

1
Thursday, 4 July 2019

1
2 (10.00 am)

3 **SIR BRIAN LANGSTAFF:** Good morning.

4 **MS FRASER BUTLIN:** Good morning, sir.

5 **SIR BRIAN LANGSTAFF:** Our first witness is Pamela.

6 **MS FRASER BUTLIN:** That's correct.

7 **PAMELA PENNYCOOK, affirmed**

8 **Questioned by MS FRASER BUTLIN**

9 **Q.** Pamela, you're here to talk about your infection with

10 hepatitis C?

11 **A.** That's right.

12 **Q.** You have spina bifida?

13 **A.** Yes.

14 **Q.** When you were 11 years old you underwent spinal fusion

15 surgery?

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

17 **Q.** What is your recollection of what happened?

18 **A.** Well, I remember waking up in the recovery room and

19 I noticed that there was the drip set up with the

20 saline and also the blood. I'd never had a blood

21 transfusion before so it was a bit of a shock seeing

22 that for the first time, and then by the time I went

23 back on the ward, the blood drip had been taken down

24 and it was just the other drip that was up.

25 **Q.** Before the operation, are you aware of whether your

3

1 future."

2 **Q.** Are there any other records of you having had

3 a transfusion?

4 **A.** No, no. Just this one.

5 **Q.** On the same day that the consultant gave you this

6 letter, she also wrote to your GP.

7 **A.** Yes, that is right.

8 **Q.** What did that letter say about your transfusion?

9 **A.** That there was no record that I'd had a transfusion.

10 **Q.** So the day you were given this, there was also

11 a letter to the GP saying there was no record?

12 **A.** No record.

13 **Q.** As part of your spina bifida you had sensory loss in

14 your right leg and right foot?

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

16 **Q.** You had repeated infections and ulceration of the leg

17 and the foot?

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

19 **Q.** And ultimately you underwent a below knee amputation?

20 **A.** That's right, when I was 19.

21 **Q.** Recently you've wondered whether your infection with

22 hepatitis C contributed to those difficulties as

23 a teenager.

24 **A.** Yes.

25 **Q.** Can you tell us why.

2

1 parents were warned that you might need a transfusion?

2 **A.** Not at all. They weren't told.

3 **Q.** After the operation, were your parents told that you

4 had had a blood transfusion?

5 **A.** No, they weren't told.

6 **Q.** Please can we have document 2242002, please, Paul. If

7 we look at the top, we can see requirements and that

8 four were being delivered, four were held on reserve

9 and total of eight units of whole blood were ready for

10 the operation.

11 **A.** Mm-hm.

12 **Q.** Then if we go to the bottom of the page, part C, we

13 can see serial number in order for a transfusion and

14 there are three numbers.

15 **A.** That's right.

16 **Q.** The bottle numbers of the blood that you were

17 transfused with.

18 **A.** Yes.

19 **Q.** Can you tell us how you came to receive this document.

20 **A.** When I was going through my treatment at the Western

21 General, my consultant --

22 **Q.** For the hepatitis C?

23 **A.** For the hepatitis C, yes, so it was many years later,

24 my consultant gave me a copy of this form and said to

25 me, "Keep it safe. You're going to need this in the

4

1 **A.** It was the fact my amputation, on the form it was due

2 to recurring infections and ulcers so I asked the

3 question because I thought it could have contributed

4 to me losing my leg, the fact that I wasn't able to

5 fight infections. So my consultant -- I took all my

6 medical records because she couldn't get access to

7 them and she went through them and she said, "Although

8 it's not the sole reason, it may be a contributing

9 factor that you lost your leg". But she said, "I'm

10 not an immunologist so, you know, I can't make

11 a definite decision on that", but she said it may have

12 been a contributing factor.

13 **Q.** Nobody is very sure what impact the hepatitis C had on

14 those infections but they may have had an impact and

15 you're concerned that they did have?

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

17 **Q.** In 2005 you were diagnosed with osteoporosis?

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

19 **Q.** Your GP decided to do some blood tests?

20 **A.** Yes.

21 **Q.** Can you tell us what those first tests showed.

22 **A.** They showed that I had an issue with my liver function

23 so I was asked to keep a drink diary and then I would

24 be retested again to see, you know, if there was any

25 change to that, so -- which I did, I went back and got

5

1 the second lot of blood tests.

2 **Q.** So you've had the second lot of blood tests and what

3 happened then?

4 **A.** Well, I was sitting at work one day and I worked at

5 that time in a telephony role. So I just thought, oh,

6 in my break I'll phone the GP to get the results and

7 the receptionist said, "Yes, you're hep C positive",

8 and I said, "What do you mean?" There was a pause and

9 she said, "Oh, I don't think I was meant to tell you",

10 and I said, "Well, I need to speak to somebody.

