deal with my future now, and now
14 I'm like I hope to get a pension. How do I get this? Do
15 they look at age?

16 So, yeah, I'm feeling better about myself and
17 I think I do have a bit of a future. It is something
18 I will approach but looking at the problems these guys
19 are getting, it's another wall to climb and I'm not
20 looking forward to it. It is hard enough battling with
21 EIBSS and trying to make a future for my children and
22 then to have another fight for something that's not my
23 fault. Yeah, tough.

24 **MR STEVEN TOWSEY:** See, with insurance there is no
25 guarantees that if something happens to me it is going

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1 to pay out. I don't know that, and that's a worry.
 2 Even though I'm paying that premium are they then going
 3 to say, "Actually, you didn't tell us about this. We
 4 are not going to pay out"? Because that is a worry and
 5 a fear of me with the insurance I've got.

6 **MS FRASER BUTLIN:** Marlene, do you have anything you want to
 7 add?

8 **MS MARLENE ELIZABETH NEVE:** Same thing, really. Sort of
 9 when they found out about the hep C contact, which is
 10 all -- you know, that's what it has been, there's no --
 11 I think someone else mentioned it earlier, there is no
 12 opportunity to say how this came about. I think they
 13 just assume it is a lifestyle situation. And that in
 14 itself is upsetting -- not to put down somebody who has
 15 problems with drugs, they've got big problems, but it's
 16 wrong because they do tar us all with the same brush,
 17 and to just say, "Right, well, okay, you might have
 18 cleared it but you are too big a risk, we are not going
 19 to do it", and you don't apply again. You don't go
 20 there.

21 **MS FRASER BUTLIN:** Wayne, do you want to chip in?

22 **MR WAYNE GATHERCOLE:** I've never applied for any due to the
 23 fact that I knew I probably wouldn't get it. I've never
 24 owned a house. I've never applied for a mortgage or
 25 anything like that. So, yeah, currently I don't have

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1 life insurance, currently I have rented my entire life.
 2 So, yeah, so I have never really experienced it, but
 3 I got told that probably I'd be rejected for most life
 4 insurances anyway due to my haemophilia and then the
 5 hep C being the -- I was kind of told that. I've never
 6 then been in a position to go and get a house, to
 7 actually go through the whole procedure of doing it.
 8 I might be now. It's something I'm looking to do in the
 9 future but, yeah, it's something I have never actually
 10 experienced it because -- the only thing I have
 11 experienced is just increased holiday insurance, which
 12 is hilarious when I go away and the family's entire
 13 insurance is like £17 and mine is like £160, just
 14 because I've clicked I had hep C. Something like
 15 haemophilia means it's about £50 and then you do the
 16 hep C thing and the price goes up. You're like, Eh,
 17 what? How does that work? It's like, that's not the
 18 main thing. The haemophilia is going to cost you the
 19 fortune. The hep C is not going to cost you that much
 20 if something happens to me. So, yeah, that's the only
 21 thing I have experienced really.

22 **MS FRASER BUTLIN:** Some of you have obviously had
 23 significant struggles with Skipton and EIBSS, and we
 24 have talked a little bit about that, but in the light of
 25 the insurance difficulties what are your reflections

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1 then on not receiving, not accessing Skipton and EIBSS?
 2 **MR STEVEN TOWSEY:** I'm just disgusted with it. That money
 3 there is earmarked for everyone that's been infected and
 4 the criteria says, yes, you can apply and then you get
 5 the response, "Oh, you don't actually meet the
 6 criteria". I feel hard done by. I feel let down.
 7 I seem to fall through the cracks all the time in the
 8 system, [... redacted ...]. {... redacted ...}; I don't
 9 get a penny. It's been hard.

10 **MR KEVIN ROBERTS:** I absolutely agree. It is says it's
 11 England Infected Blood Support Scheme, run by the NHS,
 12 with a duty of care. I'm a victim and I'm not being
 13 supported or I'm being victimised for being a victim.
 14 The records that I require are in NHS's hands. The
 15 support is in NHS's hands. Where's the communication?
 16 Why have I got to fight to get what is there -- or
 17 supposed to be there for our support? All it does is
 18 mentally make us worse. I actually am getting worse for
 19 something that's supposed to support us. That can't be
 20 right.

21 **MS MARLENE ELIZABETH NEVE:** Yes, it feels very unfair. It
 22 does feel very unfair, like you say. It is supposed to
 23 be for people who have been infected and affected by it,
 24 which we all have been and, yeah, we are just cut off
 25 and said, "Right, well, you don't really meet the

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1 criteria", and that is -- it is very upsetting and again
 2 like you say notes missing, all these things, you know,
 3 we are just not considered valuable enough.

