

Thursday, 31 October 2019

(10.00 am)

**SIR BRIAN LANGSTAFF:** Well, we begin today with the evidence of Jryna, do we?

**MS FRASER BUTLIN:** That's correct, sir.

**SIR BRIAN LANGSTAFF:** Jryna, please.

**JRYNA BATTERS (sworn)**

**Questioned by MS FRASER BUTLIN**

**MS FRASER BUTLIN:** Jryna, you're here to tell us about your own infection with hepatitis C and that of your late husband, Donald.

**A.** (Nodded)

**Q.** You and Donald were married in 1982.

**A.** (Nodded)

**Q.** And went up to the Isle of Skye for your honeymoon.

**A.** Yes. Well, we went to Mull first.

**Q.** But you fell in love with the Isle of Skye.

**A.** Yes, until -- we kept going backwards and forwards and then we got stuck.

**Q.** You had two sons.

**A.** Yes.

**Q.** And on one of your backwards and forwards, as you were up on the island in May 1985 camping, Donald had an accident at the camp site. Can you tell us what happened?

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**Q.** Then in early 1987, Donald had an operation to remove one of his toes and to connect it back to where the thumb had been. There was a complication during that operation. He was given blood plasma.

**A.** (Nodded)

**Q.** And that was the only transfusion that you were aware of that Donald required in either the original accident or in the reconstruction?

**A.** Yes, the -- it was 11 and a half hours because of -- they needed to have some vein connection for the thumb in his arm because he'd had a -- a radial artery flap, and because they couldn't find the vein through his foot, it took 11 and a half hours and he was in shock, and because of that they had to give him something.

He actually was coming around and he heard them say, "We have to give him something", and that's what happened.

**Q.** You've obtained, or your solicitors have obtained, Donald's medical records, and there's no record of him having received any transfusions at all.

**A.** Mm.

**Q.** But Donald's recollection was very clear that he had been told that he had received plasma during the surgery.

**A.** Yes.

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**A.** Well, we had camped behind a wall in a place called Greshornish, which is really gorgeous, and he had taken a -- he was doing a reconnoitre and he went down to the shore, and that year, 1985, was very wet, every day it rained, which didn't put us off, but he then thought he was -- he triangulated and thought, "Well, if I climb over the shoreline" -- you know, there was a shelf of land, he would be back on the camp, except the piece of land he chose to put his weight on came away and he pushed himself, and his glasses went one way and a piece of rock pulverised the base of his thumb.

**Q.** He was bleeding an awful lot at that point.

**A.** Actually, he got his glasses, he grabbed his elbow, stopped the bleed, and walked back the way he came, and then I drove him to Portree Hospital, who said, "We're not touching him", and then to Broadford, which was -- Portree was about 20 miles from where we were camping and then Broadford was about 30-odd pot-hole miles.

The doctors there just took the gravel out of his thumb, kept him overnight, and then he went to Raigmore to have an amputation.

**Q.** The thumb was amputated at that point.

**A.** Yes.

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**Q.** Was Donald given any information before that about any risks involved in receiving the plasma?

**A.** No.

**Q.** Then in 1989 you moved up to Inverness, and lived between Inverness and the Isle of Skye.

**A.** Yes.

**Q.** And once the house on Skye was built, the family effectively moved to the island permanently in 1990.

**A.** Mm-hm.

**Q.** Donald remained at home and home-schooled your children, and he did some odd jobs of computing and gardening and things like that.

**A.** Mm-hm.

**Q.** And you've described yourselves as a very close, tight-knit family.

**A.** Yes.

**Q.** Is there anything else you want to tell us about family life at that point?

**A.** Well, we -- you know, I would be away sometimes in Inverness with my work, and -- or on the island, and Donald would take the boys. We had double canoes and they were off down on the loch, and, you know, I would come back and walk down the shore, which is about 10-minutes' walk, and they'd be sort of like kippers on the front deck, and he'd be just sat there and they

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1 just rocked, and they had a beautiful, very gentle  
 2 life. They went, you know, wind surfing when they  
 3 were old enough and canoeing and lots of walking, and  
 4 it was a free, free, happy space.  
 5 He used to read stories -- we lived in a caravan  
 6 for about eight years before the house was completely  
 7 built, and, you know, we used to have Saturday night  
 8 beat-ups, which was like throwing them around until  
 9 they got tired, which wasn't -- it wasn't damaging!  
 10 Lots of giggles, and then they fell asleep. And, you  
 11 know, he did the voices on the books, the Lion, the  
 12 Witch and the Wardrobe was a big one, and his mum had  
 13 these fur coats and they used to dress up. We did all  
 14 sorts of lovely things. Yes, it was lovely.  
 15 Q. You were a regular blood donor.  
 16 A. Yes, when I was at school, yes, and I did get a 50  
 17 donation badge.  
 18 Q. Part of the reason you were conscious of giving blood  
 19 is because you have a rare blood type.  
 20 A. Yes.  
 21 Q. But then on 19 December 1994, you received a letter  
 22 from the Blood Service.  
 23 A. Yes.  
 24 Q. And what did that tell you?  
 25 A. That I had hepatitis C, and that I was not allowed to