11 I need to see a doctor", because previously I'd worked

12 in drug and alcohol team, HIV/AIDS team, so I had an

13 understanding of what hepatitis C was. She couldn't

14 give me an appointment with the doctor, so finally my

15 GP came on the phone and said, "You know, you

16 shouldn't have been told this information over the

17 phone. Come in and see me tomorrow."

18 So I just broke down in tears in the middle of

19 the office space. My manager took me away.

20 I explained, you know, the telephone conversation and

21 then I just had to go home. So my manager had to go

22 and get my bag, you know, colleagues were looking

23 around thinking, "What's going on here", then I just

24 went home and went on the internet basically to see,

25 to get as much information as I could about it.

7

1 **Q.** Did she explain how you might have come to be

2 infected?

3 **A.** I had said that I'd had a blood transfusion in the

4 early '80s because I knew from my understanding in my

5 previous job that the blood transfusions in the early

6 '80s could have been a transmission route.

7 **Q.** You were referred to the Western General?

8 **A.** That's right.

9 **Q.** But there was no appointment available until

10 February 2006?

11 **A.** That's right.

12 **Q.** What happened in that interim period for you?

13 **A.** I found it very difficult to come to terms with my

14 diagnosis. My Mum and Dad found it difficult because

15 they were saying, "Well, how do you get it", and I was

16 saying, "Well, through blood transfusions", and they

17 are saying, "But you've never had a blood transfusion?

18 How else can you get it?" And I said, "Well,

19 intravenous drug use, tattoos", and they said, "But

20 you've never had a tattoo", but it was the unsaid

21 thing, "Well, you know, have you taken drugs?"

22 So it was a year later that I got the proof that

23 I'd had a blood transfusion so in that time my parents

24 had this doubt as to how could I have received this

25 infection.

6

1 **Q.** What's been the impact on your mental health of the

2 way you were told that you had hepatitis C?

3 **A.** There was -- there was no professionalism there, you

4 know. It was just so matter of fact. I mean, I know

5 that she realised she shouldn't have told me but to

6 get a shock like that over the phone is unforgivable.

7 It should never have happened.

8 **Q.** You have said you went straight on to the internet

9 when you got home.

10 **A.** Yes.

11 **Q.** What did you find?

12 **A.** Well I was reading about things when I die my body

13 wouldn't be dressed, it would go into a hazardous

14 waste bag, it would be in lead lined coffins and

15 I just thought ... this is my life.

16 **Q.** You saw your GP the next day?

17 **A.** Yes.

18 **Q.** On 22 December 2005?

19 **A.** Mm-hm.

20 **Q.** What did they tell you?

21 **A.** They told me that I would be referred to the Western

22 to discuss treatments, you know, but that was a long

23 process to get to that and then she said that I needed

24 to get in touch with my previous sexual partners to

25 make them aware that I had the hep C.

8

1 **Q.** When you first attended the hospital, Western General,

2 can you tell us what it was like attending the clinic.

3 **A.** I was just totally outwith my comfort zone and the

4 fact it was called the Regional Infectious Diseases

5 Unit, you know, it's not the most welcoming of places.

6 The first time I went there I got lost but I was too

7 embarrassed to ask for directions. There was

8 prisoners there with their guards obviously getting

9 their treatment and I just thought, "This is my world

10 now". It was very, very frightening.

11 **Q.** When you got to the hospital you've said that you feel

12 you were given the information you needed --

13 **A.** Yes.

14 **Q.** -- about hepatitis C?

15 **A.** Yes.

16 **Q.** And it came at the right time for you to understand

17 the illness?

18 **A.** Yes.

19 **Q.** Can you tell us how you reacted to finding out that

20 you had hepatitis C.

21 **A.** Well, to be honest, I went off the rails. I started

22 drinking too much and ...

23 **Q.** You ended up pregnant?

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

25 **Q.** In circumstances that weren't ideal?

9

- 1 A. That's right.
 2 Q. You decided you had to terminate the pregnancy?
 3 A. Yes, because I knew there was a risk of passing it on
 4 to the unborn child. I decided that was the only
 5 option for me at that time and plus I knew I was going
 6 to be going through treatment as well that I had to
 7 terminate the pregnancy.
 8 Q. Can you tell us a little bit of what the impact of
 9 that decision has had on you in terms of your mental
 10 health.
 11 A. Even now I've never been a Mum so things like Mother's
 12 Day is a trigger for me and I've just got this
 13 emptiness.
 14 Q. You've only recently felt able to tell your family
 15 about the termination?
 16 A. That's right.
 17 Q. Can you tell us why.
 18 A. I needed to tell them because I knew this was part of
 19 my story and it also had an impact, my sister had her
 20 baby at the time of my termination; so I went from
 21 having the termination to go and seeing her with her
 22 new son.
 23 Q. She had her first child in the same place on the same
 24 day?
 25 A. Mm-hm.

