

Thursday, 4 July 2019

(10.00 am)

SIR BRIAN LANGSTAFF: Good morning.

MS FRASER BUTLIN: Good morning, sir.

SIR BRIAN LANGSTAFF: Our first witness is Pamela.

MS FRASER BUTLIN: That's correct.

PAMELA PENNYCOOK, affirmed

Questioned by MS FRASER BUTLIN

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

A. That's right.

Q. You have spina bifida?

A. Yes.

Q. When you were 11 years old you underwent spinal fusion surgery?

A. That's correct, yes.

Q. What is your recollection of what happened?

A. Well, I remember waking up in the recovery room and I noticed that there was the drip set up with the saline and also the blood. I'd never had a blood transfusion before so it was a bit of a shock seeing that for the first time, and then by the time I went back on the ward, the blood drip had been taken down and it was just the other drip that was up.

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

1

future."

Q. Are there any other records of you having had a transfusion?

A. No, no. Just this one.

Q. On the same day that the consultant gave you this letter, she also wrote to your GP.

A. Yes, that is right.

Q. What did that letter say about your transfusion?

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

Q. So the day you were given this, there was also a letter to the GP saying there was no record?

A. No record.

Q. As part of your spina bifida you had sensory loss in your right leg and right foot?

A. That's correct, yes.

Q. You had repeated infections and ulceration of the leg and the foot?

A. That's correct.

Q. And ultimately you underwent a below knee amputation?

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

Q. Recently you've wondered whether your infection with hepatitis C contributed to those difficulties as a teenager.

A. Yes.

Q. Can you tell us why.

3

parents were warned that you might need a transfusion?

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

Q. After the operation, were your parents told that you had had a blood transfusion?

A. No, they weren't told.

Q. Please can we have document 2242002, please, Paul. If we look at the top, we can see requirements and that four were being delivered, four were held on reserve and total of eight units of whole blood were ready for the operation.

A. Mm-hm.

Q. Then if we go to the bottom of the page, part C, we can see serial number in order for a transfusion and there are three numbers.

A. That's right.

Q. The bottle numbers of the blood that you were transfused with.

A. Yes.

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

A. When I was going through my treatment at the Western General, my consultant --

Q. For the hepatitis C?

A. For the hepatitis C, yes, so it was many years later, my consultant gave me a copy of this form and said to me, "Keep it safe. You're going to need this in the

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A. It was the fact my amputation, on the form it was due to recurring infections and ulcers so I asked the question because I thought it could have contributed to me losing my leg, the fact that I wasn't able to fight infections. So my consultant -- I took all my medical records because she couldn't get access to them and she went through them and she said, "Although it's not the sole reason, it may be a contributing factor that you lost your leg". But she said, "I'm not an immunologist so, you know, I can't make a definite decision on that", but she said it may have been a contributing factor.

Q. Nobody is very sure what impact the hepatitis C had on those infections but they may have had an impact and you're concerned that they did have?

A. Yes, that's right.

Q. In 2005 you were diagnosed with osteoporosis?

A. That's correct.

Q. Your GP decided to do some blood tests?

A. Yes.

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

A. They showed that I had an issue with my liver function so I was asked to keep a drink diary and then I would be retested again to see, you know, if there was any change to that, so -- which I did, I went back and got

4

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.

5

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.

7

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.

6

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?

8

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.

9

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?

11

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

10

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

12

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

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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

15

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

14

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

16

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)

(A short break)

23 (11.00 am)

24 **SIR BRIAN LANGSTAFF:** We now have Alice, do we?

25 **MS RICHARDS:** Yes, sir.

17

1 written statement to the Inquiry.

2 **A.** Yes.

3 **Q.** Robert is one of what we'll here hear as we go through
 4 your evidence has been termed the Edinburgh cohort,
 5 and I will be asking you a little bit about how you
 6 came to find that out.

7 It is right to understand at the outset you have
 8 undertaken a very significant amount of research and
 9 investigation over the last two decades or so.

10 **A.** Yes.

11 **Q.** You have given that material to the Inquiry and you
 12 know that many of the issues that it raises and the
 13 documentation you have been provided are going to be
 14 examined at later stages of the Inquiry.

15 **A.** Yes.

16 **Q.** Robert has severe haemophilia A, diagnosed at a young
 17 age?

18 **A.** Yes.

19 **Q.** But his statement tells us that despite that
 20 haemophilia, he led a very active and sporty life?

21 **A.** Definitely.

22 **Q.** He would run, play golf, play tennis?

23 **A.** Yes.

24 **Q.** What was the particular sporting passion he developed?

25 **A.** Fishing.

19

1 **SIR BRIAN LANGSTAFF:** Alice, please.

2 **ALICE MACKIE, sworn**
 3 **Questioned by MS RICHARDS**

4 **MS RICHARDS:** Sir, before we start I should say that Alice
 5 is not anonymous but at her request she's not being
 6 filmed, so there will be a live audio transmission of
 7 her evidence but not her image.

8 **SIR BRIAN LANGSTAFF:** It must follow I think that to pay
 9 respect to Alice's wishes no-one should take
 10 a photograph of her attending this hearing of the
 11 Inquiry. Please make sure that if you are taking
 12 photographs in or around the building you don't
 13 inadvertently catch her on your photograph.
 14 Obviously, if she gives you her specific permission,
 15 that's a different story but please respect her
 16 wishes.

17 **MS RICHARDS:** Alice, you're here to give evidence about
 18 the circumstances in which your husband Robert became
 19 infected with HIV.

20 **A.** Yes.

21 **Q.** But it is important we make clear, and you wanted this
 22 to be made clear, Robert is still alive.

23 **A.** Yes.

24 **Q.** You are giving evidence essentially on behalf of both
 25 of you and Robert, like you, has given a detailed

18

1 **Q.** That involved a lot of walking?

2 **A.** Definitely. He could walk for miles and I'm talking
 3 about 30/40 miles in a day.

4 **Q.** If he had a bleed when he was growing up, he would
 5 largely treat it with bed rest?

6 **A.** Yes.

7 **Q.** As a child, if he had serious bleeds but serious
 8 bleeds only he might have fresh frozen plasma and then
 9 at a later stage cryoprecipitate?

10 **A.** Yes.

11 **Q.** Until he was about 13 he attended the Royal Hospital
 12 for Sick Children in Edinburgh?

13 **A.** Yes.

14 **Q.** But then his care switched to the Royal Infirmary of
 15 Edinburgh?

16 **A.** Yes.

17 **Q.** That's where it remained for the period of time with
 18 which we are primarily concerned?

19 **A.** Yes.

20 **Q.** You started attending the Haemophilia Centre which was
 21 located, as I understand it, on ward 23 at the Royal
 22 Infirmary in 1979 with Robert?

23 **A.** Yes.

24 **Q.** What can you tell us about the facilities that were
 25 there at that time?

20

1 A. Basic. I was really quite shocked at where patients
2 were treated. It was just a side ward off the main
3 surgical ward -- it wasn't a surgical ward, it was
4 a medical ward and they were treated, there was two
5 seats, a trolley with syringes and everything on it
6 and it was a mess. I have to say it wasn't very clean
7 and the treatment to be examined by a doctor, it
8 wasn't the first time Robert was actually examined in
9 a corridor when visitors to the main ward were passing
10 or you could be examined in front of other haemophilia
11 patients that was there.

12 When patients did take their treatment nobody
13 come in to clear up a mess after them. If they didn't
14 clear it, it was left lying for however long. It was
15 not a very clean environment to be taking medication
16 anyway.

17 Q. By 1980, your statement and Robert's statement tells
18 us that he was being treated with both cryoprecipitate
19 and Factor VIII products but from February 1981 it was
20 Factor VIII only.

21 A. February '81/beginning '82, I do note that he's got
22 a notice in his medical records he has to be treated
23 with Factor VIII only after a certain point, but it
24 was factor and cryo for a while.

25 Q. As well as the shift from both to it being at some

21

1 A. From April 1982, I attended every appointment Robert
2 had.
3 Q. And a repeated refrain in your statements and Robert's
4 statement is he would repeatedly ask Dr Ludlam and
5 other doctors for reassurance or information, were
6 there any risks, and he would press for an answer?

7 A. Yeah. You have to understand Robert is -- he's not
8 scientifically minded if you understand but he always
9 wants to know everything to do with his treatment. He
10 always wanted to keep an eye on things.

11 He used to look after younger haemophiliacs. If
12 they were in hospital he would always go in and check
13 on them, check that they were being treated properly,
14 check that they were looked after, that nothing was
15 going wrong with them. If he thought they weren't
16 being treated properly, he would go and tell the
17 nurses or the staff that they have to do such and such
18 for them.

19 Robert really was up upon all these virus
20 things. He was always really careful. When I met him
21 and he actually told me about all this and we started
22 his home treatment, he always made sure I didn't touch
23 anything, there was no blood or anything because he
24 was always afraid that he could pass something on.

25 But the more he asked the more he trusted, which

23

1 point exclusively Factor VIII, there was an increasing
2 use of prophylactic treatment and home treatment as
3 well?

4 A. Yes.

5 Q. Did Robert receive any information or advice or
6 warnings about any risks of infection associated with
7 the use of any of those products?

8 A. No, but maybe -- Robert started getting home
9 treatment. When I was sitting fed up when he was
10 taking his stuff I would read the packaging for
11 inserts and on it I noticed hepatitis was mentioned.
12 But before then Robert had approached Dr Ludlam to see
13 if there was any risks to me or any future family
14 members that we had from the Factor VIII and Dr Ludlam
15 at that time says there's nothing, just the hepatitis,
16 that Robert would go a bit yellow and that would be
17 it.

18 So after I read it on the package inserts Robert
19 went back to him again and specifically asked, package
20 inserts, it states hepatitis and he was still told the
21 same thing. Maybe go a bit yellow but there is no
22 risk to any of your family members.

23 Q. That was as described in your statements and Robert's
24 statement and you used to accompany Robert to all his
25 appointments?

22

1 is something he shouldn't have done but the more he
2 asked the more he trusted these doctors and it wasn't
3 just one doctor, it was every doctor that he saw and
4 they would always come out with the same thing,
5 "Nothing to worry about, Robert", and in the end he
6 was actually told to stop asking, "You're just causing
7 trouble".

8 Q. The Factor VIII products that Robert received were,
9 with one exception, always the domestic SNBTS Protein
10 Fractionation Centre-produced Factor VIII product?

11 A. Yes.

12 Q. The one exception was I think it was the day after you
13 were married --

14 A. Yes.

15 Q. -- when you attended the hospital.

16 Paul, can we have up please document 2190011 it
17 should be.

18 We can see here it's a record of treatment and
19 if we go about -- thanks if you stop there, Paul -- we
20 can see in the left-hand column about two-thirds of
21 the way down, 7 June 1981, 3.45, left elbow, Armour,
22 and then the batch number given.

23 A. Yes.

24 Q. So that was the one occasion that Robert received
25 a commercial product.

24

1 A. Yes.

2 Q. What was Robert's response when being offered that

3 product?

4 A. Well, when he was given it, the boxes anyway, he

5 turning round and told the nursing stuff that he

6 didnae get commercial Factor VIII, that he only had

7 Scottish Factor VIII or plasma, and they turned round

8 and told him, "Well, that's all we've got, take it or

9 leave it", but what we did discover was his uncles had

10 went up the following day to get treatment and they

11 had Scottish Factor VIII, so it wasn't all that was

12 there.

13 There was also the fact that when you take a new

14 treatment you're meant to have it as not an in-patient

15 but you're meant to go in and take blood tests, blood

16 levels and everything before and after you take it.

17 There was none of that. It was just, "There's your

18 treatment. Go mix it up. Take it", and that was it.

19 Q. Was there any particular reason at that point in the

20 middle of 1981 why Robert was concerned about having

21 a commercial product as opposed to a Scottish product?

22 A. Not in that -- Robert didnae like Factor VIII, full

23 stop, all right. He had just got in his head using

24 "our stuff" and then they turned up with this

25 completely strange Factor VIII. One, he had nae been

25

1 couldn't move, he could hardly breath. They actually

2 gave him cortisone I think at the time it was that

3 bad, and we really thought he wasnae going to get home

4 the following morning.

5 Q. Was it after that reaction that Dr Ludlam issued

6 Robert with a letter that said she should be given the

7 Scottish product only?

8 A. Yes.

9 Q. You've described in your witness statement that in

10 1983 there were changes at the Haemophilia Centre.

11 What can you recall about those changes?

12 A. We went up one day and it was spotless. Couldn't

13 believe how clean it was. The cinbins -- there was

14 big notices telling everybody to use the cinbins to

15 put their used syringes in that. The trolley was all

16 nice and neat but the difference was you had to ask

17 the staff for syringes and needles and things and

18 everybody was made to clear up after them.

19 Eventually, it was round about that time that we

20 also got a small treatment room where a doctor could

21 examine you, which is something they never had. New

22 chairs come. The old ones that were covered in blood

23 had all disappeared and a couple of new reclining

24 chairs for them come. Everything just turned

25 professional.

27

1 tested for for a start and he just didnae like the

2 idea of taking commercial Factor VIII because he was,

3 as I say, he was always wary of what he got into his

4 body and the commercial Factor VIII just was not what

5 Robert wanted.

6 Q. We can see if we have up on screen please, Paul,

7 2190009 that Robert, in fact, had a reaction to the

8 commercial Factor VIII.

9 If we have the bottom half of the page, please,

10 Paul, we can see the reference:

11 "Married this afternoon, severe bleed left elbow

12 of one hour's duration."

13 And then we see at 4.30, which is probably about

14 45 minutes after the treatment:

15 "Very uncomfortable reaction following

16 commercial Factor VIII."

17 A. That's putting it mildly.

18 Q. What can you recall about the reaction?

19 A. Oh my goodness. His whole body, and I mean his whole

20 body, come out in hives, spots, everything. He could

21 hardly see in front of him. They actually gave us

22 a -- they wanted to keep him in and he wouldnae stay

23 in but what they did was they put us away in a wee

24 place, a wee room, away where ward 45 ended up and we

25 sat there for the rest of the night in a chair but he

26

1 At that time as well what we did notice was, I'm

2 not sure if it was '83/84, but the staff in the main

3 ward had all changed as well. The people that Robert

4 had -- the nurses and sisters and that that Robert had

5 grew up treating him, they'd all disappeared and it

6 was all new staff that was in. And the Haemophilia

7 Centre theirselves also got a nurse, which is

8 something they'd never had in all these years, a nurse

9 to themselves was something.

10 Q. Do you attach any particular significance to those

11 changes?

12 A. Looking back now, right, at the time we just wondered

13 what it was for but it was when the AIDS started, when

14 America started getting AIDS-infected people and then

15 people started talking about haemophiliacs in this

16 country, and it was at that time, right at that time

17 is when the centre changed and everything changed.

18 We did discover later on, which I probably

19 should mention just now, is the AIDS studies and

20 things like that, but at that time more blood was

21 starting to be taken from Robert and all these

22 different things. The whole treatment regime changed.

23 They started weighing them. Robert had never been

24 weighed that I could tell and they started taking his

25 weight as well, which is something they'd never done

28

1 before. It was just wee things that you could pick up
2 on.

3 I was friendly with one of the cleaners that
4 used to clean the main wards and she always spoke to
5 me, and this day the first time we turned up when this
6 side ward was spotless, she walked right past me. She
7 wouldn't even look me in the face and I said to myself
8 now even the cleaners knew about the risks or why they
9 were changing the wards like this before even the
10 patients knew. The whole thing was completely
11 different to what it was in '82 -- '81/82.

12 Q. As you have just said, it was at this point you
13 noticed more and more tests being undertaken, blood
14 being taken?

15 A. Not tests being undertaken, blood being taken for
16 routine, just his normal routine bloods is what we
17 were told.

18 Q. Were you told for the reasons of the weighing of
19 Robert?

20 A. It was just something new that they were to do, new
21 procedures.

22 Q. At some stage there were requests to Robert to donate
23 blood. What can you recall about that?

24 A. Not just Robert, his uncle -- well, one of his uncles
25 used to donate pints of blood. The last -- when

29

1 What did he ask and what response did he get?

2 A. Robert -- we didnae have -- our lifestyle at the time
3 was busy with one thing and another just doing things
4 so we never bought papers we didnae really watch the
5 television. It was the radio that we listened to.

6 Robert started hearing things. He didnae know
7 what to call this thing, right, he didnae know AIDS
8 HTLV-III or anything like, but he knew it was killing
9 people, not haemophiliacs specifically but people.
10 But Robert's brain told him people that are getting
11 this are blood donors, just the general public, so is
12 blood going to be safe for Factor VIII, and he was in
13 the hospital and he asked Ludlam, he asked every
14 doctor he saw about this disease.

15 As I say, he didnae know what to call it so he
16 couldnae pin them down specifically to the name and
17 every one of them told him, "Nothing to worry about.
18 Our Factor VIII's safe. It's always checked. It's
19 checked for every virus", and constantly -- and he
20 asked that much that other patients were asking the
21 doctors the same questions. They didn't know why but
22 they were asking the same questions and Robert got
23 told if he didn't stop asking, he would be barred for
24 the hospital.

25 Patients, there's been a few but I can remember

31

1 Robert donated this, he did ask, years ago he had
2 asked why they were taking the blood, why specifically
3 haemophiliac blood because it's not normal.

4 What he was told it was for heart operations to
5 stop them using Warfarin for the clotting, and then it
6 got to the stage he did ask, he kept asking but this
7 time he asked and the person that was putting the
8 needle into him says, "Well, what have you been told
9 it's for?" And Robert says, "Well, heart operations",
10 and the man actually laughed and walked away as if to
11 say, "Ken, Robert's talking out the top of his head
12 because it's not for heart operations", and we never
13 did find out what it was for.

14 In '83 Robert gave -- Dr Ludlam requested plasma
15 free -- Factor VIII-free for plasmapheresis and in '83
16 I would have thought it was a bit risky because people
17 had AIDS by then. Haemophiliacs were known to have
18 AIDS, never mind hepatitis because everybody had
19 hepatitis by then as well, but we didnae know that at
20 the time so ...

21 Q. You have explained in your statement that it was
22 around this time, approximately 1983, Robert began to
23 pick up, as others had, about the illness in America
24 that was killing people and he started asking doctors
25 about that.