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1 A. *(Nodded)*  
 2 Q. Henry, it's 2997008, please.  
 3 We can see that the first paragraph explains  
 4 that at some point in the past you've been infected by  
 5 the hepatitis C virus. There's an explanation in the  
 6 second paragraph about the virus being transmitted by  
 7 direct blood injection, so blood transfusion, or other  
 8 means of transmission. The risk of sexual  
 9 transmission is noted there:  
 10 "It can be transmitted by sexual intercourse,  
 11 although the infectivity by this route is low.  
 12 There's no evidence of risk of transmission associated  
 13 with ordinary daily contact with your household."  
 14 There's then advice not to share razors or  
 15 toothbrushes, and to use a condom, and you're then  
 16 told you can't be a donor anymore.  
 17 Were you told anything at that point about  
 18 treatment options?  
 19 A. No.  
 20 Q. Or possible future issues with your liver?  
 21 A. No.  
 22 Q. In early 1995, your local doctor asked you and Donald  
 23 to go and see him, and he tested Donald for hepatitis  
 24 C?  
 25 A. *(Nodded)*

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1 give any more blood.  
 2 Q. You were invited to make an appointment and you went  
 3 to see a doctor in Inverness.  
 4 A. Uh-huh.  
 5 Q. And what did he tell you about hepatitis C?  
 6 A. He didn't, he was just talking about the hepatic  
 7 artery, and the circulation, and not much else. And  
 8 I couldn't -- I was still sort of reeling from this  
 9 sort of what -- you know, not knowing what hepatitis C  
 10 was and, you know, why I had it, and he was -- the  
 11 haematologist at that time didn't seem to know much  
 12 himself, apart from the hepatic artery. And varices.  
 13 He did mention varices.  
 14 Q. Although you'd worked in hospital, you're not  
 15 medically qualified.  
 16 A. No.  
 17 Q. So for you, discussion about the hepatic artery didn't  
 18 mean an awful lot to you.  
 19 A. No.  
 20 Q. You said that as you left, you were given a letter to  
 21 read.  
 22 A. Yes.  
 23 Q. And you only later read it and understood it more  
 24 fully. We have a copy of the leaflet which you think  
 25 is what you were given.

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1 Q. Donald's test came back positive.  
 2 At that point in time, did Donald know how he  
 3 had been infected?  
 4 A. No, no.  
 5 Q. Donald assumed that you'd passed the virus on to him  
 6 at that point --  
 7 A. Erm --  
 8 Q. -- you've said in your statement.  
 9 A. Well, it -- probably, yes.  
 10 Q. But at the bottom of the letter from your local doctor  
 11 there's a handwritten note asking Donald if he had  
 12 received any blood transfusions. But there was no  
 13 clarity at that point that that was what had happened.  
 14 A. No.  
 15 Q. You and Donald then went across to Raigmore Hospital  
 16 in February 1995 to have liver biopsies.  
 17 A. Mm-hm.  
 18 Q. Can you tell us what happened after those biopsies?  
 19 A. We were in a sort of a ward, and there were beds and  
 20 curtains and he was in one bed and I was in the other,  
 21 and the consultant, Zentler-Munro, interrogated us,  
 22 really, and asked us about who we'd had relationships  
 23 with, and had we taken drugs, and checked --  
 24 I remember he was looking at our arms for any tattoos,  
 25 and it made me feel as though I was the guilty party

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1 having this infection.

2 Q. You've described his manner as condescending with

3 an autocratic style.

4 A. Yes, very autocratic. Well, you know, consultant

5 gastroenterologist having to deal with an unknown

6 entity and two people. It was rude, he was very rude.

7 Q. You were questioned really very intensely about your

8 sexual histories, but Donald did say he had received

9 a transfusion at that point.

10 A. Yes, he mentioned to Zentler that, you know -- he was

11 looking at his thumb, the transplant, and the

12 discussion of the operation, and Donald said he was

13 given plasma because he had been in shock because of

14 the 11 and a half hours, and Dr Monro basically said,

15 "Plasma's not a blood product" and dismissed us.

16 Q. Can you tell us a little bit about the effect of that

17 conversation on you both and how you then viewed your

18 infections?

19 A. Well, it's a three-hour drive back from -- it was

20 longer than that, three and a half with the ferry, and

21 we didn't really talk much. It was like the sword of

22 Damocles ...

23 And when it's -- it's bad enough being told

24 you've got something that is potentially going to hurt

25 your life, but not actually knowing how, what, where,

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1 how you think there may well have been an increased

2 risk of sexual transmission.

3 A. *(Nodded)*

4 Q. At the end of the February, your local doctor asked to

5 see you both and told you that treatment was available

6 for hepatitis C.

7 At some point in the autumn -- you're not

8 entirely sure -- you think that Donald was given

9 an article by your local doctor about hepatitis C --

10 A. Mm-hm.

11 Q. -- to give him a bit more information about the

12 condition and about the treatment.

13 A. Yes, yes.

14 Q. You think he was given that in the context of

15 discussions about the chances of the treatment

16 working.

17 A. Yes.

18 Q. We're just going to have a look at that article

19 because you've been able to provide it to us. It's

20 document 2997007 please, Henry, and we're actually

21 going to start on the last page of it.

22 Thank you.

23 We can see at the bottom right-hand corner the

24 date, 1 September 1995, and it's from a journal called

25 "Update", and then if we look at the last paragraph of

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1 when, and then being treated like we were pariahs, we

2 were just in a limbo. And we had two little boys.

3 Q. Partly because of that, you didn't feel able to tell

4 anyone you had hepatitis C.

5 A. Yes, mm-hm.

6 Q. Because you thought everyone else would make

7 assumptions as well.

8 A. Yes. Well, what could we explain? We didn't know it

9 ourselves. What can you explain when you're thrown

10 into this situation where you know you've got

11 an illness, you've got something, and you know there's

12 nothing -- no support, no information, beyond, "You've

13 got something and we don't want you to do bloods" and

14 this and whatever.

15 Q. Your understanding now is that you contracted the

16 hepatitis C from Donald --

17 A. Yes.

18 Q. -- by sexual transmission, and you think that you had

19 an increased chance of that route of transmission

20 because of a particular problem you have.