11

- 1 August 2006?
 2 A. That's right.
 3 Q. And that was with interferon and ribavirin?
 4 A. That's right.
 5 Q. What side effects did you have?
 6 A. They were horrendous. Mood swings which led to me not
 7 being able to -- I wasn't allowed to then be alone
 8 with my new nephew because my sister didn't want to
 9 risk ... and I totally understand that. Lack of
 10 sleep, insomnia, loss of appetite, depression, and
 11 then really dark moods. You know, didn't want to be
 12 with anybody. So it was very hard. And I'd met John
 13 just six weeks before I started my treatment so that
 14 came out the blue.
 15 So it was hard to start a new relationship while
 16 I was going through the treatment. Luckily, John's
 17 been so supportive, didn't judge me in any way and has
 18 always been there for me.
 19 He had two young sons at the time so it was hard
 20 to start the relationship with them because there
 21 would be days where I wouldn't want to get out of bed
 22 so we couldn't go swimming or go for days out, so
 23 I was letting them down as well; so it was hard to
 24 maintain relationships.
 25 Q. You were off work for about five months?

10

- 1 Q. And for you, that's been incredibly difficult --
 2 A. Extremely difficult.
 3 Q. -- to try and have any relationship with your nephew?
 4 A. Yes and I didn't want to take away from, you know, the
 5 family's joy of this baby and from taking it away from
 6 my Mum and Dad because that was their first and only
 7 grandchild so I just kept it secret.
 8 Q. When you were diagnosed with hepatitis C, did you tell
 9 any friends at that point about the diagnosis?
 10 A. No. There was only six people that knew up until two
 11 months ago when I felt able to tell friends and
 12 family.
 13 Q. Why didn't you feel able to tell friends?
 14 A. I know that there's a stigma about hepatitis C and
 15 I just -- you can't untell people if you don't get the
 16 right reaction that you're looking for, so it was --
 17 at the time I thought it was easier not to tell but
 18 now that I've shared my secret, it's such a relief.
 19 Q. You've told them because you knew you were coming to
 20 give evidence?
 21 A. Yes, that's right.
 22 Q. What was their reaction?
 23 A. Totally supportive, you know. They're behind me
 24 100 per cent.
 25 Q. You started treatment for the hepatitis in

12

- 1 A. Five months, that's right.
 2 Q. As you say, you met John and you and he decided that
 3 he should have a vasectomy?
 4 A. Yes.
 5 Q. Why was that?
 6 A. John knew the trauma that I'd gone through with having
 7 my termination and the impact on my mental health. So
 8 we decided, you know, that was the decision for us and
 9 plus with being on the treatment I couldn't get
 10 pregnant while I was on the treatment or six months
 11 after, so that was the decision that was made.
 12 Q. You've said in your statement that that closed the
 13 door on you having children of your own.
 14 A. Yes.
 15 Q. And that, combined with the termination, has impacted
 16 your mental health very significantly.
 17 A. Yes, extremely so.
 18 Q. Can you tell us a little bit more about that or would
 19 you rather I read that part of your statement?
 20 A. No, it's okay.
 21 On mother's day, I think it was about three
 22 years ago, I just thought I can't go on with my life.
 23 I'm never going to achieve what I really want, so
 24 I took off my wedding rings and left my little dog and
 25 just disappeared. John ended up phoning my Mum and my

13

1 Mum left me messages because I was going to take my
 2 own life. So my Mum kept phoning and saying, "Please
 3 don't do anything silly. We love you. Please come
 4 home."
 5 So the next day the GP told me to go to the
 6 local psychiatric hospital for an emergency
 7 assessment, which I did.
 8 **Q.** Since then you've had long periods of counselling?
 9 **A.** Yes, because alcohol's been an issue for me, so the
 10 alcohol counselling has taken months and months at
 11 a time to complete.
 12 **Q.** But you've described in your statement it's an ongoing
 13 battle with excessive drinking and depression?
 14 **A.** Yes, although I must say since this process, I feel
 15 I'm able to control it because I've got a purpose
 16 which is today and there's no secrecy now because even
 17 a friend said to me last night that I was glowing and
 18 I looked so relaxed. He hadn't seen me like that for
 19 a long time.
 20 **Q.** You underwent the treatment for the hepatitis C and
 21 successfully cleared the virus.
 22 **A.** That's right.
 23 **Q.** And after that you returned to work.
 24 **A.** Yes.
 25 **Q.** Your colleagues, other than your boss, weren't aware