30

1 one that's HIV positive come up to him and said,
2 "I didn't know why you were asking the questions
3 Robert", he says, "but I do know now", because he was
4 infected. The hepatitis, somebody that had hepatitis
5 said his Mum used to think Robert was a bit loud in
6 telling them they shouldnae be taking this, they
7 didnae need it, just don't play rugby and they wished
8 they'd listen to him because he had hepatitis and
9 ended up with cirrhosis.

10 It's all these things but Robert was always told
11 to shut up, to keep quiet, he would be barred for the
12 hospital.

13 Q. You've described it this way in your statement, he was
14 essential branded a trouble maker and they thought he
15 was frightening other patients with his questions and
16 he was told he would be banned if he carried on.

17 A. Yes.

18 Q. Did that stop Robert?

19 A. No. No, just makes him worse.

20 Q. Robert had, in fact, as I understand your statements
21 wanted if possible to stay receiving cryoprecipitate.
22 What was he told when he asked about that?

23 A. He was told that they'd stopped making cryo.

24 Q. Who told him that?

25 A. Dr Ludlam.

32

1 Q. Did he also have any discussions with Dr Ludlam about
2 whether there was in the Scottish donor population any
3 risk of AIDS that you can recall?
4 A. Robert asked about AIDS, he asked about -- when he
5 spoke to doctors he wasnae speaking about American or
6 commercial or whatever, he was always speaking about
7 "our blood" because that's what he received, and
8 whenever he spoke to Dr Ludlam or any other doctor,
9 and it wasnae just Dr Ludlam that he asked about the
10 risks, he was always told, "Our blood donors don't
11 have AIDS. It's safe. We don't have the likes of
12 that in this country". Where they got that
13 information from I don't know but he was told it was
14 safe, we didn't have AIDS in Scotland or HTLV-III in
15 Scotland.
16 Q. As you have said, apart from that one episode when
17 Robert was given an Armour product, he received the
18 Scottish-produced product.
19 A. Yes.
20 Q. If we have up on screen, please, document 2190012,
21 Paul.
22 We can see here some of Robert's treatment
23 records from 1984 and we can see the top of the page
24 there, 8 April, and we have under batch we have
25 a batch number written out as follows:

33

1 Q. We can see some documents from Dr Ludlam that confirm
2 that.
3 Paul, can we have 2189002, please.
4 A. I don't know if I should say this here but it's the
5 only batch number ever in his medical records that is
6 written out in full.
7 Q. I was absolutely going to ask that question, Alice.
8 You and Robert, looking at his records, have
9 identified that that is -- these are the only
10 occasions when it is written in full.
11 A. The only one that is written out in full, and I'm
12 talking about for 30/40 years it's the only batch
13 number, and it's not just in his treatment record
14 sheets, it's the completion sheets that the nursing
15 staff fill in at the end of the years or you're
16 getting your medical -- as you're Factor VIII the
17 nurses write in a separate form and it's in that
18 written out in full as well and it's the only number.
19 Q. Thank you, that's the one.
20 If we look at this letter it's not terribly easy
21 to read but we can see it is dated 17 September 1987.
22 It is from Dr Ludlam to Dr Wensley and we see point 3:
23 "In my opinion he [that's Robert] became
24 infected with HIV as a result of transfusion of batch
25 023110090 of SNBTS Factor VIII in the transfusion

35

1 "023110090", and it appears from that entry he
2 is receiving that batch for a right shoulder bleed and
3 then over a number of subsequent days he's receiving
4 it prophylactically.
5 A. Yes.
6 Q. Then, Paul, there should be another page of similar
7 records under the same reference. Do you have that?
8 Well, there was another set of similar records
9 for March 1984 which again show, and the date is
10 I think 2 March, that full batch number, that same
11 batch number is written out and that's shown as being
12 for a left elbow bleed and then we see the full batch
13 number again in early April.
14 We can see a contrast, Alice, that you have
15 raised in your statement, as has Robert, the full
16 batch number being written out there and then
17 abbreviated numbers being used for other batch
18 numbers.
19 A. Yes.
20 Q. It's yours and Robert's understanding that it was from
21 that particular batch, the one the number of which is
22 written out in full, that Robert became infected with
23 HIV.
24 A. Yes, we've actually been told that was the batch
25 number.

34

1 records this is abbreviated to 0090", just pausing
2 there, is that correct that it's abbreviated to 0090?
3 A. No, it's all written out in full.
4 Q. Then it tells us he was anti-HIV negative on 27 March
5 1984 and positive on 29 May 1984 and I don't think we
6 need to put them on screen but there are some clinical
7 records which show Factor VIII being administered on
8 particular dates in April which we've seen from the
9 earlier documents.
10 So that is one of the sources of your
11 understanding and Robert's understanding that it was
12 that particular batch that infected him?
13 A. Yes.
14 Q. As I understand it, it's important for you to make
15 clear and for Robert to make clear that that was
16 a Scottish-produced batch that infected him?
17 A. Yes.
18 Q. Now, some years later, in March 2003, Robert wrote to
19 Dr Ludlam asking similar questions about when he'd
20 become infected.
21 If we have up on screen please, Paul, 219 --
22 A. I actually wrote the letter.
23 Q. -- 003. Sorry?
24 A. It was actually me that wrote the letter.
25 Q. We can see it is a letter 7 March 2003 sent by Robert

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but drafted, as I understand it, by you to Professor Ludlam:

"I am writing to ask if you can give me written information on the following: the date when you started testing me for HIV/AIDS or any related illnesses, the date when I tested positive for HIV/AIDS or any related illnesses and the batch number I can contracted it from", and then similar questions in relation to hepatitis C which we will come back to.

The response from Professor Ludlam, Paul, should be at 2190004 and if we can have the first three paragraphs, please, highlighted.

So this is 14 March 2003. Professor Ludlam refers to what he says was the first reasonably reliable test for HTLV-III available in the second half of 1984:

"We first started testing individuals with haemophilia for anti-HTLV-III in the autumn of '84 and spring of '85. We tested earlier stored samples and we found that the last sample that was negative for anti-HTLV-III was 27 March 1984. The first positive result was 13 August 1984. I believe it was most likely you were infected by batch 023110090 of SNBTS Factor VIII concentrate which you received in March and April 1984."

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the very sore throat and what not that he had, so Ludlam knew at the time that Robert was infected from that specific day, well date, and I feel that he should have said something then to Robert.

It's not as if AIDS was something in '84, the beginning of '84, that nobody knew about.

Q. When you say you believe that Dr Ludlam knew that Robert was infected because of the symptoms that he was displaying, you're talking about this period in around the middle of 1984, are you?

A. It's March -- about March '84, March/April '84, Robert actually had this sore throat and he went to the GP and it wouldn't clear up so he went up the hospital and that is seemingly when Ludlam says he thinks that's his sera conversion. But he must have known at the time. He knew what he was looking for, for patients that had HIV or AIDS or call it what you want. He knew what he was looking for and Robert had these symptoms. So if he didn't know definitely, he must have thought it and that is the time he should have stopped and said to us, "Well, perhaps you might have ..." We would have accepted that, but he left us thinking Robert had a sore throat and he was okay and got on with our lives, and that is the point to me he should have said to Robert, "No, wait a minute, this

39

Now that confirms the source of the infection, the batch, again?

A. Yes.

Q. There is a difference in terms of the date given for first positive result, the earlier letter --

A. Yes.

Q. -- suggested it was the end of May. Here it is suggested it is 13 August 1984.

Do you know what the explanation or reason is for those differences?

A. No. Whenever we asked anything like that we just get ignored so you just give up asking.

Q. Robert's observation in his witness statement is, no matter what the precise timing, he says that:

"I was given an infected product at a time when the risk of AIDS from Factor VIII was well known."

That is his core point.

A. Looking at it, Robert was actually ill at the dates that they seroconverted and he was at the hospital because he had attended the GP and then went to the hospital about his sore throat and what not. So personally I know that Ludlam knew that he was infected because of what he went up to the hospital with, the sore throat that wouldn't clear up and that and when Wensley got the letter that confirms it about

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could be ..." and we would now be bothered. We would have sat back and waited until our tests come but we would have taken all the precautions that we should have taken instead of risking my life and my son's life.

Q. I should say, sir, Dr Ludlam has been asked for a response to a number of the matters set out in Alice's witness statement and Robert's witness statement and it's our understanding that he intends to provide a response where will be published in the normal way in due course.

Alice, there's one further document I just wanted to look at with you.

Paul, it should be 2189004. It's a letter of 28 April 1989. That's it. If we could just have the text highlighted, please.

So it's a letter again from Dr Ludlam:

"I should be most grateful if you could send me formal HIV reports on the above individual. According to our records he has serum samples tested on the following dates", and then there are a list of dates, 12 January 1984, 1 February 1984, 14 March 1984, 27 March 1984, what looks like it might be 9, 8 or 9 May 1984, 13 August 1984, 21 November 1984.

Was Robert informed, did he give his consent to

40

1 being tested, whatever the precise dates, for
 2 HTLV-III?
 3 **A.** No.
 4 **SIR BRIAN LANGSTAFF:** Just pausing there for a moment,
 5 although it could be the 8th or 9th in the list, if
 6 you look down to the penultimate paragraph, the first
 7 sera positive on -- and then there are two numbers, it
 8 looks like 29 or maybe 28 May so, obviously, because
 9 that date isn't in the earlier column it's either the
 10 8 or 9 May or 29 May, which is perhaps more likely.
 11 **MS RICHARDS:** Yes.
 12 So Robert was not aware of any tests being
 13 undertaken at this time for HTLV-III?
 14 **A.** No, definitely not.
 15 **Q.** It's again right to note that Robert has raised in his
 16 witness statement the question why he continued to be
 17 given Factor VIII and given it on a prophylactic basis
 18 once the risk of AIDS became known and he has said it
 19 would have been very easy for him to alter his very
 20 active lifestyle to ensure he didn't require
 21 treatment?
 22 **A.** It would have been.
 23 **Q.** If necessary by going back to the regime of --
 24 **A.** Robert would have stopped taking treatment altogether
 25 if there was any risk until something was found.

41

1 was 32 patients were getting studied, researched,
 2 studied, call it what you want. 50 per cent of them
 3 became infected. 50 per cent of them became infected
 4 with this batch, same batch, and this same batch
 5 that's written out in full.
 6 Personally, I -- I'm trying to put it
 7 diplomatically here. Personally, I think that Ludlam
 8 knew that these haemophiliacs were eventually going to
 9 get infected and I think he knew that this batch was
 10 the one. I know I shouldn't say it. I put it down to
 11 maybe they were doing heat treatment and the only way
 12 you can test if something works in a patient is by
 13 giving it to the patient. You understand what I'm
 14 saying? I think it was maybe part of a heat treatment
 15 trial, 50 per cent got it and 50 per cent didn't.
 16 I can't prove that so it's just my thoughts.
 17 **Q.** You have referred to "AIDS study", and you found
 18 references to that in Robert's medical records. If we
 19 can have up on screen please, Paul, 2190010.
 20 **A.** I just don't understand why the number is written out,
 21 the only number that infected them is written out in
 22 full and it's not just once it's whenever he had it
 23 and then the nursing staff, they wrote it out in full
 24 when they were completing their records for Robert and
 25 it's the only number again that's written out in full.

43

1 I know people say oh it's life saving treatment
 2 and this but Robert survived, his uncle survived his,
 3 friends survived without all this treatment. He
 4 didn't actually need it for all these things. Bed
 5 rest like they used to do when they were younger, all
 6 these things would have been quite happy for Robert.
 7 He would have stopped decorating, car laying and
 8 things like that.
 9 **Q.** Your statement raises this question: when did the
 10 sample come back positive? When did Dr Ludlam first
 11 receive a positive result? Because you cannot tell
 12 from Robert's medical records when that was.
 13 **A.** Yes.
 14 **Q.** You have referred to the way in which the particular
 15 batch that infected Robert was written in the records,
 16 written differently in the treatment sheets, unlike
 17 other batches.
 18 What concern or suspicion do you have in
 19 relation to that?
 20 **A.** Can I talk about Ludlam's AIDS study, because that's
 21 what the batch number is connected to?
 22 **Q.** Yes.
 23 **A.** We discovered when we got his medical records that an
 24 AIDS study was carried out on Robert and people, other
 25 haemophiliacs, from March or something 1983, and there

42

1 Why? It was highlighted for some reason and it's not
 2 retrospective highlighting either, because we filled
 3 in the forms, we had to return the forms, the nursing
 4 staff filled in their forms when Robert got his
 5 Factor VIII, they took a lot of the batches that he
 6 got before we took it home, so it was at the time this
 7 stuff was filled in, so why is this number
 8 specifically written out in full?
 9 It gets me angry to know that this number is
 10 written out in full and I don't know why.
 11 **Q.** If we look at document 2190010, which should be on the
 12 screen in front of you, Alice, this is one of several
 13 references that you have found in Robert's medical
 14 records using the phrase "AIDS study."
 15 The date on the top on this is not particularly
 16 clear but it's a 1983 date. It might be 1 April 1983
 17 but we don't at the moment have better copy of it. If
 18 we turn to the next page we can see a stamp in the top
 19 left-hand corner which is March 1983 and, again, we've
 20 got the terminology of "AIDS study".
 21 If we turn to the next page, please, Paul, we
 22 can see a date at the top, 21 November 1984, then we
 23 see the words "Haemophilia AIDS study", and then to
 24 the right we also see the term "AIDS study", and the
 25 date there is 12 June but the year is cut off.

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1 Was Robert ever given any information at the
2 time about any participation in or enrolment in any
3 kind of AIDS study?
4 A. No, and how could he have given permission for it if
5 he didn't know that AIDS existed, because at this time
6 when this AIDS study started according to Ludlam there
7 was no disease, infection, virus, call it what you
8 want, there was nothing there to worry about. So how
9 could he give permission for this to go on if he
10 didn't know about it?
11 Q. Is this correct: it was only when seeing his medical
12 records years later that Robert saw this reference to
13 AIDS study and understood or believed that he had been
14 enrolled in some kind of study without his knowledge
15 and permission?
16 A. Yes, we were looking to -- one of the reasons we
17 really read his medical records at the time is when we
18 requested them it really took a long time and every
19 time I phoned up I was told they were either at the
20 legal department or they were with Dr Ludlam, and this
21 went on for some considerable time. I think the
22 secretary I was speaking to was getting fed up me
23 phoning. I thought, well, what can they be clearing
24 out? In those days, I didn't think that doctors would
25 do these kind of things.

45

1 Q. That's the term you have seen in papers and documents
2 from Dr Ludlam and from the Royal Infirmary?
3 A. Yes.
4 Q. You've set out in your statement again various
5 extracts from later medical publications which refer
6 to this cohort as one of the most extensively studied
7 group of HIV-infected individuals in the world?
8 A. Yes.
9 Q. But Robert did not know he was being studied?
10 A. No.
11 Q. Your statement explains that in the course of 1984,
12 whilst what we've seen in the records is there
13 recorded, Robert was still asking when he went to the
14 hospital about whether there were risks.
15 A. Yes. Robert -- I don't know what made him ask.
16 Because sometimes I would even say to him, "What you
17 keep asking for? Shh." Just because he went on and
18 on and on about this and every doctor always said the
19 same thing and in the end, whether he believed it or
20 not, he accepted that there was no risk because you
21 ask it that often you have to start believing.
22 He says now he wishes he had stuck to his own
23 intuition but he didn't. He believed these people
24 that he was meant to trust.
25 Q. In December 1984 Robert received a letter from

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1 So when we got them and I started looking
2 through them and the words "AIDS study" just hit me in
3 the face, it really did, but everything just
4 started -- as soon as I saw the words "AIDS study" it
5 just fell into place for some unknown reason, because
6 years before my Dad had given us an MRC booklet,
7 didn't know why he gave us it, but inside the booklet
8 was about Dr Ludlam and his Edinburgh haemophilia
9 cohort. Well, at the time when I read it I didn't
10 think it had anything to do with Robert. I kept it
11 for 30 years almost now but at the time I just put it
12 in a drawer and left it.

But as soon as I saw the "AIDS study" I went to
the MRC booklet, it just connected straight with that,
after that I went to the library and that's when I saw
it was actually I could -- because I know the people
that were infected, one of these research papers
actually gives the dates of birth and their factor
treatment and what not and I could connect it and
Robert's was there. That's how I knew Robert was one
of his haemophilia AIDS group.

22 Q. You have put it this way in your statement Robert
23 became part of "the Edinburgh haemophilia cohort" and
24 that's not your term?
25 A. No, it's not mine.

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1 Dr Ludlam inviting him to attend a meeting in the
2 lecture theatre at the Royal Infirmary.
3 A. Yes.
4 Q. You attended that meeting with Robert?
5 A. Yes.
6 Q. What can you recall about the meeting?
7 A. To begin with it was short notice, right. It wasn't
8 well planned, it was short notice. It was supposed to
9 be two lecture theatres that were next to each other
10 but there wasn't enough people that turned up to fill
11 the two. How they were going to do anything with two
12 lecture theatres I don't know but we ended up in
13 a little lecture theatre in the old Infirmary.
14 I would say maybe about 50 people at most was
15 there and we were scattered round. We were sitting at
16 the side with friends and family that was there, a lot
17 of people we didn't know, I mean, fair enough. At the
18 front was Dr Ludlam, Dr Forbes (I remember him because
19 he was that tall), and I think it was McClelland but
20 I couldn't honestly have said at the time, but I now
21 know it was him, were standing at the front and they
22 says to us -- Ludlam actually turned round and says,
23 "It's come to our attention that some people have been
24 infected with HTLV-III", is what they used at the
25 time. "But it's safe now, because it's getting heat

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1 treated, it's all safe now".

2 But at the time we thought, well, poor soul's
3 that's got this thing because we've not been told, but
4 we were sitting and they told us one or two bits just
5 about the unfortunate people that had been infected
6 and when Robert went -- it was open to questions but
7 when Robert went to ask a question Ludlam turned round
8 and says to Dr Forbes, "Just ignore him. He's
9 a troublemaker", and they closed the meeting down, and
10 we couldnae ask any more questions after that.