21 A. Yes, yes, it was -- I think I had sort of cysts that

22 needed to be cauterised, and I had them done in

23 Raigmore a few years before we were diagnosed, yes.

24 Q. And so you had suffered a number of years of quite

25 severe internal bleeding from those cysts, and that's

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1 the conclusion, it says, just the very end of it:

2 "All those found to be infected require referral

3 for specialist advice about medical management. The

4 general practitioner has an important role in the

5 initial counselling of patients found to be anti-HCV

6 carriers and in the administration of interferon

7 therapy to those likely to benefit from treatment."

8 And from that, the understanding is that this

9 appears to a journal that was produced for general

10 practitioners.

11 A. Mm-hm. But Donald was very good at, you know, asking

12 clear questions and, you know -- and the GP said,

13 "Well, this could be of interest".

14 Q. And then if we go back to the beginning of the

15 article, we can see what the article is telling GPs.

16 It starts as this:

17 "Hepatitis C has generated much anxiety, but in

18 fact affects few people outside risk groups. Few

19 carriers will develop severe liver disease. The

20 authors review the natural history and significance of

21 this virus."

22 Then it goes on.

23 A. Mm-hm.

24 Q. "Hepatitis C has become a major media promoted issue,

25 with the focus on haemophiliacs and whether or not the

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introduction of hepatitis C testing in blood donors was delayed unnecessarily. At the same time, the licensing of interferon for hepatitis treatment has become an important issue medically, yet this virus has only been detectable for the past five years and it cannot be grown in culture.

"It is not surprising that there is much confusion about its diagnosis, natural history and significance. On the one hand it is portrayed as a killer on the loose, yet on the other hand its effects on the liver often progress only very slowly and infection is asymptomatic in most patients. Indeed, most patients with chronic infection may never be detected."

If we go over the page, under the heading "Transmission of HCV", it says:

"Very few chronic HCV carriers in the UK give a previous history of acute hepatitis or have any symptom or sign of chronic liver disease. There are several high-risk groups."

It refers to the box, and gives the statistics. Groups at high risk of infection: haemophiliacs: 80 per cent infected. Then at the bottom of the box, multiple transfusion recipients: 0.2 per cent infected. Alongside the box in the text, it says:

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injections; fatigue; lethargy; loss of libido; depression; alopecia; bone marrow suppression; abnormalities of thyroid function; and induction of autoimmunity.

**SIR BRIAN LANGSTAFF:** Could we just go back to the previous page?

**MS FRASER BUTLIN:** Of course. That's page 2 of the document, Henry.

**SIR BRIAN LANGSTAFF:** The right-hand highlighted box. The last sentence suggests that normal household contact can allow transmission.

**MS FRASER BUTLIN:** It does.

**SIR BRIAN LANGSTAFF:** That's rather different from the information letter which we saw at 008. Can we go back to that?

**MS FRASER BUTLIN:** It's 008.

Yes. The GP article indicates it's very unlikely whereas the information leaflet says there was no evidence.

**SIR BRIAN LANGSTAFF:** It says there is no evidence of risk of transmission.

**MS FRASER BUTLIN:** Indeed.

**SIR BRIAN LANGSTAFF:** Then it goes on to say, "Don't share razors or toothbrushes", which itself just raises questions.

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"Blood transfusion recipients make up only 10 to 15 per cent of chronic carriers in the UK."

There is a note further down about the relative rarity of sexual transmission.

Then it picks up the question of counselling:

"The most important part of an initial consultation, whether in the general practitioner's surgery or in a hospital clinic, is to address the anxiety of the patient. Many patients are convinced that they are infected with a virus which will cause rapid death and that they will have disseminated the infection throughout their family, who will soon be in a similar hapless state. In fact, it is estimated that fewer than 10 per cent of chronic HCV carriers will eventually die of this illness, and the natural history of the infection even in those patients is often 20 to 40 years from the time of acquisition to the development of serious consequences of chronic liver disease."

Then if we go back to the last page, the rest of the article is about interferon, and explaining to the GPs how that works.

In the final page there is a box dealing with the major side-effects of interferon, and they are set out: influenza-like symptoms following early

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**MS FRASER BUTLIN:** Absolutely.

**SIR BRIAN LANGSTAFF:** Did you know where you were after all this information?

**A.** Donald was the one that protected me from confusion. I did read it and it didn't actually give me any insights, and I actually then just denied -- you know, I just thought that that's total rubbish, and felt unsupported and confused, confused. And scared and sad and angry and all those things, you know, the -- and you can't actually process all those feelings when, you know, you have to live and cook and clean and play and look after your children.

**MS FRASER BUTLIN:** You and Donald both started treatment in October 1995.

**A.** Mm.

**Q.** Was there any discussion with you both about the wisdom of both of you starting the treatment at the same time with two small children?

**A.** No. I think the GP just said the Raigmore consultant has prescribed interferon and you inject it, which actually put me straight off, even before I even started. And we were left -- we were given a big yellow box to put the needles in in the house, so that reminded us we had strange things, and had to pick them up at the chemist, so the chemist knew we were

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1 taking interferon, so that was like, you know --  
 2 people knew to some degree. Yes.  
 3 No, no further information.  
 4 Q. What was the effect of the treatment on Donald?  
 5 A. Well, not much -- I don't know. I mean, he didn't say  
 6 anything about the treatment, he just took it. And  
 7 we -- yeah, and I was working, so I would have to  
 8 take -- I was staying over in Inverness a couple of  
 9 nights, so I would take the interferon when I could,  
 10 either in my accommodation or halfway through the day.  
 11 I think you had to do something like three injections  
 12 a week or something. Yeah.  
 13 Q. Can you tell us a little of the effect of the  
 14 treatment on you?  
 15 A. I became very stressed and paranoid, and had an awful  
 16 lot of -- not an awful lot, but the other paramedics  
 17 that I worked with started to see that I was not  
 18 functioning properly, and there was the sort of -- you  
 19 know, when somebody isn't functioning, they make  
 20 mistakes and they become bizarre, and so there were  
 21 lots of emails and letters -- just about emails then,  
 22 yeah -- basically saying that I wasn't a reliable  
 23 practitioner at the time, and so that built up to me  
 24 feeling very strange.  
 25 Q. So physically you've described being exhausted.