15

1 medical support when you're going through the
 2 treatment. I think I had a six months test and an
 3 annual test and then that's it. It's like, "There you
 4 go, you're fine" and I think it would be useful to
 5 have some sort of follow up, you know, even annual
 6 tests just to make sure everything's as it should be.
 7 **Q.** You have received payments from The Skipton Fund?
 8 **A.** That's right.
 9 **Q.** And from the Scottish Infected Blood Support Scheme?
 10 **A.** Yes.
 11 **Q.** How did you find the process of applying for that?
 12 **A.** I found it relatively easy but then I'm used to
 13 filling out forms with work and things like that, so
 14 I found it an easy process and then obviously the
 15 consultant had to complete part of the form and that's
 16 where the copy of the blood transfusion report came
 17 in, so it was a straightforward process for myself.
 18 **Q.** Those are the questions I have for you. Is there
 19 anything else you would like to say?
 20 **A.** I'd just like to thank John for all his support.
 21 Without him I wouldn't be here today at all and also
 22 my step-son, Duncan. They've both been a tower of
 23 strength.
 24 I'd also like to thank my family for their love
 25 and support throughout the years. I know it's not

14

1 of why you'd been off?
 2 **A.** That's right.
 3 **Q.** What was their reaction when you returned?
 4 **A.** Well, they actually thought I'd either had cancer or
 5 I'd been in alcohol rehab and that was hard because
 6 I'm normally quite an open person. So having to keep
 7 that secret, they were obviously really concerned
 8 about me but I couldn't be honest with them as to what
 9 was going on because, again, due to the stigma, I just
 10 couldn't do it.
 11 **Q.** Since your treatment, what's your physical health been
 12 like?
 13 **A.** Well, I cleared the virus. I get tired, difficulty in
 14 picking up, you know, new tasks at work so I've cut
 15 back on my hours there, which has helped but it could
 16 be that I'm just getting older but, yes, touch wood.
 17 **Q.** But thankfully there was very limited damage to your
 18 liver.
 19 **A.** Yes, that's right.
 20 **Q.** So in terms of your liver there's not been as much
 21 concern?
 22 **A.** That's right, yes.
 23 **Q.** Have you had any monitoring of your liver since
 24 completing your treatment?
 25 **A.** No. And that's one of the things. You get so much

16

1 been easy for them. I've got an amazing group of
 2 friends who have just rallied round me superbly in the
 3 last couple of months.
 4 I'd also like to thank my employer Lloyds
 5 Banking Group because from the day I was diagnosed
 6 through my treatment and to support me here today
 7 they've been amazing. I know that a lot of people
 8 don't have that support with their employers, so
 9 I really do support them.
 10 I'd like to thank Thompsons the solicitors for
 11 all their help and guidance. It's been invaluable and
 12 I'd like to wish the Inquiry well as you go round the
 13 other cities to hear other people's stories.
 14 **Q.** I am just going to turn and ask Mr O'Neill and
 15 Mr Dawson if there's anything they want me to raise.
 16 *(Pause)*
 17 Just one point that they'd like me to raise with
 18 you. You found out about something called C Plus
 19 Counselling?
 20 **A.** Yes.
 21 **Q.** Can you tell us how you found out about that and what
 22 it is?
 23 **A.** Yes. I went online to look for local support groups
 24 and they were based in Leith at the time and they were
 25 amazing. I got to see them almost straight away and

17

1 they gave me useful advice, lifestyle advice, about
2 preparing for treatment and about The Skipton Fund,
3 but they didn't know anybody at the time, else, who'd
4 got it through contaminated blood so there was nobody
5 else that I could speak to that had similar stories
6 but, yes, they were absolutely fantastic.

7 **Q.** They were a specialist hepatitis C counselling
8 service?

9 **A.** Yes, in Edinburgh.

10 **Q.** But it was that you found them --

11 **A.** Yes.

12 **Q.** -- not that somebody signposted you to them?

13 **A.** No, I just went on the internet looking for local
14 support groups.

15 **MS FRASER BUTLIN:** Sir, do you have any ...?

16 **SIR BRIAN LANGSTAFF:** No, I don't but I do want to thank
17 you for coming to tell us your very personal story.

18 Thank you very much.

19 **A.** Thank you.