11 But when we were leaving his friends and family
12 were all going, "Have you been told about this? Have
13 you been?" They're all going, "No. No, thank God
14 we've no got that", and that was the end of the whole
15 thing. We never heard anything about it after that.
16 So we thought, we'll get on with our lives,
17 everything's okay, Robert's not infected.

18 Q. You have described in your statement that Dr Ludlam
19 gave an explanation about HTLV-III, about methods of
20 transmission and gave some advice about if someone was
21 HTLV-III positive, about the use of condoms and
22 cleaning up spillages and using gloves and so on and
23 then talked about heat treatment and about the
24 Scottish Factor VIII now being safe to use because it
25 was going to be heat treated.

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1 doesn't matter. If the risk is there we should have
2 been informed before this meeting of this risk.

3 Q. Did Dr Ludlam or any of the doctors who were there say
4 words to the effect, "if any of you want to know your
5 specific test results make an appointment"?

6 A. No.

7 Q. You've said in your statement you left feeling thank
8 God Robert is not infected with this thing.

9 A. Yes.

10 Q. Robert's statement says this:

11 "Along with my wife and I, all the people at
12 this meeting that I spoke to thought that the people
13 who had been infected had been informed before the
14 meeting, so we all thought that we were all safe. We
15 would never have imagined that Dr Ludlam would use
16 a meeting like that as the only means by which he was
17 communicating to infected patients that they were
18 infected. All we could say to each other after the
19 meeting was, 'Thank God I don't have it'. We thought
20 that those infected had been told individually by
21 Dr Ludlam of their infection before the meeting and
22 that the meeting was to tell us the risk had passed
23 since we now had heat-treated Factor VIII produced at
24 the PFC", and then he says this:

25 "I still do not understand how I was supposed to

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1 A. Yes, but one of the things in there -- he said about
2 gloves and aprons. I was never, ever offered -- it
3 was only in the past five years I've been offered
4 gloves. I have never been offered gloves or aprons or
5 anything, and I thought if Robert had have been
6 infected we would have been issued with these things
7 and we were never. It was never even offered to us
8 for these gloves. So we just, as I say, we just
9 carried on our lives as normal. We thought great, we
10 got on with life, and that was it.

11 Q. Your assumption, Robert's assumption, was that Robert
12 had not been infected with HTLV-III, HIV --

13 A. Yes.

14 Q. -- because if he had been he would have been
15 specifically told that?

16 A. Before the meeting, yes -- well before the meeting
17 I would have thought. But even if they just got it,
18 surely as soon as a doctor found the results, they
19 would have made an appointment specifically to speak
20 to the patient to tell -- it's not just a cold or flu
21 you've got here, it's a sexually transmitted fatal
22 disease and this was known to be sexually transmitted
23 and fatal by the end of '84, and sometimes they'll
24 say, "Well, we didn't know if you were going to get
25 the virus because the tests and everything". It

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1 know that I had received the infected batch if I was
2 not informed by any doctor in any manner be it
3 face-to-face or by letter."

4 A. Yes. I mean, not everybody at the meeting was
5 infected. There was uninfected people at this meeting
6 as well.

7 Q. As you subsequently have found out?

8 A. Yes.

9 Q. You have suggested in your witness statement that the
10 trigger for this meeting was going to be -- was
11 something that was due to be published in the press?

12 A. I've learned since that time that there was -- I can't
13 remember, something posted. One of the English
14 newspapers had got hold of it and they had contacted
15 Dr Ludlam. They were going to -- they wanted
16 a statement off him. They were going to publish that
17 there was a group of patients in Edinburgh that had
18 been infected.

19 So they quickly arranged this meeting. He
20 managed to get the reporter to delay it for a couple
21 of days and the meeting was just to cover his back
22 before it went in the papers.

23 Q. Again, I should emphasise we don't yet know what
24 Dr Ludlam's response will be to these criticisms.

25 After that meeting in December 1984, you've said

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1 that at no time did Dr Ludlam or any other doctor or
2 nurse at the Infirmary mention over the following
3 three years or so HTLV-III or HIV or AIDS.

4 A. It was never mentioned once. Even in general
5 conversation it was never mentioned.

6 Q. There is a letter in Robert's medical records, 2190008
7 please, Paul.

8 Alice, your screen is tilted down but I don't
9 know if you can still see it okay?

10 A. It's okay.

11 Q. This is a letter dated 31 January 1985. It is from
12 Dr Ludlam to Dr Love, that was your GP at the time,
13 and you found this in Robert's medical records. It
14 says:

15 "You will be aware from both the medical and
16 popular press that patients with haemophilia are at
17 risk of the developing AIDS as a result of the
18 transmission of the HTLV-III virus in Factor VIII and
19 Factor IX concentrates. To date there have only been
20 three cases of AIDS in British haemophiliacs and the
21 chance of any individual patient developing the
22 disorder based on our present information is very
23 small, probably less than 1 in 1,000."

24 Then it refers to serological studies of
25 patients in the United Kingdom, including Edinburgh,

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1 anything, any information leaflet, through the post.
2 I would have panicked if I'd saw something like this.

3 Q. You have said in your witness statement this:

4 "Dr Ludlam put my life and our son's life at
5 risk by not telling me or Robert", and that makes you
6 very angry. It's also a source of great anger to
7 Robert.

8 A. Yes.

9 Q. It was in I think 1985, please correct me if I'm
10 wrong, that you were asked by Dr Ludlam if you would
11 give some blood for research purposes.

12 What can you recall about that?

13 A. It was weird. He was asking family members to give
14 blood for research. Fair enough. So I was up the
15 centre and Sister Philips was the treating nurse by
16 then and she says for blood. So we went into the
17 treatment room and she started and I says to her,
18 "What's it for? What's the research for?" Of course,
19 she says genetic purposes and both Robert and myself
20 looked at her and says, "But I'm not connected to
21 Robert that way so why would you want blood?" When we
22 were talking to her, her hands were like, it's worse
23 than mine, her hands were shaking and she made a right
24 mess in my arm taking the blood, but she didnae get
25 very much blood but she got some and she ran out of

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1 and suggests:

2 "It is clear that many haemophiliacs have
3 antibodies to the HTLV-III virus. The presence of an
4 antibody does not necessarily confer immunity and such
5 patients may be capable of transmitting the virus both
6 by semen and blood."

7 Then he refers to the importance of precautions
8 being observed. Then in the next paragraph says this:

9 "I write to let you know I have circularised
10 your patient with an information sheet about AIDS",
11 and says what the chief recommendations are and then
12 over the page says:

13 "All Scottish Factor VIII concentrates are now
14 being heat treated under conditions that are believed
15 to kill the HTLV-III virus, thus Scottish Factor VIII
16 no longer transmits the AIDS virus."

17 Did you ever see this document before you saw
18 Robert's medical records a number of years later?

19 A. No.

20 Q. The assertion is that "your patient", that's Robert,
21 had been given an information sheet about AIDS. Do
22 you recall anything about that?

23 A. From the time we got married I was the one that opened
24 up the mail. Robert used to just leave letters lying
25 so I always opened up the mail and I never received

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1 the room after that, and that's the last we even heard
2 of it. We don't even know if she got enough blood to
3 do what she was doing, but genetic purposes, I am not
4 connected to Robert that way so why would I be
5 involved.

6 They did take it from family members who were
7 connected who had haemophilia sons or things like
8 that, which is fair enough, but why would I be
9 connected to it? I couldn't understand it.

10 Q. In the course of 1985 and 1986, you've said in your
11 statement that Robert seemed healthy and well and by
12 the end of 1986 he had been offered his dream job.
13 What was that?

14 A. A gillie.

15 Q. So lots of fly fishing --

16 A. Yeah, lots of it.

17 Q. -- and lots of walking?

18 A. Salmon fishing was his dream job, shall we say. That
19 was his life. I mean, that was his life, that is what
20 he always aimed for and he got offered it. We were
21 all set and then it just all went out the window.

22 Q. You said in your statement:

23 "We couldn't have been happier. We had
24 everything planned."

25 A. Yeah.

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1 Q. Then in January of 1987 you received a letter from
2 Dr Ludlam. What can you tell us about that letter?
3 A. I can't -- it asked us to go or Robert rather to go to
4 an appointment. Robert didnae receive appointments
5 for Dr Ludlam, so that alone was unusual. But what
6 made it even worse was we had by now moved to ward 45
7 and in ward 45 there was offices, there was treatment
8 rooms, there was rooms that doctors spoke to their
9 patients and that but he told Robert to go to his
10 office. Now, his office was down in what I call the
11 dungeons in the old Infirmary and that alone was
12 unusual. I'd never, ever seen it but that's where he
13 was asked to go to.

14 So the two of us thought, well, to it not be in
15 the centre and a specific appointment there's
16 something bad -- we didn't even think anything good.
17 We automatically thought there's something bad on this
18 otherwise it would just be up at the centre.

19 Of course we went down -- do you want ...?

20 Q. Yes, describe it.

21 A. We went down -- we were a bit early and it's down by
22 where blood transfusion centre were, Blood Transfusion
23 Services was down there and McClelland's office was
24 there and Ludlam's office was there (*indicated*).

25 Q. For those who don't know, Dr McClelland was ...?

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1 infected with HTLV-III AIDS", and that was it.
2 Robert, of course, turned round and says to
3 him -- but didnae think asking when he had tested, but
4 what Robert says to him is, "How did I get that?" But
5 what Ludlam went on to say was he had met the donor,
6 the donor was a homosexual and he was dead and that
7 sort of put us off track for a start and then Robert
8 says to him, "Well, what's the prognosis?" Because by
9 this time we didnae know much about AIDS but we knew
10 enough to know that it killed, and he turned round and
11 says to Robert, "Well, I've got more chance of dying
12 of a heart attack, Robert, than you've got of dying of
13 AIDS", and that was it finished. He got up and he
14 walked out.

15 But every time he was talking to us he was
16 writing in Robert's -- what I thought was Robert's
17 medical records. He never looked at us. He never sat
18 down and said anything. He never explained -- or what
19 he did say was that we couldn't have any more children
20 and he asked what protections we were taking. Well,
21 we werenae because we were trying to have another one.

22 He got up and walked out. It was just that was
23 the end of it, and we were left sitting and we got up,
24 we left, and going home, from the time I left his
25 office we went home, we never said a word in the car,

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1 A. Scottish National Blood Transfusion Service.

2 Q. And we went in and we sat in and I thought, "My
3 goodness, how can somebody work in this?" It was
4 a small room and the whole place was full of files,
5 filing cabinets, but files on top of the cabinets,
6 files on the desks. He had his desk -- Ludlam's desk
7 was there (*indicated*) and we were sitting under this
8 high window, the seats were back here, so we sat there
9 and when Dr Ludlam turned up he looked and he saw me
10 there and he asked me to leave.

11 Of course, Robert says, "No, she's staying.
12 Whatever you've got to say she's here", and he left
13 the room. He says, "I'll leave youse to discuss for
14 also it for five minutes". So he went away, he come
15 back, and of course Robert says, "No, she's staying",
16 and he wasn't really happy that I was staying there.
17 You could see it in his face he wasn't happy, but then
18 again I don't think he was happy whenever I was there
19 at any time, I have to add that to it.

20 But we sat down and all he says -- the opening
21 sentence was, "Have you had sex with any other men,
22 women, drug users, intravenous drug users", if you
23 want to be accurate", and Robert said, "No". It just
24 come out the blue. He didnae lead us up to any of
25 this, and then, "It's come to my attention you've been

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1 30 miles or something, we sat in the car, never said
2 a word. We got in the house, Robert stayed down the
3 stairs. I went up the stairs and I cried. That's all
4 I could do. I couldnae cry in front of him because
5 then I would have hurt him.

6 So after, I think it must have been about an
7 hour or two of us separate, I went down the stairs and
8 we didn't really talk because at the time when we were
9 told the two of our minds were active. We know,
10 no-one can tell us when you get told bad news you do
11 not remember. That's what people tell us and it's no
12 true because when we get bad news we remember
13 everything. But when we got home and we had time to
14 sit and relax, if you can call it that, and things
15 were going through in our minds, the two of us worked
16 it out ourselves and then we got together and started
17 to discuss it.

18 All Robert could think of was his job, he
19 couldnae do that. We thought he had actually just
20 been tested so we didnae think my life was at risk,
21 our son's life was at risk or anybody else's. We
22 really just thought Robert. That was all that was in
23 our minds. In my mind it was Robert. Robert was the
24 one that I knew was going to die. When I don't know
25 because I really didn't believe Ludlam when he said

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1 about the heart attack because I knew haemophiliacs
2 and people were dying of AIDS. You couldn't hide it.
3 You had all these things in the newspaper and
4 everything else telling you that people were dying of
5 AIDS and we sat down.

6 My Mum had actually, for some unknown reason, we
7 dropped my son off at my Mum's the night before
8 because we just had this feeling and we couldn't even
9 go and collect him that day. We left him with my Mum
10 for a couple of days. We just says we had something
11 else to do. We didn't say to my Mum what was wrong
12 and we had to actually be on our own to get our heads
13 round it and we collected my son. My Mum had said,
14 "Well, what was the appointment about?"

15 "Ach, nothing, just routine", and that was all
16 we said to her and everything was left.

17 Q. There's a couple of other details of that meeting that
18 you and Robert have recorded in your statements I just
19 wanted to ask you about. You were told by Dr Ludlam,
20 you've said in your statements, not to tell anyone
21 because of the stigma.

22 A. That was really emphasised. Not even to tell our
23 families. At this time we didn't know that his uncles
24 and cousin was infected, but we were even not to tell
25 them. How on earth, if I wasn't there, how did he

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1 A. We thought he had just been -- it never even crossed
2 my mind that it was all these years ago. We actually
3 thought he had just been tested.

4 What we think about now is that it was heat
5 treated so how could he have been infected, but we
6 didn't think about that at the time. We actually
7 thought Robert had just been tested and he had just
8 gotten the result.

9 Q. Were you offered any counselling or psychological
10 support at that time?

11 A. No.

12 Q. Was there is any offer of a test for you?

13 A. No.

14 Q. Robert describes the circumstances in which he was
15 informed of the diagnosis in January 1987 in his
16 statement as, I quote:

17 "Unforgettable and unforgivable."

18 A. Yes.

19 Q. And says this, again quote from Robert's statement:

20 "We were left to go home, keep secrets and just
21 live the rest of our lives with nothing ahead of us
22 but lies."

23 A. That's what we lived like. It was lies and secrets,
24 secrets and lies. That's all we lived from that point
25 on. That was it. That was our life. Secrets. You

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1 expect Robert to go home and tell me? I really feel
2 that it should have been the husband and wife that was
3 there when he told them. I would have went crazy if
4 Robert -- if I'd left the meeting and Robert was told
5 that, because it's not something he should have been
6 told on his own.

7 The way he was told and the way his family was
8 told. It just is not -- I'll put it politely --
9 acceptable. It's the only word I can put, that
10 I wouldn't use words that I shouldn't use.

11 Q. Is it right that Robert or you asked Dr Ludlam how
12 many haemophiliacs were infected?

13 A. Robert asked at the 1984 meeting to begin with. That
14 was one of the questions he had tried to raise when
15 the meeting was closed down. So when he had this
16 meeting he had says to him, "Well, how many are
17 infected with this", and all Ludlam says was just
18 a few. That was it.

19 Q. That was the question he asked again in January 1987
20 and the answer was just a few?

21 A. Yes, just a few.

22 Q. Your impression, is this right, and please correct me
23 if I'm wrong, your impression as you've described it
24 in your witness statements and in your oral evidence
25 just now was that this was a recent diagnosis?

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1 couldn't talk to anybody. You couldn't tell them the
2 truth. I don't know if I should say, we did say to
3 one family member and we got asked to leave their
4 house and that just -- well, Ludlam must be right.

5 What can you do if a family member can't
6 understand it, you don't tell anybody and that's how
7 we lived. The three of us lived as a family from then
8 on.

9 Q. I am just going to ask you about Robert's diagnosis
10 with hepatitis C. You say in your witness statement
11 that in February 1990 in a letter dated
12 20 February 1990 from the Royal Infirmary of Edinburgh
13 you were told this:

14 "A new blood test has recently become available
15 for assessing hepatitis and we would like to evaluate
16 its usefulness. If the early promise of new test
17 holds good it's likely to be very valuable for
18 evaluating both the suitability of blood donors as
19 well as the safety of Factor VIII and IX concentrates.
20 We wish, therefore, to review case records to assess
21 if and when individuals have had hepatitis or been
22 jaundiced. We also want to relate the blood test
23 results to the use of different forms of treatment."

24 What was yours and Robert's understanding of
25 what that letter was telling you?

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1 A. It was just a new test for hepatitis and by hepatitis,
 2 we knew hepatitis as hepatitis A and B. We didnae
 3 know about non-A non-B or hepatitis C, and we actually
 4 thought that much about it we didn't even return the
 5 questionnaire and we didnae sign anything. So whether
 6 they actually went to Robert's records and done it or
 7 not because we didn't return anything giving written
 8 permission to do it, whether they actually checked his
 9 records or not I don't know.

10 Q. Then you have described in your statement a meeting
 11 in May of 1993 at ward 45 at the Royal Infirmary when
 12 Dr Ludlam suggested that Robert would need a liver
 13 biopsy or endoscopy to see if he had hepatitis C?

14 A. Yes.

15 Q. What can you recall of that discussion?

16 A. They says to Robert about this new hepatitis and as
 17 soon as they mentioned liver biopsy Robert, "No".
 18 Robert actually -- I'm putting it more politely when
 19 I say, told them it wasn't a good idea to cut into
 20 haemophiliacs and anyway. So he told them no and they
 21 offered him an endoscopy and he says he would think
 22 about it but he said no in the end to that as well
 23 because it was still too risky for him.

24 But they never said to him hepatitis C or what
 25 exactly it was. They didn't say that they could test

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1 50mls of blood, 60 -- I've even seen two full
 2 syringes, two full 50 mls syringes of blood getting
 3 taken off of Robert at one time, and the amount of
 4 times I actually says to these nurses, "What are you
 5 wanting all that blood for, because he's going to go
 6 need to go and get a blood transfusion if you dinnae
 7 stop taking as much blood off him" and all they would
 8 do is "ah-ah", turn round and walk away.