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1 know, something I would never even think of, a piece  
 2 of suicidal thought telling me to go and sleep and  
 3 rest.  
 4 Q. You managed to drive home.  
 5 A. Yes.  
 6 Q. And broke down.  
 7 A. And then -- and poor Donald, you know, he was in  
 8 tears, because he didn't see me breaking down because  
 9 I was so shielded, you know ... (unclear) and I needed  
 10 to be strong and have a shield, and it broke.  
 11 Q. It's okay, take your time.  
 12 A. Yes. So, yes, and then he realised I was very ill,  
 13 and I just basically was in the house and went to bed  
 14 and, you know, I wasn't able to sleep properly. And  
 15 he just would be there 24/7. He explained that  
 16 I wasn't well to the boys and they were good, and we  
 17 had a dog that looked after me, and I didn't have to  
 18 be sectioned, although at one stage -- I mean, the  
 19 other incident was where I had this compulsion to go  
 20 and sit in the car because somebody was going to take  
 21 some wheel nuts off one of the tyres and that tyre  
 22 would fall off the car. So I went out with my  
 23 sleeping bag on and my nightie and an axe, just in  
 24 case that person was really going to be quite bad, and  
 25 then I realised it was a bit cold, and they were in

19

1 A. Yes, I was, also -- yes.  
 2 Q. Unable to sleep.  
 3 A. Oh, totally. In fact, that was really a strange time,  
 4 yes, I -- when your brain is in stress, you know, it's  
 5 just like 100 per cent. You're just dream -- not  
 6 dreaming, you're just talking all the time in your  
 7 head, this sort of pressure to constantly be  
 8 processing things that you know you can't do anything  
 9 about, you know. And, you know, like people in  
 10 stress, you start to see everybody as enemies, and  
 11 I don't do that, so, you know, you're sort of having  
 12 a fight in your head about, you know, wanting to  
 13 damage somebody.  
 14 I mean, all that violence that I -- you know, as  
 15 well as being exhausted, as well as not sleeping, just  
 16 was scary.  
 17 Q. You've described that you felt you became psychotic.  
 18 A. Very, mm-hm.  
 19 Q. Can you tell us about the two particular occasions  
 20 that you've discussed in your statement, the first one  
 21 of driving your car through Portree.  
 22 A. Yes. Well, I was just approaching Portree and there's  
 23 a river, and it was a lovely day, and I just -- the  
 24 thought came into my head that you could just drive  
 25 off and go to sleep, you know. And that was like, you

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1 the kitchen. I came back -- because I said where  
 2 I was going when I went out with the sleeping bag and  
 3 the axe, they said, "Where are you going?" and they  
 4 looked at me and I said, "Oh, I'm just going out to  
 5 the car", and then came back in and they sort of said,  
 6 "Is everything okay?" And I said, "Yeah, yeah."  
 7 But then the other bit, after that, I was --  
 8 I had that idea that -- again, I think this is sort of  
 9 like the time in the 1990s, there was all this thing  
 10 about photographs of kids, you know, in baths and, you  
 11 know, taking kids away because you were doing  
 12 pornographic stuff and that, so I spent a lot of time  
 13 pulling out all our photograph albums and taking all  
 14 the pictures out that had them playing without any  
 15 clothes on, and that was a rattled person most nights  
 16 doing something, and they just put up with me.  
 17 And I -- and that was the whole of November.  
 18 And I basically thought with the snow and things that  
 19 I'd missed Christmas, but I actually hadn't. But, you  
 20 know, time was irrelevant and -- yes.  
 21 And we were so close that, you know, when I was  
 22 having my nightmares, and I screamed in my head for  
 23 Donald and he woke up, you know, he -- I didn't  
 24 vocalise, he knew I was in stress. That's how  
 25 close ...

20

1 Q. You could no longer go to work.  
 2 A. No.  
 3 Q. And in fact you'd also stopped the treatment after  
 4 a month.  
 5 A. Yeah. Well, I -- as soon as I stopped I was -- you  
 6 know, I realised that that was how it had affected me,  
 7 yes.  
 8 Q. But the impact on your mental health continued despite  
 9 having come off the treatment.  
 10 A. Mm-hm, yes.  
 11 Q. Before we talk about work, your behaviour had  
 12 obviously become very erratic, and you said in your  
 13 statement that must have frightened the boys.  
 14 A. Yes.  
 15 Q. Were you offered any form of counselling or  
 16 psychological input at that time?  
 17 A. Not for interferon. I mean, I did actually see  
 18 a counsellor for talking about my work. And, you  
 19 know -- and anyway, I don't think anybody knew what to  
 20 counsel for hep C, so what was the point of talking  
 21 about hepatitis C when I didn't know what it was?  
 22 When I didn't want to talk about it anyway.  
 23 Q. You have said in your statement that the interferon  
 24 cost you your job.  
 25 A. Yes.