4 **MR WAYNE GATHERCOLE:** I'm slightly feeling guilty because
 5 I have it. I have been awarded my EIBSS. I didn't get
 6 the Skipton. That would have helped my life a lot, at
 7 the age I was, but I'm sat here feeling guilty because
 8 I can imagine my medical notes are probably identical to
 9 you guys' and I feel like it's just because of the
 10 supporting letter that came from the medical team in
 11 Sheffield helped me get that, but the anxiety and
 12 everything of going through that, everything that I had
 13 to -- we had to get together and how long it took and
 14 the stress of it and the worry and then the anxiousness
 15 of, "Jesus, if we do get awarded this, it is kind of
 16 a little bit life changing for me", but that -- sat
 17 there and worrying about that process, it took a long
 18 time. If I had then got to that point and then been
 19 rejected, I would have appealed but that would have been
 20 more stress and everything, and then I feel like if that
 21 appeal had gone, there is no way I would have done it
 22 again. I'd have just gone, "There you go, that's
 23 something", how it happened with Skipton, years ago
 24 I got told, "You're not going to get it". I was like,
 25 "Fair dos", put that at the back of my mind, never do

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1 that again, walk away, and I would have done that with
2 the EIBSS. If they'd turned around and said, "You can't
3 get it", I'd have gone, "Okay, there we go. Don't get
4 it. Walk away", and just have to deal with the fact
5 that this thing happened to me a long time ago but I've
6 put that aside.

7 But I'm sat here feeling really guilty. There's
8 people in this room who deserve it more than I do, who
9 haven't got it, and I'd feel guilty for that.

10 **MR STEVEN TOWSEY:** You shouldn't feel guilty for that.

11 **MS MARLENE ELIZABETH NEVE:** No, don't.

12 **MR KEVIN ROBERTS:** No way, we are all victims and we all
13 should be supported. Everyone has got their own story
14 but you should never feel guilty.

15 **MS MARLENE ELIZABETH NEVE:** I think the fact that you got
16 it, other people have had the supporting letters and
17 haven't, which in a way makes it a little bit of
18 a postcode lottery, doesn't it?

19 **MR WAYNE GATHERCOLE:** That feels wrong, that.

20 **MR STEVEN TOWSEY:** I think the system itself is very, very
21 divisive.

22 **MS MARLENE ELIZABETH NEVE:** It doesn't work.

23 **MR STEVEN TOWSEY:** It's flawed.

24 **MS FRASER BUTLIN:** Sir, those are the questions I have for
25 the panel. Is there anything you would like to ask?

65

1 **MR STEVEN TOWSEY:** It's just my opportunity to get my story
2 over, to be heard. I'd applied to the various funds and
3 always told, "No, you don't qualify. You don't meet the
4 criteria". I've done various statements. Again, they
5 just -- they never seem to get me anywhere, even with
6 the supporting letters from various doctors and
7 organisations. No one was listening. And I just kept
8 that all to myself over the years and this was my
9 opportunity to be heard.

10 **SIR BRIAN LANGSTAFF:** Wayne?

11 **MR WAYNE GATHERCOLE:** I agree with everybody on the panel,
12 with everyone here. For me it feels, having been
13 awarded it, it feels like an opportunity to say it seems
14 a bit unfair that my notes should be virtually the same
15 as theirs and I have been awarded it and they haven't.
16 It seems, yet again, a bit random luck that a scheme
17 that's there to help people and support people is
18 a little bit on luck.

19 I don't know who assessed it that day to award it
20 me, what supporting evidence was given, but most of my
21 medical notes aren't there. All the supporting evidence
22 isn't really there apart from the fact that I had
23 a liver biopsy and there's a couple of little random
24 notes in it and that gets me support, where everybody
25 else here isn't entitled to it.

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1 **SIR BRIAN LANGSTAFF:** Just this, you have all spoken about
2 the effects of it and how, in the words of Kevin, you
3 have felt like victims who have been victimised, but
4 where in the set of consequences that you've faced do
5 you place coming today and facing the stresses of having
6 to bring yourself, because you want to, but being in the
7 position where you feel you have to give evidence?

8 **MR KEVIN ROBERTS:** I wanted to give evidence. I wanted to
9 have a voice. Everyone, including my own doctors, told
10 me I'm not a victim, "Bit of bad luck but you're not
11 a victim", yet I speak to these people in this room,
12 they look me in the eye and they say, "You're one of
13 us". I'm not wrong; they're not wrong. EIBSS is wrong.
14 My doctors are wrong.

15 **SIR BRIAN LANGSTAFF:** Marlene?