9 It's not as if when they were taking blood off
 10 Robert it was 20 mls, which is to me fine, it's
 11 suitable, but we're talking -- I don't know if you
 12 understand how much 50 mls of blood is in a syringe.
 13 It's a lot and it was a lot for me to keep on saying
 14 to them, not just once or twice, I'm telling you on
 15 a regular basis, every nurse that took blood off of
 16 Robert I would say to them about the amount and "What
 17 are you taking this for?" And they never said a word.
 18 They never even explained for research. They never
 19 explained for hepatitis. They never explained for
 20 AIDS or anything else, and we just assumed it was his
 21 routine blood tests for his haemophilia to check his
 22 levels.

23 Now I think I must have been that stupid,
 24 I really do.

25 Q. Robert says in his statement that he only understood

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1 for it, they didn't say they could take a blood test
 2 or there had been taking blood tests for it, they
 3 didn't say any of these things and Robert -- well, we
 4 left the hospital thinking, well, when they come up
 5 with a blood test they'll tell us about a blood test
 6 and then we'll find out if you've got it.

7 We didnae know that they knew Robert was already
 8 infected. No-one told Robert that he was already
 9 infected.

10 Q. The basis for your understanding that it was already
 11 known that Robert was infected is again something
 12 you've subsequently seen in his medical notes.

13 Paul, it should be at 2190002, please.

14 If we look at the date in the top right-hand
 15 corner, we can see 29 April 1992 is the date received,
 16 12 May 1992 is the date reported and then we can see
 17 the test is -- the text is faint but the hepatitis C
 18 virus, the two tests there described are coming back
 19 as positive?

20 A. Yes.

21 Q. Did Robert know that he was being tested for
 22 hepatitis C in 1992?

23 A. No, but what I've not said here is from '83 onwards
 24 when I say Robert was given more blood samples, right,
 25 for his routine testing, it got that they were taking

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1 that he had hepatitis C in 2000 during a routine
 2 appointment with his HIV consultant?

3 A. Yes. I can remember the shock on his face. Robert
 4 had problems with sweating, right. He could --
 5 crumbs, it could be 100 degrees outside, fine, I could
 6 understand it, and then when it goes down to minus 5
 7 he'd still have all the doors and windows open in my
 8 house. We couldnae go into any shop; we couldnae go
 9 into any building without him actually really
 10 sweating. His temperature would go through the roof
 11 and everything else.

12 When we used to say to the doctors at the
 13 Infirmary they just made us assume that it was the
 14 AIDS that was the problem with it. Well, when he went
 15 to see [redacted] at the AIDS -- well, for his AIDS
 16 treatment, [redacted] says him, because the sweats
 17 weren't stopping, he says to him, "Well, it could be
 18 down to your hepatitis C", and I could see Robert's
 19 face. I'd never been told, right, but because I'd
 20 heard so many haemophiliacs with hepatitis C I suppose
 21 I just assumed. Maybe I shouldn't have assumed but
 22 I did, but it was neither here nor there to me because
 23 all our protection was for the AIDS and that's all
 24 I was interested in because that's what I was fighting
 25 to keep Robert alive from.

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1 But when [redacted] says to Robert about
2 hepatitis C, his face -- you could see the shock and
3 he just shut down. He can remember being told about
4 it and we left and I can remember him in the car
5 saying to me, "When did I get hepatitis C?" And
6 I says, "I don't know when you got it but I do know
7 that I thought you had it".

8 A doctor should maybe have told me but because
9 I was not Robert's power of attorney at that time they
10 wouldn't have discussed, I would imagine they wouldn't
11 have discussed it with me anyway and I never even
12 thought of saying to Robert because, as I say, we were
13 fighting to keep him alive with AIDS and at that time,
14 in about 2000, Robert was only given six weeks to live
15 and any time after that it was a fight to keep him
16 going and I didn't want to put any more pressure on
17 him.

18 There's loads of things that come up about that
19 time that Robert couldn't even tell you about anyway.
20 The first thing he remembers is [redacted] saying to
21 him "hepatitis C" and then it all just blew up again.
22 I thought here we go again and it just ...

23 Q. Your suspicion or belief that he might have
24 hepatitis C was based upon your general understanding
25 by then that many haemophiliacs had been infected with

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1 I was more interested in the AIDS. CJD or anything
2 else to me was just something extra. Nobody told me
3 the seriousness of all these other things. To me the
4 seriousness was the AIDS, so I returned the form and
5 says we didnae want to know anything.

6 We got another one and I'm sure I done the same
7 with the second one. The third one, Robert was
8 feeling better again so we went and we turned up and
9 Dr Ludlam says to Robert that he hadnae received any
10 batches but he could have still received it through
11 eating meat and Robert's reaction was, "But I'm
12 a vegetarian". He's not -- let me say that, he's not,
13 but his reaction was, "But I'm a vegetarian and
14 Dr Ludlam just looked at him as if to say, "Oh my God,
15 what have I done". He shouldn't have said that. But
16 he was putting down if Robert got CJD it was because
17 he ate meat not because of the Factor VIII or the
18 blood or anything else that he received, which
19 I really think was something that he shouldn't have
20 been saying because that's where he would have got it
21 from.

22 But even then to us -- people worry about it.
23 To us, it's just another thing that you might die of,
24 if you understand what I'm saying. It's nothing
25 extra. Our life circulates round AIDS not hepatitis,

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1 hepatitis C?

2 A. Yes.

3 Q. It wasn't on the basis, as I understand your evidence,
4 correct me if I'm wrong, of anything that was said to
5 you by any medical professional?

6 A. No, no-one ever said. They used to say to Robert
7 about drinking but you drink too much, a doctor will
8 say to you cut down your drink, you smoke too much
9 they'll tell you cut down your smoking. So Robert all
10 this time just thought, I mean, he knew he was
11 drinking, don't get me wrong, he knew he was drinking
12 too much but it's just something a doctor says. They
13 never says to him, "You've got hepatitis C, Robert.
14 Take care of your liver for this reason or other".
15 They never come out with anything like that to him.

16 Q. Robert received in 2004 letters about potential
17 exposure to the risk of vCJD. We've got letters.
18 I am not going to ask you to go through them in the
19 course of your oral evidence, but what do you recall,
20 if anything, about the receipt of those letters and
21 yours and Robert's reaction?

22 A. We did receive -- we received maybe three different
23 times we received them, and the first time I actually
24 ticked the box and sent it back saying we didnae want
25 to know anything because, again, I keep saying this,

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1 because AIDS is the thing I have to deal with. AIDS
2 is -- when Robert's ill a doctor will say to us,
3 "Well, I don't know if his haemophilia or if it his
4 AIDS or if its hepatitis that's the problem", so what
5 do you do? You have to narrow in on something and my
6 problem that I narrow in is the AIDS because now,
7 touch wood, he's cleared the hepatitis. I know he's
8 got all the side effects and everything else that come
9 with that, but that does not catch up with what he is
10 actually dealing with, with AIDS, how he lives with
11 it, what he has to do with it, all the illnesses that
12 we have to actually solve ourselves because the
13 hospitals aren't interested, and Robert'll no go to
14 his GP because his GP does not understand haemophilia,
15 they don't understand the AIDS, they don't understand
16 hepatitis.

17 So when you go to a doctor how can you say to
18 a doctor, "Well, I've got this infection", and he'll
19 say, "Well, it will clear up on its own", and you will
20 say, "But I'm worried because I've got ..."

21 "Oh that's okay. It will just clear up on its
22 own", and you go away, so we've got to go and try and
23 find cures, remedies, all these things to solve
24 Robert's problems and we don't go to doctors and
25 hospitals unless there's something that, after

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a certain length of time, we cannot clear.
 We go up to the Infirmary and it got to the stage they didn't want to discuss things with Robert. If he had an illness at the beginning of all this we were told any problems go to the Infirmary, the Haemophilia Centre, and they don't want to know. They really just don't want to know because they don't know. They don't know haemophilia, AIDS, hepatitis. They do not know the difference in the illnesses and they don't know what to treat.

We go to the Infectious Diseases Unit and she is very -- the doctor we have there is now very understanding and she will sit and listen and if she can help us with anything, give Robert a medication or that, she will. But she's very careful because it could cause bleeding. So the doctors don't know -- what they need is somebody that is there to be able to tell and treat a haemophiliac that is infected with more than one thing, more than haemophilia and there is not anybody out there and the doctors will admit that. There is nobody out there that can treat a haemophiliac with all these different viruses and that is something that should have been done years ago.

We just keep having to fight ourselves. We

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us that they stored blood. 20/30mls storage. What on earth are they doing with all this blood? Who's seen it? What are they using it for?

It's just not right the way they're treating haemophiliacs, as a whole. I'm not just talking about Robert. I'm talking about a whole group in the population that deserve to be treated better than they are. I'm sorry. I've got off track, I'm sorry.

Q. That's all right.

A. I'm really sorry.

Q. No, no, not at all, in fact, you have covered some of the questions I was going to ask you later so don't worry in the slightest.

Can I take you back to life after you discovered Robert had HIV in 1987 and the years that followed.

Robert did not embark upon his dream job because he felt he would have had to tell his employer and that would be the end of it?

A. Yes.

Q. You've put it this way in your witness statement:

"Normal life stopped", and you began a life full of lies, deceit, secrecy, more secrecy and lies and in a way a life full of loneliness and isolation.

A. Yes.

Q. You have explained you tried to tell some members of

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shouldn't have to fight for all this. Somebody should be there for us. Somebody should be there to advise us. "If something's wrong, tell us, it's okay, we'll sort something out, we'll get our heads together and we'll discover what's wrong", and not once I've never seen that.

I did complain once with Dr Ludlam and another doctor in the room about Robert's treatment because I kept asking, "Well, is this treatment for AIDS going to affect his treatment for haemophilia?"

"Well, we don't think so", and I maybe didn't say the right thing and Dr Ludlam says, "Well, she's doing the best she can", because I turned round and says, "Well, your best's not good enough", and he looks as if I'd said something I shouldn't have. And I don't think the doctor was too kind to me after that, since every time I saw her after that she wasn't really talking to me.

They just don't get it. Honestly they don't get it. They treat haemophiliacs not even as patients, not people, they just treat them as experiments. That's the way I look at it now. It doesn't matter what you go for, they take blood and they take that much blood, they don't tell you what they're taking blood for. They have stored blood. Nobody ever told

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the family and they didn't want to know.

A. Mm-hm.

Q. In 1988, you and Robert had your first encounter, this is how you put it in your statement, with full-blown AIDS, when you saw a patient, someone that you knew. Without mentioning any names, what can you tell us about that encounter?

A. Robert and him were raised together, if you can call it that. They were in the hospitals together. They were really close friends and this person was more scientific, if you want to put it that way. He used to read all these, if he got his hands on these research papers and that and he used to read them.

But this time when we went in it was late at night, Robert went up to collect some stuff and he heard somebody shouting, of course, Robert being Robert again, nosey, went in to check that everything was okay because he recognised the voice, and this person saw Robert and he started screaming at him and shouting at him, "They've murdered us, Robert. They've murdered us. Get the -- they've murdered us". He was going, really -- he was in a really bad way.

I can't even describe how bad he looked, which shocked me because I'd never actually seen anybody with AIDS and the next thing was the staff come in,

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1 cut us off, literally threw us out the hospital. But
 2 the car -- the old infirmary, there was a car park
 3 just down the foot of where the wards were and we were
 4 getting in the car and he was still screaming and
 5 shouting and that's the last we heard.
 6 Q. That friend died?
 7 A. He died just not long after, yes. That was the first.
 8 Q. It was the first but not the last of deaths amongst
 9 friends and family.
 10 A. No.
 11 Q. And by 1996 you have described in your statement how
 12 it all became too much for Robert and he began to
 13 change in his behaviour and habits.
 14 A. Even before that it gradually, it really gradually
 15 got, if I think about it, but you learn to accept
 16 changes and I always -- I had this thing that he
 17 deserved anything he wanted, if you understand. Even
 18 if it was getting drunk or partying or whatever, he
 19 deserved it because he wasnae going to survive this
 20 and he just got worse and worse. But what -- Robert's
 21 brain worked in a stupid way. After seeing all these
 22 people dying, after seeing the way it affected family,
 23 Robert decided one day that he was going to make sure
 24 everybody hated him, and I mean hated him, and that
 25 goes for our son as well.

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1 your Dad", and all this.
 2 In the end when he was 18 that's when we told
 3 him and he just ... I don't know if he was hurt at us
 4 not telling him or what but what I says to him at the
 5 time as well was, "It's up to you if you tell your
 6 friends because we know the difficulties that we had",
 7 and we he said to me was, "If there are any friends
 8 they wouldnae bother, they'll just get on with life
 9 and that will be it", and some, I have to admit he's
 10 still got some friends and other ones disappeared
 11 because of what was wrong. Fair enough.
 12 But that was another thing. We should have been
 13 maybe advised on how to tell children because it's
 14 them that are the ones that suffer. They are the ones
 15 at home and I think we should have been advised or
 16 someone should have said to us do you want us to help
 17 you explain. All these years Robert went through
 18 trying to get our son to hate him and our son did hate
 19 him for a long time and it wasnae fair. It really was
 20 not fair. He couldnae do anything with him.
 21 When his friends used to come in and would go up
 22 the stair because I liked my son to be close, if you
 23 understand. I liked to keep an eye on him. Maybe it
 24 was just over-protectiveness, I don't know, so his
 25 friends would come and they'd go up to their room and

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1 Q. Robert's reasoning --
 2 A. Was that if he hated him he wouldnae miss him when he
 3 died. But now because he's on his feet again, shall
 4 we say, after 2000 he regrets it. We can never get it
 5 back. My son now understands because he didnae know,
 6 we didnae tell him. Maybe we should have but we
 7 didn't tell him.
 8 Q. What did you tell your son?
 9 A. We didn't tell him until he was 18. Before that we
 10 used to say your Dad was ill and then it got that bad
 11 I had to go to the school to say something so I said
 12 it was cancer. So all through [redacted] schooling,
 13 you could say the school thought his Dad had cancer
 14 because sometimes if Robert was up during the night
 15 [redacted] would be -- could you take out [redacted].
 16 Q. Yes. Hold on a moment. We will stop the live
 17 transmission. (Pause)
 18 We will not refer to any names.
 19 A. Right. The school, because we were up during the
 20 night and things like that, he was going to school
 21 maybe late or his homework wasnae getting done because
 22 of the atmosphere in the house and things that were
 23 happening. We should have maybe said to him then but
 24 eventually I says to him his Dad was dying of cancer
 25 because his friends started to ask, "What's wrong with

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1 they'd do play whatever it was up there, and his
 2 friends used to start asking questions but when Robert
 3 again started on the drink, it got that their parents
 4 were passing remarks about his Dad being a drunk and
 5 in the end I think [redacted] preferred ...
 6 Q. We'll stop the live transmission. (Pause)
 7 You were telling us about the impact upon the
 8 relationship between your husband and your son.
 9 A. My son actually preferred going to his friends' house
 10 rather than stay in our house because of the way
 11 things were. I tried to keep it calm, I tried to do
 12 things but when he was at his friends' house he would
 13 hear his friends' parents' talk about a drunk. Yes,
 14 Robert drank. I knew why he was drinking. I knew it
 15 was his coping mechanism. I knew what he was doing
 16 but nobody else did.
 17 Walking along the street people would, "Oh,
 18 she's the one that's married to ..." I just thought
 19 I've had enough of this. You just can only take so
 20 much.
 21 Q. There came a time when you stopped opening the front
 22 door to people.
 23 A. Even now I don't answer telephones, I don't open up
 24 the doors, I don't even -- I don't have any friends.
 25 I actually had to stop having friends in '87. When

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1 I say it became a life of lies and deceit and what
2 not, that it was the three of us, right. I mean, it
3 was the three of us. I had no friends because how can
4 you -- you cannae keep telling the same lie because
5 lies always come out, if you understand what I'm
6 saying.

7 As for family, I stopped visiting them because
8 I couldnae lie to my family, so I just stopped and my
9 family, it's a big family as well, and we were close
10 and I say the word "were" because not anymore.

11 Robert's family, Robert made them hate him so
12 much they stopped visiting. Now, they are the people
13 that always says to me, "If at any time you need us,
14 we'll be here. If Robert gets it, we'll be here", but
15 as soon as Robert started, because the way Robert
16 ended up, everybody disappeared. His family all
17 disappeared, and it is a life of loneliness. I did
18 not answer the door. I don't answer the phone.

19 You'll find in Robert's medical records,
20 "I tried to phone Robert but there's no answer".
21 I told these doctors loads of times not to phone
22 because they'll no get an answer, but what they put
23 down is because there's no answer we're out enjoying
24 ourselves, and that was the words from one of them.

25 I used to get up in the morning, go up to the

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1 meeting not to try to have any more children.
2 A. It's not a case of we took the decision. We got told
3 we couldn't and no-one ever informed us that there
4 was -- when other things come there, no-one ever
5 informed -- as much as we would have liked to but
6 no-one told us it would maybe have been possible.
7 No-one approached us to say, look, if you're still
8 young enough, if you're still wanting, but no-one ever
9 says that.

10 Q. So sperm washing, things like that were never raised
11 with you?

12 A. Never. The first I heard of that was through someone
13 Andrew Evans on Tainted Blood. Sorry.

14 Q. No, that's okay. He has already given evidence about
15 it.

16 A. Him on Tainted Blood. That was the first time I even
17 heard that it was possible for an infected person to
18 do that but by then we're all too old.

19 Q. You describe that in your statement as one of your
20 biggest sorrows?

21 A. Yes.

22 Q. In terms of the treatments that Robert has undergone
23 over the years, he was offered AZT but he declined
24 that.

25 A. It was a trial treatment and Robert will not do

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1 shop and come back and that has been my life for the
2 past 30 years.

3 I know Robert's spoken out and things like that
4 but me I'm still no there. I've still got no cameras
5 on me. Yes, I'll talk but I still cannot stand in
6 front of somebody and say, "Yes, Robert is such and
7 such". I still cannot do that.

8 I don't know if it's because I've lived with it
9 for so long the way I've lived with it or because, as
10 you can see, I get very angry or because I'm still
11 frightened.

12 Q. Robert's physical health and mental health over the
13 years deteriorated to the extent that again, as
14 I understand it from your statements, Alice, he
15 effectively now requires 24-hour care which you give
16 him.