21

1 A. No, no. It was a surprise. I mean, if I had seen  
 2 that letter with all that information about  
 3 hepatitis C, the interferon treatment and the  
 4 potential for it being a chronic possibly killer,  
 5 I think I would've been more aware of trying to get  
 6 some better treatment.  
 7 Q. Let's look through the letter step by step.  
 8 It talks first about you having been found to  
 9 have hepatitis C when you donated blood.  
 10 In the last section of the first paragraph it  
 11 records that Dr Zentler-Munro had advised you start  
 12 interferon treatment, which you'd done  
 13 in October 1995.  
 14 "About one month after starting treatment she  
 15 appeared to have a reaction to the treatment such that  
 16 she was unable to cope with her work. It is not  
 17 unusual for patients undergoing interferon therapy to  
 18 suffer from profound changes of mood. She stopped  
 19 interferon on 18 November 95 and gradually began to  
 20 recover."  
 21 Had you been given any information about the  
 22 fact that it was the interferon that had caused the  
 23 profound changes of mood?  
 24 A. No, but when I actually came out of the effects of the  
 25 interferon, I had -- I did read -- I mean, I had read

23

1 Q. Can you tell us about that.  
 2 A. Well, I was -- this is in the occupational health, and  
 3 I was actually going back to the hospital, and --  
 4 Q. Where you worked.  
 5 A. Where I worked, and I -- you know, they -- there  
 6 wasn't that much sympathy with the -- you know, as  
 7 a head of the service, and the other service managers  
 8 had been the ones that had orchestrated an awful lot  
 9 of, you know, "This person isn't right", and personnel  
 10 were on their side, and I was advised to not be able  
 11 to go back to work.  
 12 Q. You ended up taking early retirement.  
 13 A. Yes, I was recommended early retirement, yes.  
 14 Q. In 1996.  
 15 A. (Nodded)  
 16 Q. But since getting your medical records, you've found  
 17 a letter from your GP to your work.  
 18 A. Mm-hm.  
 19 Q. Could we have a look at that, please. It's 2997009.  
 20 We can see it's from February 1997.  
 21 First of all, were you aware that your GP had  
 22 been asked to provide any form of letter?  
 23 A. No.  
 24 Q. And until you got your records, had you ever seen this  
 25 letter?

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1 the information paper in there, you know, about how  
 2 long it is and everything is thrown in, and then I saw  
 3 the psychiatric problems could occur.  
 4 Q. And then if we look at the last paragraph of the  
 5 letter:  
 6 "Needless to say the hepatitis C remains in her  
 7 system and it is quite impossible to predict whether  
 8 her chronic hepatitis will progress to the stage of  
 9 hepatitis."  
 10 **SIR BRIAN LANGSTAFF:** That must mean cirrhosis.  
 11 **MS FRASER BUTLIN:** It must mean cirrhosis, sir, yes:  
 12 "In the longer term, hepatic carcinoma is  
 13 a known risk. At present, her liver disease does not  
 14 produce any symptoms. She does of course still suffer  
 15 from the stress related to the knowledge that she has  
 16 a potentially fatal condition which is transmissible  
 17 to others and for which there is no guaranteed cure at  
 18 present. I think it is most unlikely that she will  
 19 ever be able to cope with the additional stress of  
 20 a job, which was mostly based in Inverness and which  
 21 involved considerable amounts of travelling and  
 22 staying away from home."  
 23 Here, as you say, the GP set out the long-term  
 24 risks of hepatic carcinoma.  
 25 A. Mm.

24

1 Q. Were you aware of those at that stage?  
 2 A. No.  
 3 Q. From the time you stopped treatment until 2018, were  
 4 you provided with any follow-up or monitoring?  
 5 A. No, not on the hepatitis C.  
 6 Q. Were you offered any further treatment between 1995  
 7 and 2018?  
 8 A. No.  
 9 Q. And was Donald?  
 10 A. No.  
 11 Q. Donald had gout between 2000 and 2012 and had some  
 12 liver function tests. They were raised and his  
 13 records suggest that this was said to be because of  
 14 alcohol consumption. Was Donald told anything about  
 15 that?  
 16 A. No. If he had, he'd have been really insulted.  
 17 Q. Donald's brother is sitting next to you and has just  
 18 laughed when we discussed alcohol consumption, but did  
 19 Donald drink?  
 20 A. No. Only like Christmas and New Year, possibly, but,  
 21 no, he was sent to -- well, I have a sort of a band  
 22 called VibesUP, and he used all sorts of other  
 23 alternative therapies and things, and he treated his  
 24 water with various different things. He wouldn't  
 25 drink water from the tap. He would eat seaweed on the

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1 you had had no monitoring?  
 2 A. **(Indicated dissent)**  
 3 Q. Was there any discussion at all about your  
 4 hepatitis C?  
 5 A. None. In fact, the second wrist that I broke that  
 6 I had a plate in, in 2012, I picked up a sense that  
 7 I was a nuisance on the ward, that, you know, it was  
 8 an accident, I'd slipped and hit a rock, and I do --  
 9 I felt that the nurse on the ward saw me as  
 10 an inconvenience.  
 11 Q. Do you have any understanding now as to why there may  
 12 have been no follow-up over that time?  
 13 A. Well, the liver nurse that subsequently, when Donald  
 14 became ill and I was picked up then, last year -- this  
 15 year, this year in fact, and she said that she had  
 16 only been in place in her job in Raigmore from  
 17 2002/2003 for the whole of the Highlands and the outer  
 18 isles, and that Munro had been fighting to get funding  
 19 for specialist -- the nurses. And that was it,  
 20 really, that was funding qualified people, and she hit  
 21 the ground with a massive brief.  
 22 Q. Because one specialist nurse was covering the whole of  
 23 the Highlands, all the outer isles.  
 24 A. Orkney, everywhere.  
 25 Q. Throughout all of this time, you and Donald told no