16 **MS MARLENE ELIZABETH NEVE:** For me, it's -- yeah, we've all
17 been wronged by this. There are a lot of people who,
18 for whatever their reasons, haven't been able to come
19 and be a part of this today or any of the other days and
20 I would like to feel that I'm here to say, "This isn't
21 okay", not just for me but for those who can't come.

22 **SIR BRIAN LANGSTAFF:** You are all nodding. The reason I'm
23 mentioning that is that nods don't go down in the
24 transcript. You have heard me say that before.
25 Steven?

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1 It just feels a little bit wrong and I feel like
2 I just needed to make people aware of that. That there
3 is that -- what feels a bit of a wrongness in the way
4 the system is set up at the moment.

5 **MR STEVEN TOWSEY:** Even now on the EIBSS criteria, you read
6 through it, "Ah, I do match that criteria, I can apply".
7 But it is specifically that they want the liver function
8 test results and if that section is missing from your
9 medical records, you can't apply, and that's the biggest
10 problem.

11 **SIR BRIAN LANGSTAFF:** That's all that I ask.

12 **MS FRASER BUTLIN:** Kevin, is there anything else you would
13 like to add?

14 **MR KEVIN ROBERTS:** To sum it up, please, Sir Brian, and all
15 your staff, thank you for your compassion. It means so
16 much to us. We have belief. We have a voice, something
17 we've never had before. I really appreciate that.
18 Thank you. My wife and family for putting up for me,
19 because I can be a handful, especially when I sometimes
20 leave here dark. I built up a wall years ago to hide
21 this away. That wall came down and it opened up some
22 very dark times and I'm glad I'm starting to be open
23 about it. Thank you for letting me do that. I'd also
24 like to thank the bravest, most beautiful, caring people
25 I have ever known in my life, that's my Blood family.

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1 You mean so much to me, thank you.
 2 **MS FRASER BUTLIN:** Marlene?
 3 **MS MARLENE ELIZABETH NEVE:** Very similar. Thank you to all
 4 of you and Sir Brian for the Inquiry and for letting us,
 5 like you say, have a voice. Let us be heard as to how
 6 this has affected even us who were supposedly very lucky
 7 and have cleared it, that we have actually still got
 8 a lot of things to live with every single minute of
 9 every single day and we don't know where this is going
 10 to go but it's definitely, as I said before, not taken
 11 our lives but it has taken the lives we thought we
 12 should have had and we'd worked hard for, exams,
 13 qualifications, just simply working hard, and it all
 14 comes to nothing because we are no longer capable of
 15 following that through. And, yeah, that needs to be
 16 heard and recognised.
 17 **MS FRASER BUTLIN:** Steven?
 18 **MR STEVEN TOWSEY:** I would just like to say the same, thank
 19 you for giving me a voice. I'm disgusted by the
 20 treatment I've received over the years, me and my family
 21 and everyone else in this room. It should never have
 22 happened and it is something we've got to live with for
 23 the rest of our lives.
 24 **MR WAYNE GATHERCOLE:** I just want to mirror everything
 25 everybody has said and just thank you, Sir Brian, and

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1 **GRO-A**, Sally Davis, Linda Kitson and
 2 Dorothy Wright.
 3 **SIR BRIAN LANGSTAFF:** Thank you. So tomorrow hepatitis B,
 4 10.00.
 5 (12.11 pm)
 6 (The Inquiry adjourned until 10.00 am on Wednesday,
 7 28 September 2022)

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1 the whole team here, for giving us this opportunity, and
 2 then, last, I would like to thank my wife for support
 3 and my mum and my dad for everything they have ever
 4 given me and, yeah, just say thank you.
 5 **SIR BRIAN LANGSTAFF:** Well, can I for my part thank you
 6 because this Inquiry, as you know, depends upon people
 7 from different perspectives telling their account and
 8 you have done that and done that I think -- there is one
 9 theme that links a lot of what you've said, you've felt
 10 that you have been giving voice not only to yourselves
 11 but to others, and a sense of the community that you
 12 feel now at least part of, even if you may not have done
 13 throughout it all. So thank you for that and thank you
 14 for making the effort and coming today.
 15 It's never easy, even though each of you have said
 16 you wanted to do it, which is why I asked, because it is
 17 simply not easy being in the spotlight and in
 18 an unfamiliar situation -- even though you may be
 19 familiar with the Inquiry, an unfamiliar situation. So
 20 it is very much appreciated that you have been prepared
 21 to be there as part of this panel. Thank you.
 22 Tomorrow?
 23 **MS FRASER BUTLIN:** Sir, tomorrow we will be hearing from
 24 a panel of witnesses about the experiences of people
 25 infected with hepatitis B. The panel will be

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