17 A. Mm-hm.

18 Q. He can't be left alone because he has panic attacks?

19 A. Mm-hm.

20 Q. Or outbursts of anger?

21 A. *(The witness nodded)*

22 Q. You panic too. You get anxious, you don't like being
23 in noisy places.

24 A. Mmm.

25 Q. And you took the decision after the January 1987

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1 something that he does not know what is there, and I'm
2 glad he didn't because *[redacted]* did say to Robert
3 that they had overdosed them on AZT and can we sit and
4 think about it.

5 We saw family members taking AZT and, yes, they
6 did deteriorate after that. I can mind Robert saying
7 to one of them, "Just leave it, don't take it, it's no
8 good for you, they don't know what it's going to do to
9 you yet?"

10 "Ach, it's all right. The doctor says it's
11 great." This person, believe it or not, believed
12 Dr Ludlam to the point that he thought he was never
13 going to die of AIDS. He actually believed he kept on
14 saying to Robert, "Robert, it's okay, we're living,
15 we're never going to die of this. This is just
16 something that's there. I got told it's okay. I'll
17 live for the next 100 years", sort of thing, and
18 that's what Ludlam told him and he actually believed
19 this and when he went on AZT, Robert had says to him,
20 "I don't really think ..."

21 "Ah, but he says it will keep me going", and he
22 died just not long after it.

23 Q. By 2000 Robert's health physically was very, very
24 poor.

25 A. Yes.

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1 Q. He described didn't know what was going on, he lost
2 weight there were times when he couldn't eat or drink.
3 He couldn't or wouldn't go to bed. He would sit in
4 the chair for prolonged periods?

5 A. He sat in a chair for maybe two years. He started
6 sitting sort of in a comfy chair living room and then
7 for some unknown reason he got up and he went in the
8 kitchen and he sat at the dining table and he sat
9 there and he was like that (*indicated*). That's all he
10 done, never moved all day. That was Robert's life for
11 about two years.

12 It wasn't until we eventually -- I don't know if
13 you are coming to it but we eventually met [*redacted*]
14 but one of the reasons Robert wouldnae take treatment
15 was (1) they were all dying, right, (2) he didn't
16 trust the doctors enough, because if you look at the
17 way things were going, right, they're giving these
18 people medications but they're dying so what was the
19 point? It's just trial treatments and Robert's not
20 one for volunteering, shall we say. If you don't know
21 what works out and doesn't work.

22 We were also told we would be treated at the
23 Infirmary for everything and I don't understand that,
24 that he said -- that Ludlam had said we would be
25 treated at the infirmary for everything but because it

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1 I accepted life, right. I knew he was ill. I knew he
2 was going to die but the word "palliative" care and
3 I thought to myself no.

4 We walked out. She never mentioned it ever
5 again. That was the only time help from the hospital
6 was given, was offered, if you can call it offered.
7 "We'll have to talk about palliative care", and we
8 left the hospital and maybe a week it took me to
9 persuade Robert to actually go on this treatment.

10 At the time, [*redacted*] says to me, "If there's
11 any problems, if you find any concerns, just let me
12 know and we'll listen to you", and I thought, "Fine",
13 so we went away. I finally got him to start the
14 tablets and I wish I hadnae, I really do. I wish
15 I hadn't. Look what it put us through after it.

16 Q. There is was medication for his HIV?

17 A. Yes.

18 Q. And what was the effect of the treatment regime which
19 he started with?

20 A. Life was bad. Believe me life was hell after it. He
21 turned round, in a sense, where he wanted everybody to
22 hate him, right, when he started this tablet our son
23 or myself could not move he was that protective of us.
24 I could not even step out the back garden without him
25 holding my hand and making sure no-one was going to

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1 was so late Robert, technically Ludlam's cohort had
2 died, right, apart from three Ludlam's cohort had died
3 by the time Robert got seriously ill and Robert was
4 told he would have to go to the Western Infectious
5 Diseases Units in the Western and he refused and he
6 refused, because of the place, he knew what the place
7 was like and in the end they got [*redacted*] to see him
8 at the Infirmary.

9 Anyway, [*redacted*] says to me that if he doesnae
10 take his tablets he's got about six weeks. Now,
11 Robert was sitting right next to me and he can't even
12 remember going to the hospital, never mind sitting
13 listening to what a doctor was telling him. So in the
14 end they were going to send him home so I says to him,
15 "Why don't you give me the tablets to take home for
16 Robert and we'll see how we go because I've got more
17 persuasion than what they have". When we come out he
18 says to me he's give him about six weeks.

19 That's what he actually says to me but when we
20 come out, I was speaking to the sister that was behind
21 the desk and all she says to me was, "We'll have to
22 start talking about palliative care", no leading into
23 it. I knew Robert was ill, right. Don't get me wrong
24 I knew he was ill but maybe I didn't accept how ill he
25 was. It was our life. It was how we lived. It's how

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1 hurt me. I couldnae walk along the street. If
2 we walked along the street and somebody looked at me,
3 just, you know you pass somebody and you maybe look at
4 them, Robert would have went for them. He really
5 was -- his whole manner and everything changed.

6 He was when I say aggressive -- he was bad
7 enough before because he was ill and that but when
8 I say aggressive Robert was aggressive. He started --
9 because he was starting to feel a bit better he
10 started fishing again. His friends by now -- Robert
11 was lucky. He still had friends, fishing friends,
12 right, but his friends didn't understand him but they
13 accepted him for the way he was, and he was up fishing
14 one day and this man come and parked his car in front
15 of a farmer's gate. Robert just about went -- well,
16 I say his friends had to actually keep him back only
17 because the man parked in the wrong place but he
18 shouldn't have been there. Robert would have killed
19 him. I'm not joking when I say he would have killed
20 him. He had that much anger. I can't even say. It
21 wasn't even anger.

22 Anyway, he changed just like that. No-one and
23 I mean no-one could speak to him and I says to
24 [*redacted*] about this, "No, no", just ignored me.
25 They really ignored me. We went through about nine

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1 months of this and I'm telling you tell hell wasnae
2 the word, it really was not the word that you could
3 describe for the way we lived. Even my son, if his
4 friends did come in the house they'd go up the stair
5 and I'd be sitting on edge until they left.
6 I couldn't get them out the house quick enough, which
7 technically was throwing my son out the house because
8 the way Robert acted if his friends looked at him the
9 wrong way.

10 Robert -- I just -- I can't even say it. Anyway
11 I said to [redacted] lots of times and at this time
12 when we're going up the infirmary he was marching
13 about, he couldn't really, he had a really -- people
14 here that know him will still say he's got this but he
15 had a really aggressive manner the way he stood, the
16 way he walked, he never walked, he marched. People
17 are still scared of him because of his manners and
18 I says to them at the infirmary and they ignored me
19 and it wasnae for about eight/ten months there was
20 a case in Perth where a young girl had done something
21 anyway and it turns out that it was her AIDS
22 medication that caused her aggressiveness and it turns
23 out that this medication, one of the medications
24 Robert was on, had psychotic side effects.
25 I'm telling you as soon as he stopped taking

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1 A. Yeah, what he's got now, the doctor keeps on trying to
2 update it, right, but we're happy in that what he's
3 got works, we've got Robert to take it. I know I've
4 never been to my bed before 12 o'clock at night for
5 the past 20/30 years, right, but it's worth it because
6 the medication he's on, touch wood, is working and if
7 you change it we're always afraid in case it doesnae
8 work and when it doesnae work he cannae really go back
9 to what he's had, so we stick with what we've got,
10 what we know works.
11 Q. What about treatment for hepatitis C? There did come
12 a point where Robert did take treatment for that.
13 A. He did get offered all this interferon or what not
14 eventually from the Western, from his AIDS doctors,
15 but Robert, no, he's seen too many people go through
16 what they went through and I'll tell you the doctor at
17 the Western actually stated Robert is not in the right
18 frame of mind to go through anything like that because
19 he was bad enough as it is without having to go
20 through the side effects and we suffered it, kept
21 going through it, he had all these illnesses and it's
22 the sweats is really the thing with him.
23 So when Harvoni come on the market we asked and
24 his AIDS doctor says that he wouldn't be able to get
25 it because of he wasnae ill enough in the sense of his

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1 that tablet he turned just like -- when I say he
2 turned, he stopped being as bad as he was and it made
3 life bearable after that but Robert still -- people
4 are still afraid of Robert. When he walks, he talks,
5 he is, he's a frightening person. I'm sitting here
6 trying to not to laugh because I can see people here
7 that are frightened of Robert, whether they'll admit
8 it or not, they are afraid of him because of his
9 manners, the way he goes, and Robert was never like
10 that.

11 He was -- yeah, before he was infected he would
12 stick up for people, right, he was never one to back
13 away from a fight, if you know what I mean. He was
14 there. If he thought he was right, he would put his
15 point but when he started this -- he was bad enough
16 before this medication because of the anger that was
17 building on what he had already seen and been through
18 with his family and his friends. This medication
19 just -- oh, I can't seen explain it, but he's never
20 come down from it. He really hasn't. His family talk
21 to him but there's still not what should be there.

22 My family, some speak to him and some don't
23 because he is not an easy person.

24 Q. Does Robert continue to be on a regime of treatment
25 for HIV?

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1 liver wasnae stage 2 or whatever it was. So we
2 actually had to go to a haemophilia doctor in Dundee
3 and he was speaking to Robert and he sent a letter
4 down to say that he recommended that Robert go on the
5 Harvoni, which no side effects except a couple of
6 broken legs.

7 He walked about -- he kept going up the hospital
8 and saying to them about his legs. He couldn't even
9 walk, his legs were that bad and, "Oh there's nothing
10 wrong. It's just arthritis", and all this carry on.
11 I would phone them and I would say and all this carry
12 on, and I shout at you, I'm sorry I shout at you, but
13 the only way I can be heard at this hospital is if
14 I shout and raise my voice, and I was on the phone to
15 one of the nurses one day and I lost it on the phone
16 and it was, "Well come in, and we'll maybe get him an
17 x-ray".

18 So we went along for the x-rays and they come
19 back, of course the doctor come, "Robert, Robert,
20 you've got a broken leg. You have got a fractured
21 leg", so that was it and we went home and the next
22 morning, another phone call at 9.00 in the morning,
23 "You have to come in right away, Robert. Your other
24 leg's got a fracture in it". After months, and I mean
25 months, of complaining of this pain and he told them

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1 it wasnae bleeding. It wasn't anything to do with the
2 haemophilia. There was something wrong, so now
3 they're arguing was it his AIDS tablet or was it the
4 Harvoni and, again, we're back in the catch 22
5 situation.

6 It happened when he was on this medication but
7 it could have been the combination. It could have
8 been just his age catching up with him and things like
9 that. But you do not get these doctors to listen.
10 They know what they know and that's it. You are not
11 allowed to educate them and if you are living with
12 something for so long, you learn to know more about
13 what your body is like than what these doctors do and
14 the doctors don't listen. Again, they still don't
15 listen.

16 Q. In terms of employment and financial consequences,
17 Robert, as we've heard, had to give up his dream job
18 as a gillie and you have had to be for many, many
19 years his full-time carer.

20 A. Yes.

21 Q. You have no pension?

22 A. No.

23 Q. Robert worries greatly about how you will manage when
24 he dies.

25 A. Yes. The older we get the worse it gets in the sense

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1 was all we worried about was the mortgage because
2 I couldn't have kept it up if I wasn't employed or
3 that, and that's what we done with that money, was
4 paid off the mortgage so that at least I have a roof
5 over my head. It doesn't matter what else, I can
6 starve, I can go round family, my son or that, get
7 fed, that's no bother but I've got a roof over my head
8 and that took some of the worry off of Robert.

9 But he does not want me to live in what he would
10 call poverty and that really affects him. It upsets
11 him a lot because of what we've went through and he
12 just keeps saying he's ruined my life. That's all he
13 keeps saying. I should have -- what he'll say is,
14 "You should got rid of me years ago and married
15 somebody rich that will set you up in your life", you
16 know, that's the thing with him now. He really
17 worries that I'm not going to survive it.

18 Don't get me wrong, I'm one of the lucky ones.
19 Robert's still here. Robert is old. Robert is old
20 compared to a lot of normal people nowadays his age.
21 I've got -- I've had him all these years but it's not
22 been a life. It really has not been a life and it's
23 nothing that anybody could even ever have imagined it
24 could be.

25 No-one, I wouldnae wish it on my worst enemy and

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1 of a pension because even if Robert -- the Government
2 keeps changing retirement ages, right, and every time
3 I just about reach a retirement age they jump it up.

4 So all Robert sees is me working from the time
5 if he's not here anymore to when I'm able to retire
6 for a start and nowadays I have no qualifications that
7 would do anything like that.

8 My health, I'm healthy, I'm fit, don't get me
9 wrong, but I can't go into work in a shop because
10 I couldn't cope with it. Certain things like that,
11 and an employer nowadays would look at my past history
12 and what history do I have for the past 30 years?
13 I don't have any work history that is suitable, that
14 takes a youngster more than they would take somebody
15 my age that's only got another X amount of years to
16 work.

17 So if I ever reached pensionable age, Robert
18 would feel a bit more settled because I would have
19 a pension, a state pension is what it is -- it's not
20 much but it's a state pension and then he worries how
21 am I going to survive on a state pension when he
22 realises just how much a state pension is and he
23 starts panicking on that.

24 We're lucky that the payments we received from
25 the new Scottish scheme paid off our mortgage. That

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1 it's all because, to me, it all goes down to a doctor
2 that thought he -- how will I put it? A doctor that
3 thought he knew best, to put it mildly, that a doctor
4 that preferred rather than inform patients of the
5 potential -- I'll not say risks, I'll say potential
6 risks, not to inform them of these potential risks
7 that could have saved us all this hardship, all this
8 worry, all this stress, this whole life.

9 We could have had a life because we had our
10 plans worked out, we had it worked out. I know plans
11 don't always work, well ours definitely didnae, but
12 you change plans now and again, when you get married
13 you have your set of things. Ours stopped. 1987 it
14 just ... disappeared and our life stopped because we
15 have any had a life for the past 30 years, really have
16 not.

17 Q. Robert says in his statement that had he been warned
18 of the risk of AIDS he would not have taken the
19 Factor VIII products that infected him in 1984 and he
20 describes it in his statement. His phrase is it was
21 all completely avoidable.

22 A. It was. It definitely was. Had -- when Ludlam
23 started his AIDS studies, right, his AIDS studies
24 linked up a ubiquitous virus. What is a ubiquitous
25 virus? This ubiquitous virus as I know it could have

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1 killed Robert anyway, right. Maybe it wasn't
2 infectious in the sense of transmitting it to me but
3 he could have caught something from this so-called
4 ubiquitous -- why didn't he warn him about this or
5 other patients who got -- not just Robert, all these
6 other patients, infected and non-infected, he should
7 have warned them of this and he never.

8 That would have been the point to us where
9 Ludlam said to Robert, "Look, we have got this. We
10 don't know what it is. We don't know how it's going
11 to affect you. Do you want to -- it's through the
12 Factor VIII, do you want to keep taking this? You
13 can't get cryo. We don't make cryo anymore", is what
14 Robert was told, "but you can't get cryo even if we
15 made it again. Do you want to go back to the old way
16 of life", and Robert would have said yes because
17 Robert's life was good enough for him. He was happy
18 with it because he had a life.

19 When he was infected he didn't have a life after
20 that and that's the difference. Without Factor VIII
21 he could have survived and they come up with heat
22 treatment a year later. Robert would have survived
23 even right up to now, he would have altered his life
24 completely and I mean altered it. Even if it meant he
25 just sat in a chair and done nothing, Robert would

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1 it down because it's when my son was born, right.
2 I wasn't working and I went with Robert to the
3 hospital and that man never acknowledged me. I could
4 sit in that room in a corner and he didn't even know
5 I was there. And I used to sit and listen to
6 everything. That's why I know everything that's going
7 on. I used to sit and listen and I would leave the
8 room and he still wouldn't even acknowledge that I was
9 there.

10 It got to a point there was his GMC and
11 whatnot -- I don't know if I can mention that -- but
12 anyway it got to the point of that, and I'd had enough
13 one day and I says to him, "Look, why do you never
14 acknowledge me? Why do you never call me by my name?
15 Even if it's Mrs Mackie, I wouldnae mind" and he gave
16 a smile and the next time I saw him it was, "Hello
17 Alice" and that's the only time he's ever called me my
18 name.

19 The man -- as I say, whether he's afraid of
20 females, because there is some people that don't like
21 talking to females about certain things, or whether he
22 doesn't like them or whether it's just his attitude
23 because his attitude to me is nae good. If it's the
24 same with other people, I feel sorry for them.
25 Just -- I don't know. He's not a people person, I'll

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1 have -- and I would have been quite happy with that,
2 but we didn't get the choice.

3 It could have been avoided.

4 Q. In 2003, you and Robert met with Dr Ludlam and you
5 asked him about the AIDS study. What was his response
6 as you recall it?

7 A. He stood up. That's what he done, he stood up, went
8 behind his chair, he pushed his chair in, thought for
9 a minute and says to us, "That's all in the past" and
10 walked away.

11 Q. Was it all in the past for you?

12 A. No. That's what I -- when we were going home that's
13 what I says to Robert, "But it's not in the past.
14 We're living with it. We are living with it. We
15 don't have any choice". But the man got up, pushed it
16 slowly. He didn't even do it fast, slowly push it in,
17 "it's all in the ..." -- and just disappeared.

18 I mean, I don't swear. I'm telling you the
19 amount of times in my past that I've really, really
20 would like to stand up and screaming the words that
21 that man deserves because he doesnae deserve civil
22 conversation with anybody because he doesnae have it.
23 He doesn't -- Dr Ludlam whether he is afraid or
24 whether he doesn't like females, I don't know. I was
25 going to this hospital from April/May 1982. I can put

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1 put it that way.

2 Q. You mentioned the GMC and, again, just so there's no
3 mystery about it -- I am not going to ask you any
4 details, it's referred to in your witness statement --
5 but you made a complaint to the GMC about Dr Ludlam.
6 You and Robert also made a complaint to the police.

7 A. Yes.

8 Q. Again, you have given some details about that in your
9 witness statement.

10 A. When we made the second complaint to the GMC, that's
11 when Robert ended up without a doctor, a treating
12 doctor, for quite a while.