27

1 shore, which was always very good, all the bits of  
 2 brown seaweed and green, and he always had -- we went  
 3 on various clean diets with kale and -- no. And he  
 4 stopped meat, really, he didn't really eat much meat.  
 5 He didn't like it. He ate fish, but even fish -- he  
 6 was very much one that went out and foraged and came  
 7 back and would have -- and he was a banana on toast  
 8 person with blackcurrant jam, that was his main  
 9 staple, but apart from that -- and porridge.  
 10 But no, the drink -- I used to make damson gin,  
 11 but he never touched that apart from the fruit at the  
 12 end of the --

13 MR BATTERS: Well, we did!

14 MS BATTERS: I know you did!

15 MS FRASER BUTLIN: At that time, 2000 to 2012, when there  
 16 was this question of whether Donald had gout, was  
 17 there any follow-up at that point in relation to  
 18 Donald's liver?

19 A. None, unless they talked to him about it, but I don't  
 20 think so, I don't know.

21 Q. You attended Raigmore Hospital on a couple of  
 22 occasions with broken wrists. You had to have surgery  
 23 to repair the fracture, and were put at the end of the  
 24 list because of the hepatitis C.

25 At that point, was it picked up with you that

26

1 one about the hepatitis C.  
 2 A. Mm-hm.  
 3 Q. Can you tell us why that was?  
 4 A. I think that initial biopsy and the -- feeling like  
 5 pariahs, and we had children, and the interferon, and  
 6 I think it just, you know, there was a block, put my  
 7 head in the sand, you know, I just did not want to  
 8 know, did not want to be seen to be a broken person.  
 9 Q. Donald was very close to his brother, who sits with  
 10 you today, but he didn't feel able to tell him either.  
 11 A. **(Indicated dissent)**  
 12 Q. So absolutely nobody knew.  
 13 Donald had no faith in doctors.  
 14 A. Mm-hm.  
 15 Q. And refused to go and see them.  
 16 A. Yes.  
 17 Q. But he then became unwell in about June 2018.  
 18 A. Mm-hm.  
 19 Q. Can you tell us what happened?  
 20 A. Well, he pulled -- he said he pulled -- he was doing  
 21 heavy gardening, lifting big Jewsons blue bags full of  
 22 grass and sticks, and he also went off and collected  
 23 wood and things, and he thought he'd pulled a muscle,  
 24 and he had diarrhoea for a fortnight. And then he --  
 25 because of that and not eating and everything he drank

28



or ate just shot away, he then got a chest infection, and then sinusitis, and then the ascites came and his leg swelled up. And we went on 21 December, my son and myself -- my eldest son was at home -- the GP had organised an ambulant emergency care clinic consultation in Raigmore, so we went at 6 o'clock in the morning and drove for the 9 o'clock opening of the clinic, where he had a battery of CT scans and bloods, and they couldn't do an MRI because that was a busy machine that day on the Friday. And at the end of the day, when Louis and myself came back at something like 2 o'clock, they said, "Well, there are lesions in his liver and we'd like to keep him in over the weekend and then we can send him home on Monday. You can have him for Christmas."

And -- it was a horrible discussion, and basically, you know, the attending doctor was very adamant that it should -- he should stay and they'll look after him and reduce the edema, and Donald did not want to stay there, and, you know, Louis, my eldest son, also has more mental awareness of Donald's needs, and he said, "We're going home", and we did.

And if we'd have left Donald in the hospital, I think he would've just packed up his bags and died then, because he wanted to be home.

29

which they were more aware of than anything else, and that there could be an instant blood loss or whatever, which actually happened.

**Q.** March 2019, while he was at home, Donald collapsed.

**A.** Yes. Louis was just taking him -- he was walking backwards and forwards. We'd had him -- we'd done an intervention. Richard had come up in January and we had managed to get a ripple bed and district nurses. It was five of us to one.

And -- yes, and he was -- Louis was the one -- I was in the kitchen, and he was holding onto Donald, and he just collapsed at the door and vomited a bucket load of blood. We couldn't pick him up, so I phoned up the ambulance and the ambulance came and they gave him just a drip, and we went to Broadford for an overnight stay. He was on drips to just bring back his water levels and balance everything, and they were -- they were lovely. I mean, you know, they looked after us all night. I was in a chair next to him. And the family came up the next day, and he was bright and breezy.

**Q.** Went back home.

**A.** Went back home.

**Q.** There were some other occasions of bleeding varices, but Donald had palliative care, predominantly at home.

31

**Q.** You then went back to see the doctor --

**A.** The following week.

**Q.** -- the following week.

**A.** With the results.

**Q.** What were you told?

**A.** Donald was quite aware that he was very ill, and he wasn't eating properly. And he -- like a Heath Robinson thing, you know, he was using pallets for beds in the front room, with his legs up to drain them, and he would not -- there was no interference to be had with anybody. Couldn't even get the district nurses. I was trying to persuade him to get district nurses.

And he -- the doctor -- he just said, "Tell me the full story". So she read out all the processes that they'd done and what was involved and how much damage there was. And he said, "And what's your prognosis?" And she said, "There isn't any, it's palliative care". He said, "Well, how long have I got?" She said three months to a year. But it could be any time, yes. Yes, because there was a discussion on the phone as well to one of the GPs, when he was home, about a potential -- because of the swelling of his stomach, they were concerned that there was blood leaking from the damaged varices,

30

**A.** Yes.

**Q.** You have said that the district nurses were absolutely excellent in their care.

**A.** You know, they had left all their home and mobile numbers, that was five or six of them, so -- and only once we ever used -- because he was such a gentleman, he would not want anybody to be out of -- you know, to be taking them out of their -- inconvenience, yeah.