20 **SIR BRIAN LANGSTAFF:** We'll take a break now until 11.00.

21 **(10.26 am)**

22 **(A short break)**

23

24

25

<p>MS FRASER BUTLIN: [3] 1/4 1/6 17/15 SIR BRIAN LANGSTAFF: [4] 1/3 1/5 17/16 17/20</p>	<p>appointment [2] 5/14 7/9 are [5] 1/25 2/14 3/2 7/17 15/18 around [1] 5/23 as [12] ask [2] 8/7 16/14 asked [2] 4/2 4/23 assessment [1] 13/7 attended [1] 8/1 attending [1] 8/2 August [1] 11/1 August 2006 [1] 11/1 available [1] 7/9 aware [3] 1/25 6/25 13/25 away [4] 5/19 10/4 10/5 16/25</p>	<p>circumstances [1] 8/25 cities [1] 16/13 cleared [2] 13/21 14/13 clinic [1] 8/2 closed [1] 12/12 coffins [1] 6/14 colleagues [2] 5/22 13/25 combined [1] 12/15 come [4] 5/17 7/1 7/13 13/3 comfort [1] 8/3 coming [2] 10/19 17/17 complete [2] 13/11 15/15 completing [1] 14/24 concern [1] 14/21 concerned [2] 4/15 14/7 consultant [5] 2/21 2/24 3/5 4/5 15/15 consultant -- I [1] 4/5 contaminated [1] 17/4 contributed [2] 3/22 4/3 contributing [2] 4/8 4/12 control [1] 13/15 conversation [1] 5/20 copy [2] 2/24 15/16 correct [5] 1/6 1/16 3/15 3/18 4/18 could [6] couldn't [6] counselling [4] 13/8 13/10 16/19 17/7 couple [1] 16/3 cut [1] 14/14</p>	<p>directions [1] 8/7 disappeared [1] 12/25 discuss [1] 6/22 Diseases [1] 8/4 do [8] doctor [2] 5/11 5/14 document [2] 2/6 2/19 dog [1] 12/24 don't [5] 5/9 10/15 13/3 16/8 17/16 door [1] 12/13 doubt [1] 7/24 down [3] 1/23 5/18 11/23 dressed [1] 6/13 drink [1] 4/23 drinking [2] 8/22 13/13 drip [3] 1/19 1/23 1/24 drug [2] 5/12 7/19 drugs [1] 7/21 due [2] 4/1 14/9 Duncan [1] 15/22</p>	<p>fine [1] 15/4 first [7] five [2] 11/25 12/1 follow [1] 15/5 foot [2] 3/14 3/17 form [3] 2/24 4/1 15/15 forms [1] 15/13 found [7] four [2] 2/8 2/8 FRASER [1] 1/8 friend [1] 13/17 friends [4] 10/9 10/11 10/13 16/2 frightening [1] 8/10 from [8] function [1] 4/22 Fund [2] 15/7 17/2 fusion [1] 1/14 future [1] 3/1</p>
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<p>10.00 [1] 1/2 10.26 [1] 17/21 100 per cent [1] 10/24 11 years [1] 1/14 11.00 [1] 17/20 19 [1] 3/20</p>	<p>C Plus [1] 16/18 called [2] 8/4 16/18 came [5] 2/19 5/15 8/16 11/14 15/16 can [13] can't [3] 4/10 10/15 12/22 cancer [1] 14/4 cent [1] 10/24 change [1] 4/25 child [2] 9/4 9/23 children [1] 12/13</p>	<p>fact [4] 4/1 4/4 6/4 8/4 factor [2] 4/9 4/12 family [3] 9/14 10/12 15/24 family's [1] 10/5 fantastic [1] 17/6 February [1] 7/10 February 2006 [1] 7/10 feel [3] 8/11 10/13 13/14 felt [2] 9/14 10/11 fight [1] 4/5 filling [1] 15/13 finally [1] 5/14 find [2] 6/11 15/11 finding [1] 8/19</p>	<p>had [37] hadn't [1] 13/18 happened [4] 1/17 5/3 6/7 7/12 hard [5] 11/12 11/15 11/19 11/23 14/5 has [5] 9/9 11/17 12/15 13/10 14/15 have [24] having [5] 3/2 9/21 12/6 12/13 14/6 hazardous [1] 6/13 he [4] 11/19 12/2 12/3 13/18 health [5] 6/1 9/10 12/7 12/16 14/11 hear [1] 16/13 held [1] 2/8 help [1] 16/11 helped [1] 14/15 hep [2] 5/7 6/25 hep C [2] 5/7 6/25 hepatitis [14] hepatitis C [13]</p>	
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