13 Q. We've made a number of references to your obtaining
14 Robert's medical records. Do you believe that you
15 have seen all of Robert's medical records?

16 A. No. I know we've not because -- well, I know for a
17 fact his 1980s records aren't full because when he was
18 telling Robert, he was sitting writing in his medical
19 records when he was informing Robert of his infection.
20 I know that for definite.

21 But I also know that according to that letter
22 that he kept separate two blood test results and
23 I also know that he kept a separate file on Robert.
24 What's in it, I don't know because I can't discuss the
25 police thing, right; so what's in it I don't know.

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1 And ...

2 Where was I?

3 Q. I was asking you about what you think might be missing

4 from Robert's medical records.

5 A. Yes. I don't understand how someone can do research,

6 and I'm talking about research for 20-odd years, and

7 not have records. His blood test results, all the

8 things that they mention in these research papers.

9 Where's all this information? Where's it coming from?

10 So it must be out of Robert's medical records and

11 somewhere else for him to be able to research, if you

12 understand what I'm saying. You can't research on

13 something that there's no information on, if that's

14 clear enough, is it? You understand what I'm saying?

15 Q. Yes. In terms of the meeting you had in 1987 with

16 Dr Ludlam where you were given the information about

17 Robert's diagnosis, do you have or have you seen any

18 records of what it was Dr Ludlam was writing? You

19 described him writing during that consultation.

20 A. It's not in Robert's records, no. We've never seen

21 it. We've had maybe three sets of medical records and

22 it's not in any of them.

23 Q. Now, I referred at the beginning of asking you

24 questions to the research you've undertaken and I'm

25 not going to ask you about the detail of that for

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1 out on him for having AIDS if he didn't know he had

2 it.

3 Q. Robert has in his statement sought to emphasise that

4 not only was he not asked for his consent to

5 participate in any study, he was not asked for his

6 consent to be tested.

7 A. No.

8 Q. Other than the routine haemophilia tests which he

9 understood would be undertaken, he was not informed of

10 the outcome of any tests except to the extent that you

11 and he have described in your statements. He did not

12 consent to stored samples being given to any other

13 person in relation to research.

14 A. Stored samples -- can I ask here what exactly happens

15 to these stored samples? They seem to take blood

16 continuously and we're talking -- I've got in Robert's

17 medical records 20/30 mls for storage. What have they

18 done with all this blood? Where has it gone?

19 As far as I -- I know one thing, not

20 specifically Robert's, but I do know that students are

21 doing their thesis on the Edinburgh haemophilia cohort

22 and stored blood samples from this group of people are

23 being used and students doing their thesis. Is this

24 what the stored serum's for? Or is it for medical

25 purposes like it's supposed to be?

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1 reasons I know you understand we will be looking at at

2 a later stage of the Inquiry, but you've identified

3 a number of pieces of correspondence and publications

4 about the Edinburgh cohort and the studies undertaken

5 on what's described as the "Edinburgh cohort".

6 A. Yes.

7 Q. You've worked out Robert's part, you believe, as

8 a member of the Edinburgh cohort.

9 A. Yes.

10 Q. Amongst other matters, you've identified applications

11 for an ethics approval in relation to a study --

12 A. Yes.

13 Q. -- which talks about obtaining informed consent from

14 patients for their participation in that study, and

15 talks about patients being given information about the

16 study.

17 A. Yes.

18 Q. As far as you understand from yours and Robert's many

19 dealings over the years with the hospital and with the

20 doctors, was Robert ever asked for his consent to

21 participate in any AIDS study?

22 A. No, and what we can't understand is the ethics one

23 that we've seen, right, how can Robert have agreed to

24 this if he didn't know he was infected? I don't

25 understand how he can agree to research being carried

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1 Q. One of the things that has most upset Robert is what

2 you and he have described as the culture of secrecy.

3 A. Yes.

4 Q. That's something that's had the most profound effect

5 upon him.

6 A. Yes. Have you tried living in secret? Have you tried

7 living without being able to tell someone why you're

8 ill? Have you tried living constantly lying to

9 someone? Have you tried -- I'm not talking about

10 strangers, I'm talking about family, constantly lying

11 to them. You can't do it. The secrets that you have,

12 you talk and somebody walks in the room and we have to

13 stop and they give you -- I'm talking about family

14 members. They give you these looks as if to say

15 you're talking about them and it sort of stirs up

16 troubles. It's not. We're talking about what was

17 wrong with Robert. You cannae live with secrecy, you

18 really can't, and the Government, and I blame the

19 Government as well, and Ludlam especially, by telling

20 us not to tell anyone. This just emphasised or put

21 the stigma for haemophiliacs that we were dirty.

22 That's what is coming out, is because AIDS -- people

23 were going on about drug addicts and that but, I'm

24 telling you, haemophiliacs got put into their class

25 and people used to treat you -- they still do if it's

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AIDS that you've got -- as dirty, they really do.
I go to the Western with Robert and I have never, ever been in anything like that before. We turned up when we first started going and we were sitting in the -- I mean, when we go to the Western we get ourselves really uptight. It's just automatic. But when we first started going, we didn't like to go but we had to go, and everybody was there, as somebody's already mentioned about prison officers and all this.

Rather than sit beside this crowd, I went outside one day, Robert went to the toilet. He says, "I'll see you outside" and I went outside and this man come up to me and put a knife to my throat, right. Now, I was lucky that Robert wasnae far behind me but the man was lucky that he didnae see what Robert was doing. Of course, when I went in and I says to [redacted] and [redacted] put it down to that I didn't like his clientele. Youse have all to be treated the same, everybody's got an illness, blah, blah. Fair enough. I know everybody deserves treatment but I don't deserve what I got, and then you sit in the waiting room and we were sitting not just the males, the females, the things that they come out with. The language, the -- oh, just everything they said and

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has given up so much and made the ultimate sacrifices in her life. She has given up her right to have children and her career. She has perhaps not suffered physically but has definitely suffered mentally, not only by having to watch her haemophiliac family and friends die a most horrific death but now she has to watch me suffer the same fate. Even after my wife has made all these sacrifices, she is still with me after all these years. This most of all to me is the ultimate sacrifice."

And that's one thing Robert wanted expressly to have recognised in these written statement about you.

Alice, I don't have any further questions for you. What, if anything, would you like to add?

A. I've just got a wee bit to say.

We were told, and continued to be told, that Scottish Factor VIII was safer than English and commercial products. Whether it was safer than other products is, however, not the point. The question is whether it was safe, and it was not.

Robert, his family and friends, which are 16 in total, were infected with HIV by the same batch of Factor VIII concentrate which was given to them in early 1984. Only three of them are still alive. Blood was collected to make it by the Scottish

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what they done and what they were doing, it was -- it is scary. Not "was", it is.

And yet we can go in -- we would go in and there'd be people sitting and I have to say here it was the homosexual side, right, community and they would sit down and talk and that is where we learned -- believe it or not, that's where we learned a lot of things in how the treatments reacted and all this and they were really, really, friendly.

But what happened was because I complained, they eventually put up a security camera in the waiting room and our day got changed to another day in the week. It doesnae make it any easier. We still turn up but there isn't really any other patients there now but it doesn't make it any easier to go there and it's the word, as the person before said, Infectious Diseases Unit. Everybody looks at you going in and I think, "What can we do? It's not our fault but what can we do?"

Q. Alice, before I ask you if you've got anything you want to add, I just want to read one bit from Robert's statement because he says this in his statement:

"I want the following to be recognised as it's very important to me. The worst and saddest thing that this disaster has brought to me is that my wife

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National Blood Transfusion Service. It was manufactured by the Protein Fractionation Centre in Edinburgh and it was injected into them in Edinburgh, and it was not safe like they told us.

We were led to believe that Scottish blood donors did not carry harmful viruses. However, the only difference between Scotland and commercial manufacturers was that here in Scotland we did not pay for the blood which was collected. In Scotland, blood was collected from high risk donors, prisoners, borstals and from American forces personnel. By 1983, we lived in what was a global village. By that time, Edinburgh was populated by a well-established community of IV drug users and became one of the AIDS capitals in the world. The products made from blood which these people donated were not safe and, in addition to that, the products made here in Scotland were known to be 100 per cent infective for another deadly disease, which was hepatitis, and that was before the AIDS came along.

In conducting your investigation, please remember that this Inquiry is not just about products imported from abroad. It's also about products made here in Scotland. It is about whether they were safe. They were not. Their own risks were kept secret.

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Further, you must identify those who are responsible for giving Robert, his family and haemophiliac friends these products. I've no doubt who was responsible. Robert, his family and his haemophiliac friends put their faith in their doctor, Dr Ludlam. He told them the products were safe. He told them that while conducting non-consensual AIDS research on them. Those patients are now recognised throughout the world as the Edinburgh Haemophilia Cohort. Dr Ludlam carried out research on this group before their infection, at time of their infection, and after their infection. His research was kept secret from them and he made sure they only received Scottish products. The question here is: why?

They trusted Dr Ludlam to put them first. Instead, Dr Ludlam sat back and continued to give them what he knew to be harmful products. Personally I think he put his research before his patients welfare in any way, and even when Dr Ludlam knew of his patients being infected it took him over two years to inform us of Robert's infection.

His infection was what was known to be a sexually transmitted and fatal disease was kept secret. Having not only put Robert at risk for many years he put me at risk and he put our son at risk.

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actually warned by several of his doctors to keep an eye out, to watch Dr Ludlam because he was employed as a scientist and not as a treating doctor, and Robert wishes now that he'd listened to what they were saying and how they were saying it.

They were, in a sense, warning him to be careful of what this doctor was doing and he never really paid the attention that he should have, because had he paid the attention he would have kept more eye on him and he would have -- he couldn't ask any more questions but he would maybe have been more alert to certain things that were happening.

Q. The second point was in relation to cryoprecipitate treatment. You described how Robert would have preferred to remain on cryo when he needed treatment but was told by Dr Ludlam that it would no longer be produced.

Did you as a result of the investigations and research you have undertaken uncover anything about the possibility of continued production of cryoprecipitate?

A. Well, at that time they were still making cryo. Robert could have still had cryo but, according to Ludlam, they were stop making it. He couldn't have cryo. Robert actually asked for cryo. He told them

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I find this absolutely unacceptable, unethical and indeed criminal.

This Inquiry is about secrets and lies. It's about secret risks. It's about the secret research. It's about secret infections. It's about making sure that these things are never kept secret again. I wish to thank you, Sir Brian, your Inquiry team, Jamie and Lynn, for giving me the opportunity to speak here today and I, and I know many others, hope that by the end of this Inquiry the secrets will be exposed along with those responsible for keeping them.

Thank you.

Q. Alice, I am just going to ask Mr O'Neill and Mr Dawson if there's anything further they would like me to ask.

(Pause)

Alice, there's just a small number of matters that I'm asked to raise with you.

The first is in relation to your understanding of Dr Ludlam's background and primary interests when he was engaged to take over as a director of the Haemophilia Centre in Edinburgh.

A. Well, Robert was friendly with doctors going up the hospitals and that, doctors and patients were quite close, and when Dr Davis was leaving and the job was advertised and Dr Ludlam got the position, Robert was

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he preferred cryo. I don't know if it was Dr Davis kept him on cryo and it was something he was used to, and Robert also thought cryo worked better on him than what Factor VIII did. And he was insistent quite a few times that he would have preferred cryo, but he didn't have a choice. He was told literally, "This is what you're getting, take it".

Q. You have referred to the genetic testing that was suggested that you should participate in. Without, please, mentioning either any names or precise relatives, is it right that other members of Robert's family were also asked to give blood and participate in that at the time?

A. Yes.

Q. Then in terms of the specific family impact, you have referred to some of Robert's wider family. Again, without mentioning either any names or anything particularly specific in relation to anyone who might still be alive, please, but two of Robert's uncles died?

A. Yes.

Q. You described in your I think it may be in one of your statements one uncle being in the unit next to his brother and lying there with his brother dead beside him.

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1 A. Yes.
 2 Q. Then there was also a cousin who died.
 3 A. Yes.
 4 Q. Again, as a result of infection through infected blood
 5 products.
 6 A. Yes, and they all received the same batch.
 7 Q. Then finally, as well as the blood tests and the blood
 8 samples that were being taken that you've described,
 9 is it right also that there were skin tests that were
 10 being undertaken by one of the doctors, Dr Tucker?
 11 A. Yes.
 12 Q. What can you recall about that?
 13 A. Dr Tucker says to Robert -- this was '83/'84, you know
 14 that time period, and Dr Tucker was doing it with
 15 quite a few patients but he says to Robert for a skin
 16 test for sort of just virus infections -- not viruses,
 17 but infections. You know your BCG thing, you know how
 18 they stamp you with these wee needles on your arm
 19 first and see if anything comes up, and it was to see
 20 if Robert had any allergic reactions to whatever
 21 I don't know but it was whatever was in the
 22 Factor VIII according to them. Robert done it, fair
 23 enough.
 24 But what we did discover was that this was
 25 actually part of Ludlam's AIDS study. Now, again,

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1 MS RICHARDS: Thank you for that clarification. Thank
 2 you.
 3 SIR BRIAN LANGSTAFF: Alice, thank you very much indeed
 4 for your evidence. Thank you.
 5 We will take a break for lunch until just after
 6 2.30. 2.35.
 7 (1.28 pm)
 8 (Luncheon Adjournment)
 9 (2.38 pm)
 10 SIR BRIAN LANGSTAFF: Our next witness is anonymous.
 11 Those of you who were here the first day we sat this
 12 week will know what that means and will know that I'm
 13 about to read out an order which is made restricting
 14 the extent to which you can identify her after she has
 15 given evidence or, for that matter, during her giving
 16 evidence.
 17 It reads like this: it is ordered that the name
 18 and address of witness W2315 (that's Ms S to you and
 19 me) and any other identifying information such as the
 20 witness's image or a description of their appearance
 21 cannot be disclosed or published in any form unless
 22 express permission is given by me or by the solicitor
 23 to the Inquiry acting on my behalf.
 24 Witness W2315 must be referred to only as Ms S.
 25 This order remains in force for the duration of the

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1 I go back to Robert asked Dr Tucker about AIDS, not
 2 AIDS but this disease, and he denied anything of it.
 3 Then he's giving him this and this is part of the AIDS
 4 study. Why couldn't he just say? What was wrong with
 5 opening up his mouth and saying, "Oh, Dr Ludlam's
 6 doing some research on this new virus. It's called
 7 such and such. Is it okay if we try it out?" But
 8 they didnae. Again, they actually lied to his face.
 9 It wasn't even in secret. They lied to his face that
 10 they were doing these things, but not telling them the
 11 truth why.
 12 Q. Your understanding that the skin tests were as a
 13 matter of fact part of the AIDS study is based upon
 14 the material that you've subsequently obtained through
 15 your various research?
 16 A. Because an ethics request that was put forward
 17 actually mentions the continuation of a previous,
 18 which was the skin test.
 19 Q. That's the ethics approval application that you've
 20 referred to in your statement in 1985?
 21 A. No, that will be a -- there's two ethics requests: one
 22 for the AIDS side of it and one for the skin test, but
 23 Dr Ludlam says on his request form that he's already
 24 had acceptance for the first part and this is the
 25 second part.

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1 Inquiry and at all times thereafter unless otherwise
 2 ordered and I may vary or revoke the order by making
 3 a further order during the course of the Inquiry. It
 4 goes without saying, of course, that you will take
 5 care in taking photographs around the place so that
 6 you don't inadvertently capture her.
 7 Could we have Ms S please.
 8 MS S, affirmed
 9 Questioned by MS FRASER BUTLIN
 10 Q. Ms S, you have von Willebrand's disease?
 11 A. Yes.
 12 Q. So did your mother and so do other family members?
 13 A. Yes.
 14 Q. You also worked as a technician in the Royal Edinburgh
 15 Infirmary haematology lab for a period of time?
 16 A. Yes.
 17 Q. First of all, can you tell us what your experience is
 18 of the difference in terms of the type of bleeding
 19 between haemophilia and von Willebrand's disease?
 20 A. A couple of things. With haemophilia, it's my
 21 understanding from working there that in haemophilia
 22 if somebody in the family has severe haemophilia then
 23 any that inherit it will again have severe
 24 haemophilia.
 25 In von Willebrand's disease one member can be

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1 more affected, they can have more severe
 2 von Willebrand's and another family member further
 3 down the chain, a child, might have it a bit milder.
 4 Also, in haemophilia they have more joint bleeds
 5 and in von Willebrand's it's mucus membranes tend to
 6 bleed: so nose bleeds, gum bleeds, bruises, heavy
 7 periods and, in my case and my mother's case, as we
 8 got into our 50s, gastrointestinal or GI bleeds.
 9 Q. We are going to start by discussing your mother?
 10 A. Mm-hm.
 11 Q. And over the course of her life, did she require much
 12 treatment for her von Willebrand's?
 13 A. Not too much given her length of age but she did go
 14 through a particular time in the early '80s one where
 15 she'd fallen downstairs in her house and had hurt her
 16 ankle and she had cryoprecipitate for that and then in
 17 '82 when she had banged her thigh and that proved
 18 particularly troublesome and she was in and out of
 19 hospital for quite a period of time and had a lot of
 20 cryoprecipitate, bed rest, would come out, have to go
 21 back in hospital because it had reoccurred and then in
 22 order to get her home in the February of I think it
 23 was '82, she was -- it was '82 or '83, I can't --
 24 Q. '83.
 25 A. '83, she was sent home with some Factor VIII so it

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1 A. Yes.
 2 Q. When your Mum was changing from cryoprecipitate to
 3 Factor VIII, are you aware of whether she was warned
 4 of any risks of doing so?
 5 A. I'm not aware and neither was I warned of any risks
 6 when I was asked, "If we give you this product to take
 7 home to give to your Mum, are you willing to do that?
 8 It will get her out of hospital. It will much easier
 9 for everybody", my Dad, everybody involved, and
 10 nothing was said to me about any risks, and I was the
 11 one infusing the product.
 12 Q. During that time-frame were you receiving any
 13 treatment?
 14 A. No.
 15 Q. You and your Mum attended a meeting at the Edinburgh
 16 Royal in about 1984. Can you tell us what that
 17 meeting was and what happened at it?
 18 A. I don't remember too much detail about it. I do
 19 remember it being in -- by that time I had left
 20 Edinburgh. I was working in Falkirk but I'd come back
 21 for this meeting and there was a big group of people
 22 from the bleeding community, as I'll call them, and it
 23 was in the ground floor of the old Royal Infirmary in
 24 a lecture theatre and it was about some people might
 25 have been infected but I don't have a huge

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1 would get her out of the hospital and needing to be
 2 just lying in a bed all day.
 3 Q. You're clear that that was Factor VIII rather than
 4 cryoprecipitate?
 5 A. Yes. The reason it was Factor VIII instead of
 6 cryoprecipitate is at that point I was still working
 7 in Edinburgh Royal Infirmary and part of my job was to
 8 go and take bloods off people, get their results ready
 9 before they saw the doctor, if they had leukaemia,
 10 anaemia, et cetera. Because I was used to taking
 11 blood, they said that if we could take -- couldn't
 12 take the cryoprecipitate home but if they put my Mum
 13 on to Factor VIII could send her home and I could --
 14 I wasn't staying at home but I could go, have my tea
 15 at home and then give her the Factor VIII that she
 16 needed on that day.
 17 This only happened two or three times from my
 18 memory because her veins had been used quite a lot and
 19 I wasn't used -- I am now because I take prophylaxis
 20 myself, but I could take blood out but to find
 21 her veins it was difficult, so then she had to go back
 22 and get it done at the hospital as an out-patient.
 23 Q. We can see in your Mum's records that by
 24 21 February 1983 it's recorded that she had had
 25 multiple Factor VIII infusions?