**Q.** But sadly Donald died on 8 July 2019.

**A.** (Nodded)

**Q.** Can you tell us something of the impact of Donald's death -- I know it's very fresh.

**A.** Yes.

**Q.** On you and your children.

**A.** It was a Sunday evening, and it was like he'd gotten to the stage on the Thursday before he died that he could not actively do the things that we do every day, you know, in private, in the toilet, and needed to have enemas and district nurses. That was the first time we phoned, that was the Thursday we phoned, and then the Sunday he had to have another -- and he felt that he'd lost his dignity and his self-reliance, and he knew.

I didn't. I kept trying to feed him. When you see somebody just fading away ... He stopped -- he

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1 couldn't breathe, you know, gasping for breath, and  
 2 Louis -- well, he had done a meditation, he did lots  
 3 of meditation, he was very much into, you know,  
 4 calming and self-help, and he had lots of connections  
 5 across the world with all these people, you know,  
 6 energetics, it's to do with spiritual and emotional  
 7 strength, which he was.  
 8 And he started to ... (unclear) and I went with  
 9 him, and I held him. And Louis was there, we both  
 10 held him, and, you know, when somebody's dying -- and  
 11 it was at home, thank God -- and he just was gasping,  
 12 and big gaps in between like, you know, you're holding  
 13 your breath, and we did that with him, and then he  
 14 stopped. And then we just waited and waited to see if  
 15 there was another breath, and then he died.  
 16 Q. And you've said in your statement you've lost the love  
 17 of your life.  
 18 A. Yes.  
 19 Q. "Our plans to grow old together in the home we both  
 20 loved and Donald built was cruelly taken away."  
 21 And the boys, although they're adults, are both  
 22 utterly devastated.  
 23 A. My eldest son has been very good, he stays at home  
 24 with me, but has not grieved. Even in the cremation,  
 25 he sat away from the front. You know, he hasn't

33

1 himself. And he wanted me to live.  
 2 Q. He encouraged you to take the treatment. You took it,  
 3 and you've recently discovered that you have cleared  
 4 the virus now.  
 5 A. Although I do have damage to the liver from the years  
 6 of not being treated. 11 per cent of my liver is not  
 7 functioning properly.  
 8 Q. Once you realised there was nothing more that could be  
 9 done for Donald, you decided to seek legal advice, and  
 10 you were then, through that contact, given information  
 11 about the Scottish Infected Blood Service, and you've  
 12 received payments from them.  
 13 A. Mm-hm.  
 14 Q. But you feel very strongly that it was too little too  
 15 late.  
 16 A. Mm-hm.  
 17 Q. Can you tell us a little bit more about that?  
 18 A. Well, Donald got a one-off payment, I got a one-off  
 19 payment, and then he got a monthly income, and I did.  
 20 But he only survived for one monthly pay. And I have  
 21 the widow's -- but, you know, that's -- you know,  
 22 that's not really saving his life, it's -- you know,  
 23 money just does not bring back the person that you  
 24 want to spend the rest of your life with.  
 25 Q. And you had retired early.

35

1 processed it. Yet.  
 2 Q. In the midst of Donald's final illness, you were  
 3 advised to start treatment for your own hepatitis C.  
 4 A. Yes.  
 5 Q. And you did.  
 6 A. (Nodded)  
 7 Q. Can you tell us about how you coped with your  
 8 treatment?  
 9 A. Well, you know, I was caring for Donald, between Louis  
 10 and myself we were looking after him, and we had  
 11 a great timetable, a great sharing. I mean, such  
 12 a support from him and the district nurses. And --  
 13 but I felt so guilty that he wasn't able to have this.  
 14 There was -- it was too late. And I felt -- I felt  
 15 like it was ... I was disloyal to our relationship.  
 16 Q. But you've also said in your statement watching him  
 17 deteriorate made you decide that you would try.  
 18 A. Well, he told me to. I mean, you know, again -- and  
 19 it's -- you know, his support, even then, and he knew  
 20 that. So strong, and even -- you know, he hardly took  
 21 any morphine. Richard was saying he was on the pump,  
 22 and then he came off the pump and just had oral  
 23 morphine and tablets twice a day because he was  
 24 conscious. He did not want to go into any sort of  
 25 fugue mind, non-thinking state. He wanted to be

34

1 A. Mm-hm.  
 2 Q. And your finances had been very limited.  
 3 A. Absolutely, yes, yes.  
 4 Q. And throughout that time you had not been aware of the  
 5 financial assistance schemes.  
 6 A. Well, again, we probably would not have chased it up,  
 7 we're terribly proud people, I suppose. And I got  
 8 jobs working as a -- supported employment and latterly  
 9 now working as a volunteer support manager for  
 10 a garden project in Skye, and so we've always coped,  
 11 although we've always had to be careful. And Donald  
 12 really hardly ever spent money. Everything was sort  
 13 of, you know -- he would -- we were sort of like, you  
 14 know, we'd just take things that people had thrown  
 15 away and recycle them. We were quite good at  
 16 recycling things.  
 17 And he just collected wood and built things  
 18 around with bits that were given, and he actually had  
 19 a -- we did buy one of those Lorgasill(?) metal  
 20 benches to chop our own -- which he did, he cut logs  
 21 of trees and built a shed at the back of the house,  
 22 with solar panels eventually put up.  
 23 So he was very much into self-reliance, very  
 24 much into using his abilities and his mind. And he  
 25 always had really unusual ways of solving things and