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1 recollection.
 2 But I do remember, I think my Dad was there as
 3 well, and I do remember going away not being overtly
 4 worried about anything we'd been told. So I think if
 5 I was told anything too much in detail I'd have
 6 been -- remember, in those days there weren't
 7 computers, there wasn't, you know, mobile phones and
 8 things but I don't remember leaving that meeting
 9 thinking, oh, this will really be affecting my Mum or
 10 me or ... so I don't have too much -- I do remember
 11 the meeting but the detail of it ...
 12 Q. And the infection that was being discussed was
 13 HTLV-III?
 14 A. Yes.
 15 Q. Shortly after that meeting your Mum was told she
 16 tested negative for HTLV-III.
 17 A. Mm-hm.
 18 Q. And then Dr Ludlam sent your mother's GP a letter. If
 19 we can have 2315005, please, Paul, and if we look at
 20 the second paragraph we can see reference there to
 21 a letter that had been sent about AIDS and
 22 haemophilia/VWD.
 23 This morning we looked at a copy of what we
 24 think is the letter that's being referred to there
 25 which was dealt with by the previous witness.

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1 A. Yes.
 2 Q. Then it says:
 3 "I really think the chances of her having
 4 received the virus are infinitesimally small,
 5 particularly as she is anti-HTLB3 V3 negative. I,
 6 therefore, do not think it appropriate for her husband
 7 to wear a contraceptive sheath. We are much more
 8 concerned about the possibility of virus in sperm on
 9 a haemophiliac male being transmitted to his sexual
 10 partner. I have reassured Mrs X on these accounts."
 11 Before you saw your Mum's medical records, were
 12 you aware of any letter like this?
 13 A. No.
 14 Q. In her records, your Mum's liver function tests were
 15 abnormal over a number of years and you have
 16 identified those records. You've also noted that from
 17 1987 her blood requests had risk of infection on them.
 18 Do you think your Mum was aware of that in 1987?
 19 A. No. She wouldn't have seen -- when you go you were
 20 just told your results. You don't get shown, "Here's
 21 your results".
 22 Q. Was she aware that her liver function tests were
 23 abnormal --
 24 A. I don't.
 25 Q. -- as far as you're aware?

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1 that she was hepatitis C positive?
 2 A. No, she wasn't told until the September.
 3 Q. It seems from here that other treating physicians were
 4 also unaware in August 1993?
 5 A. Yes.
 6 Q. Then if we have 009, we have a letter dated
 7 September 1993 from a clinical assistant to
 8 Professor Ludlam to your Mum's GP and it says at the
 9 bottom:
 10 "This patient, as with a number of others, has
 11 been found to be hepatitis C antibody positive and
 12 this must relate to her having received blood products
 13 in the past, when hepatitis C could not be identified.
 14 I have discussed this with [your Mum] and said that we
 15 are currently running a joint clinic with one of the
 16 GI and liver consultants ..."
 17 As far as you're aware, 15 September, around
 18 about that time, was that the first time your Mum was
 19 told about hepatitis C?
 20 A. Yes. Well, she's not told me but since looking
 21 through her notes and I've spent many an hour looking
 22 through her notes a couple of times and this is the
 23 first thing I could find about her.
 24 Can I just go back to her being tested and found
 25 hepatitis C positive in the September of '92, that the

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1 A. As far as I'm aware, no.
 2 Q. Is that the kind of thing your Mum might have said to
 3 you if there was a concern?
 4 A. I don't know because, you know, there's that bit of
 5 protection and not saying but she might have queried
 6 it, knowing that I was a scientist and worked in the
 7 lab, she might have asked what does this mean and she
 8 never had that conversation with me.
 9 Q. In September 1992 your Mum attended the hospital and
 10 said she was more tired than usual but put that down
 11 to her age.
 12 A. Mmm.
 13 Q. Her bloods were taken and if we can have 007, please,
 14 Paul, date reported is 1 October 1992 and we can see
 15 that she tested positive for hepatitis C.
 16 Then if we can have document 2315012, this is
 17 a letter from August 1993 from a consultant physician
 18 to your Mum's GP. They had been treating her for
 19 resolving pneumonia, and if we look at the second
 20 paragraph there, it's noted that her gamma GT and ALT
 21 were both raised.
 22 "I checked her liver function tests again today
 23 but wonder if there is any record from the haematology
 24 department of abnormality in her liver function."
 25 At that stage in August 1993 was your Mum aware

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1 letter in September she went and saw the doctor and
 2 said that she was feeling lethargic and unwell on the
 3 very day that the sample was sent for hepatitis C
 4 testing and it was put down that her increasing
 5 lethargy -- the letter from that doctor to her GP
 6 about increasing lethargy and tiredness she put down
 7 to her old age. She was 65, the same age just about
 8 as I am. I take great offence to that because on the
 9 same day as they have taken a sample or sent a sample
 10 to virology to be tested, and two days after this
 11 letter has gone to the GP to find she's positive,
 12 never mentioned to my mother or to the GP that, in
 13 fact, this lethargy and tiredness could be to do with
 14 having hepatitis C affecting her liver but let her
 15 think, and for a full year after, that it was her "old
 16 age", being that "old age" myself I take great offence
 17 at that.
 18 Q. In your Mum's records, and it seems to be connected to
 19 the September 1993 diagnosis, it's a little bit
 20 difficult to tell, but there's an information sheet
 21 enclosed. It's 2315014.
 22 We can see at the top that it sets out that:
 23 "The sheet is to give you more information
 24 regarding the hepatitis C virus. Your blood tests
 25 show that you have the hepatitis C virus. This may

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1 cause inflammation of your liver, known as hepatitis.
2 In some individuals the inflammation in the liver may
3 become chronic giving rise to more long-term damage to
4 the liver which can in some cases be severe."

5 There is then discussion of a possible treatment
6 of interferon.

7 If we go to the next page, we can see the
8 heading "Sexual transmission and pregnancy", and the
9 information sheet provides that:

10 "Studies have shown that there is a very low
11 risk of sexual transmission of hepatitis C. This can
12 be discussed with you at the clinic. We will be
13 offering testing to all sexual partners of patients
14 who have hepatitis C infection."

15 Then if we go down to the section headed:
16 "Alcohol. You will know that alcohol can damage your
17 liver. As you may have inflammation of your liver due
18 to the hepatitis C virus it may be prudent to limit
19 your alcohol intake to a moderate level", and they
20 recommend no more than 21 units of alcohol per week
21 for a man, 14 units per week for a woman and it says:

22 "The lower your alcohol intake the better."

23 Are you aware of whether your Mum received this
24 information sheet?

25 A. Yes, that was the --

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1 We will come back to your Mum's experience shortly.

2 **SIR BRIAN LANGSTAFF:** Do we know who drafted the
3 information sheet?

4 **MS FRASER BUTLIN:** Unfortunately, it's not very clear
5 where it's come from but it appears to have been
6 drafted within Edinburgh Royal because of the letters
7 it's with, but I'm afraid that's somewhat inferential
8 of who's drafted it.

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

10 **MS FRASER BUTLIN:** After her diagnosis with hepatitis C,
11 you and your Mum had a conversation about having
12 treatment in preparation for any procedures she was
13 undergoing. Can you tell us about that.

14 A. Yes. My Mum was always the doctor's right, you do
15 whatever the doctor tells you, he is God, basically,
16 whatever he tells you, you know, we'd never question,
17 and I remember her saying, you know, "Oh, I'm going to
18 the dentist, I'm going to hospital, I need something
19 to do with my teeth scaled and polished but I need to
20 go and I need to get", she actually said to me,
21 "Factor VIII before it", and I said, "Why, when you're
22 just getting, you know, scaled and polished? I go to
23 the normal dentist get scaled and polished no
24 problem". She said, "Because they told me I had to
25 have it". I said, "No, it's your choice. You could

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1 Q. It was in the records but at the time were you aware
2 of her receiving anything?

3 A. No, she wouldn't, again she ...

4 Q. But does this chime with the advice that you think
5 your Mum and your Dad were given about the
6 hepatitis C, of what was discussed at home?

7 A. Yes, because one thing I do remember, my Mum was never
8 a bigger drinker, but then interestingly in her older
9 age she went totally teetotal.

10 Q. So this marries up with your experience of what your
11 Mum seemed to be doing in response to her diagnosis?

12 A. Yes.

13 Q. Just before we leave this document, if we can look at
14 the second page again, something we'll come back to,
15 the second paragraph discussing the interferon
16 treatment. It says in relation to side effects:

17 "At the beginning of a course of treatment

18 injections maybe followed by a fever for a few hours.

19 This is less troublesome if the injections are given
20 in the evening along with two paracetamol tablets.

21 With interferon persistent side effects are uncommon.

22 Occasionally, there may be tiredness, depression and
23 a fall in the blood count. These side effects are
24 reversible if the dose of the drug is reduced."

25 That's what was in the information sheet then.

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1 have it on stand-by and then if you bled you can have
2 it but you don't have to have it before it, if you
3 don't want to", and she went, "But they told me", and
4 I went, "It's your choice. It's your body. It's
5 your ..." she went, "Can I?" I remember her phoning
6 me after that going, "I didn't take it, I didn't take
7 it, I didn't need it", and being so excited that she
8 had been the one to decide, you know.

9 Q. After your Mum was diagnosed with hepatitis C what was
10 her health like?

11 A. Well, she was -- my Mum and Dad had planned to travel
12 quite a bit, to go on different holidays, to bowl and
13 she was just no energy, lethargic and, I'll be honest,
14 my Mum could be a bit nippy and, you know, my husband
15 would pick up, you know, "Your Mum's not right", and
16 I go, "What?" He said, "Because I can tell by her
17 behaviour", and I was putting it down to normal
18 behaviour but now, you know, it's when, sorry, I
19 preempted but it's when she was having interferon
20 treatment it was just like couldn't live with her and
21 I just put that down to normal. But my husband picked
22 up when she was feeling -- either going through that
23 treatment or feeling particularly bad, queasy, she
24 couldn't eat a lot of things, eggs in particular. She
25 just couldn't eat, no energy, just not -- not feeling

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1 well.

2 Q. You've said in your statement you thought that your

3 Mum was an old 65.

4 A. Yes. Well, I suppose given now people are, you know,

5 50 is the new 40 or whatever but, yes, she didn't have

6 that. You'd think that because she would retire at 60

7 and you think, well, the family have grown up, this is

8 the time to go out and enjoy yourself and, you know,

9 go and do different things and they just, my Dad and

10 her just couldn't do anything.

11 My Dad will say there was one particular, went

12 to Spain to enjoy a holiday, got one day out of it and

13 then could only go out for a meal at night and it

14 ruined and they've never been on holiday again since

15 because what was the point, just you know wanting the

16 comforts of home, didn't want -- couldn't go anywhere.

17 Q. You have said that your Mum tried some interferon

18 treatment. That was in about 1995. What happened

19 with that?

20 A. Just felt absolutely awful, was flu-y, shaking,

21 shivery, just sick, just everything to the point that

22 she just said, "I've tried it", and totally point

23 blank refused from that point on to put herself

24 through that.

25 Q. Could we have document 2315013, please, Paul.

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1 business and even though my Mum's been dead for

2 a number of years she did get the Skipton payments and

3 just this year, earlier this year, a relative said to

4 my Dad, you know, oh -- I nearly said my mother's name

5 there, that my mother, you know, "Oh, they would have

6 got some money. Aren't you lucky getting some money".

7 My Dad was like, "Money, it's worth that (*indicated*).

8 You can do nothing with it. Might as well be a piece

9 of paper and what are you talking about? I don't know

10 what you're talking about. Infect, what infection?"

11 So even all this time later and then went, "There's

12 the door. Go through it".

13 So there was -- he got that feeling that people

14 weren't interested in her health and how it affected

15 her but weren't you lucky you got some money. So no,

16 they wouldn't -- they would keep -- they even didn't

17 say -- I didn't know until they got a stage 2 payment

18 that they'd even got the first stage payment.

19 Q. Your Dad's reaction was a little bit different,

20 though, wasn't it? He was much angrier?

21 A. Oh, yes.

22 Q. Can you tell us about that.

23 A. Well, for him, you know, they've brought up a family,

24 they've been together, this is, you know, "We've got

25 our plans. We can go holidays. We enjoy bowling. We

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1 It's a letter from August 1995 which notes that

2 she'd had quite a bad reaction, particularly with

3 headaches, to her recent trial of interferon therapy

4 for HCV:

5 "I would be quite keen for her to try the

6 interferon therapy again because she has type 3A which

7 is particularly responsive to interferon. She was,

8 however adamant today that she did not want it at

9 present."

10 If we look at the last paragraph she had been

11 warned of the long-term risks of liver disease,

12 particularly cirrhosis and hepatocellular carcinoma

13 but she wasn't prepared to try interferon again.

14 A. It shows how bad it was that she would rather go

15 forward and maybe -- and she did get cirrhosis, get

16 carcinoma, than put yourself through that treatment.

17 Q. Ultimately, your Mum's liver did become cirrhotic but

18 she continued to decline any treatments?

19 A. Yes.

20 Q. Did your Mum talk much about the hepatitis C?

21 A. No.

22 Q. Why do you think that was? Why not?

23 A. A couple of things. One is she wanted to protect her

24 family but also my Mum and Dad are very private people

25 and they didn't want, you know, people to know their

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1 like dancing. This is our time", and that time was

2 taken, taken away from them.

3 Q. Since you have got through your mother's records you

4 discovered that in 1996 your mother wrote to the

5 Health Minister at the time, Mr Horam.

6 Can we have 2315011, please.

7 This is the reply she received on his behalf.

8 It was written by one of his -- who seemed to be one

9 of his staff members, and it says this in the second

10 paragraph:

11 "As ministers have consistently stated, for

12 example, in the adjournment debates in the House of

13 Commons in July and December 1995, the Government has

14 great sympathy with those patients who may have become

15 infected with hepatitis C through blood transfusions

16 or blood products. Factor VIII brought many

17 advantages to people with haemophilia. It greatly

18 increased life expectancy as well as improving the

19 quality of life."

20 If I can pause there, you were upset by that

21 reference in the letter to haemophilia, weren't you?

22 A. Well, my Mum's got von Willebrand's disease. It

23 appears to me to mention haemophilia not

24 von Willebrand's. My Mum had von Willebrand's.

25 Q. Your concern is this: a generic letter that's gone out

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1 rather than anything responding to your Mum.
 2 A. Yeah, it was like, "Somebody writes in. Throw that
 3 one out at them".
 4 Q. It goes on:
 5 "However, medical procedures rarely come without
 6 risk and these are not always fully known or capable
 7 of being guarded against at the time. Most
 8 haemophilia patients were infected with hepatitis C
 9 before blood products were treated to destroy viruses.
 10 Those patients received the best treatment available
 11 in the light of medical knowledge at the time."
 12 It goes on to say that the Government does not
 13 accept that there's been negligence and they have no
 14 plans at present to make payments to such patients.
 15 If we go over the page it is explains why payments
 16 were being made to those with the HIV virus and it
 17 says this:
 18 "In the case of patients inadvertently infected
 19 with the HIV virus the decision to make payments to
 20 those affected, and to establish a hardship fund, was
 21 taken in light of their very special circumstances.
 22 Those affected were all expected to die very quickly
 23 and were subject to significant social problems,
 24 particularly ostracism. Hepatitis C is different from
 25 HIV. Many people infected with hepatitis C may live

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1 my father for his financial affairs, it was actually
 2 too late. I would have had to have gone to
 3 guardianship for my mother because at that time she's
 4 deemed to have dementia. So I was filling in the
 5 forms that Edinburgh Council needed on my mother's
 6 behalf but really for my father. So it was about all
 7 the income you got, your pensions, and also -- and
 8 I was aware -- and you had to give six months' bank
 9 statements to the Council.
 10 But I was aware a big amount of -- they only had
 11 a pension, a small pension, so I was aware a big
 12 amount of the money that they had was Skipton money.
 13 It wasn't anything that they had got from anywhere
 14 else. So I was saying to them, "Well, my Mum's got
 15 this money", and I also had someone that knew somebody
 16 that worked at the Care Inspectorate and they had
 17 spoken to a lawyer and they said -- and I said, "So
 18 it's not to be counted", and he said, "Oh, I've spoken
 19 to the lawyer, and what I was being told by the
 20 Council is you've got this extra money, you can
 21 voluntarily give extra to pay for your Mum's care",
 22 and I said, "No, but that was because my Mum had
 23 hepatitis C", so I was being told it had to be counted
 24 in and somebody from the Care Inspectorate, I had
 25 spoken to the Care Inspectorate lawyer who had said,

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1 for a long period without any symptoms occurring and
 2 only a very small proportion are expected to die from
 3 the disease."
 4 It then indicates that the Government is always
 5 ready to listen to further evidence. Were you aware
 6 of what your Mum thought of this letter? Was anything
 7 around the Government's position discussed at home?
 8 A. No.
 9 Q. You just found this in her records?
 10 A. Yes.
 11 Q. In about 2002 you think your Mum applied for money
 12 from the Skipton fund and, again, in her records
 13 there's a letter from Professor Ludlam to her GP
 14 saying your Mum had been to see him and she had been
 15 told by the Scottish Office that compensation would
 16 only be given if infection occurred after March 1988.
 17 Were you aware of that at the time?
 18 A. No.
 19 Q. She did ultimately receive Skipton payments, as you
 20 have said. When your Mum had to go into a care home,
 21 what difficulties did those payments cause you?
 22 A. Quite a bit. Because my Mum and Dad, they've shared
 23 everything so they've got a joint bank account, so the
 24 money all went into their joint bank account and
 25 because at that point I had got power of attorney for

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1 "No, no, no, this money does have to get counted in.
 2 It's like Disability Living Allowance. It's meant to
 3 improve your Mum's care and if that money can be used
 4 to get your -- you know, used towards her care in the
 5 care home then it should be counted", and I said --
 6 I looked her in the eye and I went, "You're wrong".
 7 Then I had to get in touch with Skipton who got
 8 a letter from the Caxton Fund saying it was to be
 9 discounted, but I had to go through all the hoops at
 10 a very difficult and emotional time to prove to them
 11 they didn't know that this was true. I had to get the
 12 evidence to prove, "No, you cannot use it when trying
 13 to" -- because they've got to work out how much
 14 because, for example, my parents' married couple's
 15 pension had to be separated into single people's
 16 pension and my Mum's attendance allowance, et cetera,
 17 but then I had to go through that loop to say you
 18 cannot take this amount into account because it's to
 19 be discounted.
 20 But I was the one that had to prove it. They
 21 didn't -- they were telling me the contrary.
 22 Q. For you that was an added stress when your Mum was
 23 really very unwell?
 24 A. Yes.
 25 Q. And she died --

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1 A. It was more even, you know, maybe not even so much for
 2 my Mum, she had dementia and didn't know so much, but
 3 can you imagine the loss for my Dad of over 60 years
 4 together of having to give up that care of somebody
 5 you love to strangers. No, it was horrible trying to
 6 deal with it and deal with our emotions, his emotions,
 7 and all the loss then.
 8 Q. Your Mum died about three months later --
 9 A. Yes.
 10 Q. -- in 2012 when she was 85.
 11 A. She was just -- she would have been 85 quite soon
 12 after.
 13 Q. On her death certificate it records that she died of
 14 pneumonia as the main cause and it lists
 15 cerebrovascular accident, dementia and
 16 von Willebrand's disease.
 17 You're unhappy about that. Why is that?
 18 A. Well, you know, there's no mention at all of
 19 hepatitis C and I can only surmise but one of the
 20 things I think why that happened is when my mother was
 21 moved to the care home. It was in a different part of
 22 Edinburgh and so the GP that comes to the care home is
 23 the GP that my mother had. So that GP only knew my
 24 mother for three months before her death, maybe he saw
 25 her, I don't know, two, three, four times, whereas the

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1 available, and it wasn't until I was up one morning,
 2 quite early, leafing through my iPad as I do,
 3 I thought, "Oh", well it was a bit ambiguous as well
 4 because it said if it's a widower still staying with
 5 the person I thought, "Ah, my Mum was in a care home
 6 so they're not actually staying", but I thought
 7 I might as well find out because my Dad did used to go
 8 and visit every day and he has been awarded that money
 9 and, on a personal note, gets an amount every month.
 10 And on the 15th of the month, although he doesn't walk
 11 very well, will -- I'm going to get upset now -- will
 12 go to Tesco's with his cash Link card on 15th of the
 13 month, put it into the machine, so that he can see
 14 he's got "Mammy's money", that he can do diddly-squit
 15 with but it's "Mammy's money" and it's still
 16 a connection to her.
 17 Q. But he worries every month whether the money will be
 18 there?
 19 A. Yes, "What if it's stopped. What if they don't give
 20 me it", you know, and it's like, "But you don't need
 21 it".
 22 "But it's Mammy's money."
 23 Q. And he's worried that one day it will be taken from
 24 him?
 25 A. Yes.

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1 GP that we'd had since 1954 and who knew the family
 2 history, who knew how much better and I think would
 3 have attributed hepatitis C -- I think it was just put
 4 down -- well, the first two are pneumonia and CVA, so
 5 it was just put down to, "Oh, she's got to 84, old
 6 age".
 7 Q. You feel quite strongly that the hepatitis C and the
 8 cirrhosis should have been recognised on her death
 9 certificate?
 10 A. Yes.
 11 Q. That in itself caused problems for your Dad in terms
 12 of financial assistance?
 13 A. Yes.
 14 Q. What happened?
 15 A. Well, in Scotland there is -- my Mum was getting
 16 money. That stopped, but then there's a Scottish
 17 system where a widower can get 75 per cent of the
 18 money and I asked a couple of people and they said,
 19 "Oh well, if hepatitis C's not on the death
 20 certificate ..." and I suppose in people's defence
 21 I could have looked it up but also in their defence
 22 how many people have actually reached into their 80s,
 23 but I was told if hepatitis C isn't on the death
 24 certificate then the chance of your Dad continuing to
 25 get any money is nil, and so when money became

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1 Q. I want to move on to talk about your own situation.
 2 First of all, your work in the haematology lab at the
 3 Infirmary until 1983. Professor Ludlam was your boss?
 4 A. Yes.
 5 Q. Can you tell us about your experience of testing
 6 bloods and in particular the handling and labelling of
 7 high risk blood.
 8 A. Well, when a blood came in you've got a whole load of
 9 bloods together and you would put a sticker on the
 10 form that would ultimately go back to the patient's
 11 notes and a sticker, it's good that I've got this with
 12 me, a sticker on the sample that would then go through
 13 machines, and these samples would come in, you'd have
 14 the form, it still happens today, form and the sample
 15 of blood and it would be in a plastic bag.
 16 But those that were labelled as high risk would
 17 be kept to the end. So there would be a sticker on it
 18 saying "Risk of infection", you would keep them to the
 19 end, you would put all the other samples through the
 20 machines and then at the end the ones that were
 21 high-risk would be labelled and some tests would be
 22 done in a fume cabinet but other ones would be put
 23 through the machine. At the end of the day you would
 24 have to get dressed up in a neck to floor apron,
 25 gloves on, a visor over your face, and once the

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1 samples were put through, results out, the machine
2 would be cleaned at the end of it.

3 Q. What did you understand the risk to be at that stage
4 before 1983?

5 A. Well, before -- you discuss -- well, I suppose 1983 it
6 would have been query HIV or maybe even hepatitis B
7 was a big problem in the labs.

8 Q. At the very least you were conscious that it was
9 high-risk blood and there was something you had to be
10 careful of?

11 A. Yes.

12 Q. In the lab were you aware of blood samples being taken
13 and stored?

14 A. Yes, because some had "Serum for storage", you know,
15 maybe put on the side, so you would test the blood and
16 then keep a little sample and these could be frozen or
17 put elsewhere, some to be tested maybe straight away
18 and others, I don't know when they're tested, but
19 maybe stored for a later date.

20 Q. Were you aware of people in the lab undertaking
21 research?

22 A. Yes. I wasn't involved in it but there were a group
23 of maybe four people that were for research. That was
24 a new thing. You didn't have people doing research
25 and then there was a few people taken away to do

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1 safe, you can have it now", but I said, "No, I don't
2 want it", and then the same when I needed the
3 emergency caesarean, had wanted me to have Factor VIII
4 before the caesarean and I said, "No, I'll have it on
5 stand-by if I need it. I don't want to put myself at
6 any risk, unnecessary risk".

7 Q. You've not been infected with HIV or hepatitis C but
8 what are your feelings about that now?

9 A. My feelings are that I've kind of dodged a bullet
10 because -- can I speak a bit about when I was at the
11 Penrose?

12 Q. Absolutely, I was going to ask you that next.

13 A. Okay, I went to the Penrose Inquiry final report and,
14 as I said, in kind of October '90 and March '91
15 Factor VIII was -- and then a heard -- what I heard
16 was, you know, blood until 1991 wasn't tested for
17 hepatitis C and I think at that point I went into
18 shock because I thought October '90, March 1991, my
19 Mum's got hepatitis C, because the Penrose was in
20 2015, I could have had hepatitis C.

21 And then it wasn't actually until I spoke to
22 Jamie, you know, from Thompsons -- thank you, Jamie --
23 that he assured me that it was, the Factor VIII was
24 tested for hepatitis C before that. It was the blood
25 that wasn't, like red cell concentrate wasn't tested

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1 research.

2 Q. But you're not sure what that research was?

3 A. No.

4 Q. Because you weren't involved?

5 A. No, I wasn't involved.

6 Q. What's your understanding of the high risk blood meant
7 for you when you've needed to receive blood products?

8 A. Well, high risk is -- well, I can only give my example
9 of when I was pregnant in 1990 and then had an
10 emergency caesarean in '91. Dr Ludlam wasn't only my
11 boss he was my doctor, and when I was having the
12 amniocentesis, said, "Oh, I want you to have
13 Factor VIII before you have amniocentesis", and
14 I went, "No". I remember we had -- because I remember
15 at one point I said, "Oh, we had this argument about
16 it and he said, "No [redacted], we had a discussion".

17 Q. Can we just stop the live stream, please. (Pause)

18 You were just saying that Dr Ludlam wasn't only
19 your boss he was your doctor and you needed to have
20 the amniocentesis and you had an argument about
21 whether you should have Factor VIII.

22 A. Yes.

23 Q. What did he say to you about it?

24 A. And he told me -- and I said, "No, I'll have it on
25 stand-by but I don't want it", and he said, "It's

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1 until '91.

2 But then I thought later but if after the
3 amniocentesis or I had the caesarean, if I'd bled
4 I would have just been given a blood transfusion no
5 questions asked. It would have been you need this and
6 so I could have got the hepatitis C.

7 So, yes, I think I was just in a bit -- you've
8 told me it was safe and it wasn't.

9 Q. That had quite a significant impact on your mental
10 health.

11 A. Mm-hm.

12 Q. You have had some psychological support and
13 counselling but only very recently?

14 A. Yes. I mean, I'm known as -- I'm actually known as
15 the eternal optimist; so the fact that I went into
16 shock and that after I don't think ever in my life
17 I've felt so bad as after that Penrose report.

18 There was -- I did go -- there was a church
19 round the corner from the museum where the final
20 report was read out and there was people from
21 Haemophilia Scotland, it was great. But I just --
22 I spoke to a couple of people but then I thought
23 I need to get away. I remember going down to Prince's
24 Street and there was a really lively band and normally
25 I'd be dancing along the street, and I felt so low, so

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sick to my stomach.

And I kind of laugh about it now but as I was waiting for the bus, there was this man, he looked a bit dishevelled and down and out and I went up and I said to him, "Excuse me, I've had such a horrible day, I want it to end on a better note". I thought he was homeless. "Would you take £10 off me, just to make my day a bit better" and he went, "Okay, thanks", thinking he's homeless. He might have a guy just going home from his work or something. But it was what I did to make myself feel better.

And then I can't prove it but, interestingly, although I'd been quite steady, chronic and acute blood-wise in my gut, two weeks later I had an acute GI bleed and went through a horrendous time and had to have -- from then started to need prophylaxis for my GI bleeds.

Going back to something you've shown before where it was the letter from the Government, I remember reading that and being so incensed and a family member was in and known about that I'd had the bleed two weeks after the Penrose Report and not being able to link it 100 per cent, but when I was actually spitting blood at the wording on that letter, said, "Mum, please take care of yourself. You know

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that gave that because I took it home only maybe two or three times but it still could have been me. And then I have that huge empathy for people given what they thought was the best thing for their child to use, you know, and I've done it to my Mum. My Dad still misses my Mum all these years later. "By the way, Dad it could have been me injected it". No. So I can't tell him. If he asked me it, I'll say it's to give you and mum a voice but if he was sitting there now, I couldn't speak. I couldn't tell any of this because I couldn't say that to him.

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

A. Yes, a couple of things.

Going into -- I know maybe you don't want to dwell on Penrose but there was one thing I remember also from being in shock of I could have been infected and I remember -- what I was left with was from the Penrose final report was to think of the doctors, they were affected to. And I was like -- I've held that for all these years. So when I had this and I knew I'd sworn an oath and I thought, did I really hear that? So I actually went online and I looked at the Penrose Inquiry final report and I've got it word for word, the executive summary, and it was March 2015,

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what happened to the Penrose. Please, please, calm down. Think of yourself. Stop". It was difficult but ...

Q. You have also said in your witness statement that people have said to you that that's all in the past now and move on and you've said:

"I remember inside thinking for you maybe but not for me. I think that's what happens a lot with hepatitis C. There's some money, let's move on but it doesn't go away. I injected my mum a couple of times and it could have been me that gave her the infected a products too. Can you imagine doing that to your child."

That's something else that you've struggled with?

A. Yes, and I can't tell my Dad.

Q. Your Dad's too frail to cope with --

A. He's not frail at all. He's really --

Q. -- too elderly to manage it.

A. I just don't want to be the one to tell him that possibly I could have injected Mum. How can I say that to my Dad? He loved her to bits. How could I say it?

I didn't even realise myself until I actually read the notes, and I swore. It could have been me

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and it's under "communication of results", the last paragraph.

Is it okay if I read out where I've taken that from?

Q. Of course.

A. "Were a new disease like AIDS to emerge today, the patients would probably be made aware of the medical profession's ignorance of it [and this is the sentence] and share all the uncertainties and anxieties consequent on that."

So the doctors are holding the uncertainties and anxiety.

"There would still be suffering and probably anger against the disease but the sense of betrayal would be absent."

Sorry, but I still say it's crass in the extreme. So that, you know, the medical -- so I read the doctor's share, they were the ones with all the uncertainties and the anxieties and if they'd shared, we could have shared that too. What about all the uncertainties and anxieties and ill-health that you're putting down to your old age? That just infuriates me, sorry.

Q. I'm just going to turn and ask Mr O'Neill and Mr Dawson if there's anything they would like me to

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1 raise.
2 (Pause)
3 Mr Dawson has said that he thought you had
4 something you had wanted to read out, not just the
5 point about Penrose?
6 A. No, I've got a final thing.
7 Q. Now's a good time if you want to say something else
8 before I ask you Mr Dawson's.
9 A. I've written it down because I'll probably get upset
10 again.
11 I wanted to take this opportunity to tell my
12 parents' story to give them a voice. The Inquiry's
13 heard what happened to my Mum and I'd like to conclude
14 by using my Dad's words, something he says on
15 a regular basis but I also feel has further meaning.
16 Firstly, my Dad says this as he fondly
17 reminisces about the 60 plus years he spent with my
18 Mum. That saying is: thae days, they'll no come back.
19 Secondly, in recognition of both the quality and
20 quantity of time those infected and affected have been
21 denied, thae days, they'll no come back.
22 And, finally, to Sir Brian and his team guarding
23 the responsibility and, dare I say, hopes resting on
24 their shoulders to get answers, to sort out
25 inequalities in the financial and psychological

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1 things you think you've dealt with, they're over or
2 whatever, they don't. Actually, today thankfully I've
3 had the Red Cross to speak to as well because it's not
4 just going in this process, it's not just going
5 through the notes that are pertinent to this Inquiry,
6 but it's finding out other stuff in the notes nearer
7 my Mum's death that I wish I hadn't read but I had.
8 I'd like to say actually one more thing. For
9 those infected and affected who feel they can't give
10 a statement or can't come here and give evidence,
11 I salute you. Take care of yourself because for you
12 that's the right thing, because this isn't easy.
13 Q. Part of why you found that counselling so positive is
14 because it is specialist to people with bleeding
15 disorders?
16 A. Yes.
17 Q. And there's a real understanding, you've said, of that
18 situation?
19 A. Yes, because it's just for -- because it's so
20 specific, that the kind of counselling. I actually
21 have a counselling advanced diploma so in part of it
22 I had to have counselling about this, that and the
23 next thing. But to actually have focused counselling
24 about what it's like being in hospital, going in
25 hospital, everything involved in it, and fears around

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1 support people are afforded and to hold those
2 responsible for this disaster to account, thereby
3 ensuring thae days, they'll no come back.
4 Q. Mr O'Neill and Mr Dawson have two points they wanted
5 me to raise in addition.
6 Firstly, you spoke earlier about Dr Ludlam
7 telling you that the products were safe in 1990/1991
8 when he told you you needed it for the amniocentesis
9 and the emergency caesarean section. Did he explain
10 to you what he meant when he said they were safe?
11 A. No.
12 Q. How do you feel about that?
13 A. Incredulous. I worked in labs. I've got a scientific
14 background. But that's how it was. It was like, "You
15 take my word. I tell you something. You believe it.
16 You do it. Full stop". Even the fact we had the
17 argument, which was then called a "discussion", about,
18 "No, I'll have it on standby" that didn't please him
19 but I was adamant, no, I will have it on standby.
20 Q. Secondly, we mentioned that you had had some
21 counselling and that was actually bespoke counselling
22 for people with a bleeding disorder?
23 A. Yes.
24 Q. What has your experience of that been?
25 A. Oh, invaluable because I think it is important because

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1 that is invaluable and should be expanded.
2 **SIR BRIAN LANGSTAFF:** Can I make one comment. In my view,
3 you are no more guilty of infecting your mother than
4 was the syringe. It needs to be said publicly.
5 But I do appreciate and thank you for your
6 courage, despite your feeling that you were guilty, in
7 coming to tell us about your mother. It takes -- as
8 you said, it's not easy. You've done it. Thank you
9 very much.
10 A. Thank you.
11 **SIR BRIAN LANGSTAFF:** That is the end of the evidence for
12 today. Tomorrow we start at 10.00, and who are we
13 hearing from tomorrow?
14 **MS FRASER BUTLIN:** We will be hearing from Bill Wright,
15 Rosemary Wright and Richard Titheridge.
16 **SIR BRIAN LANGSTAFF:** Tomorrow 10.00.
17 (3.33 pm)
18 (Adjourned until 10.00 am the following day)

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