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1 tripping me up. I could never, you know, guess what  
 2 he was going to do next, which was part of the  
 3 relationship, always surprising, and lovely.  
 4 **Q.** Those are the questions I have for you, I'm just going  
 5 to turn and ask if there's anything from behind.  
 6 **A.** Yes.  
 7 (Pause)  
 8 **MS FRASER BUTLIN:** Mr Dawson just asked me to raise  
 9 a couple of matters with you.  
 10 When you had the liver biopsies in 1995, were  
 11 you told anything about the extent of liver disease  
 12 that you both had at that time?  
 13 **A.** No.  
 14 **Q.** And you stopped the interferon treatment after  
 15 a month, the first one. Donald also stopped treatment  
 16 at that time. In his records it suggests that it was  
 17 because he couldn't tolerate it.  
 18 Why did he stop the interferon at that point?  
 19 **A.** Well, it was me. I was -- I had fallen apart. And we  
 20 had two little boys and if -- I suppose -- I don't  
 21 think -- I don't know whether it affected him because  
 22 he would not say if it had. But, you know, it was  
 23 solidarity. We stopped because I couldn't take it,  
 24 and the risk was too much. We couldn't care for the  
 25 boys if both of us were behaving like lunatics, and

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1 hours and minutes to keep Donald alive. And holding  
 2 my breath as he gasped his last at 5.00 am on  
 3 8 July 2019.  
 4 I held Donald gently to wash and dress him so  
 5 that he looked asleep. I heard my son calling family  
 6 and all the people that needed to know.  
 7 And then being called a widow. This inquiry is  
 8 a first, and the evidence from our experience should  
 9 show the loss of health, life, happiness and dignity,  
 10 and we all deserve better.  
 11 I'd just like to thank Sir Brian Langstaff for  
 12 this inquiry, and yourself, Sarah, and Jamie and Lynn  
 13 and the people that have brought this here.  
 14 It's been very painful, but cathartic.  
 15 Thank you.  
 16 **SIR BRIAN LANGSTAFF:** Well, you're entitled to our  
 17 admiration, in particular describing the devastating  
 18 effects on you, your mental health, your physical  
 19 health, explaining your feelings of guilt, however  
 20 unreasonable they may have been to have, but you've  
 21 told us those details, and to describe Donald's last  
 22 days, particularly when it's a sad reflection for all  
 23 of us, I think, that the day he died was as recently  
 24 as the first day of the last week that this inquiry  
 25 was sitting in Edinburgh.

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1 I wasn't very stable at that time.  
 2 **Q.** Finally, there was one other opportunity that  
 3 Mr Dawson wanted me to raise with you that you  
 4 could've been followed up in the hospital. I don't  
 5 want to discuss why you were in the hospital, but you  
 6 were in visiting someone in 1988/1989, and you saw  
 7 Dr Zentler-Munro.  
 8 **A.** Yes.  
 9 **Q.** What happened?  
 10 **A.** Well, we were in the corridor visiting a relative, and  
 11 he recognised us. I was in the lift with him. We  
 12 were stood in the corridor looking out of the window  
 13 and there was an acknowledgement that he was aware we  
 14 were there, and then he went one way and we stood at  
 15 the window, waiting to visit our ailing person, and  
 16 that was nothing ...  
 17 **Q.** Is there anything else you would like to say?  
 18 **A.** No. Enough. No, just this statement, a little bit.  
 19 Is that -- should I just read this?  
 20 **Q.** Yes.  
 21 **A.** Yes.  
 22 Okay, so since late last year, I've experienced  
 23 many firsts. I became a carer. And I really was  
 24 infected with hepatitis C. Hearing these words from  
 25 Donald, "Do not resuscitate". Praying for more days,

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1 **A.** Really?  
 2 **SIR BRIAN LANGSTAFF:** So it's as recent as that, within  
 3 the last four months.  
 4 **A.** Mm-hm.  
 5 **SIR BRIAN LANGSTAFF:** And although you've had your  
 6 moments, you've been remarkably composed. I wouldn't  
 7 have blamed you if you had simply broken down  
 8 altogether. But thank you very much.  
 9 Well, we'll take a slightly longer coffee break  
 10 than usual and we'll start again at 11.40.  
 11 (11.00 am)  
 12 (A short break)  
 13 (11.40 am)  
 14 **SIR BRIAN LANGSTAFF:** Our next two witnesses, together,  
 15 are known as Myles and Paul, are they?  
 16 **MS RICHARDS:** Yes, sir.  
 17 **SIR BRIAN LANGSTAFF:** Myles and Paul, please.  
 18 **MYLES HUTCHISON and PAUL HUTCHISON (sworn)**  
 19 **Questioned by MS RICHARDS**  
 20 **MS RICHARDS:** Myles, you and Paul are brothers?  
 21 **MYLES HUTCHINSON:** Yes.  
 22 **Q.** You're the older of the two by one year and 10 months.  
 23 **A.** That's correct.  
 24 **Q.** And you've got moderate haemophilia B.  
 25 **A.** Yes.

40

1 Q. That was diagnosed when you were a baby.  
 2 A. Mm-hm.  
 3 Q. There's not a family history of haemophilia; it's been  
 4 described as a spontaneous genetic mutation.  
 5 A. That's correct.  
 6 Q. You were, as was Paul -- we'll come on to Paul in  
 7 a few minutes -- under the care of the Royal Infirmary  
 8 in Edinburgh from about 1980 onwards.  
 9 A. That's correct, yes.  
 10 Q. You were roughly 8 years old when your care  
 11 transferred there.  
 12 A. Yes.  
 13 Q. Paul would've been about 6. And you came under the  
 14 care of Dr Ludlam.  
 15 A. That's correct.  
 16 Q. You describe in your statement being there very  
 17 frequently as a child.  
 18 A. Yes, unfortunately I was quite prone to bleeding  
 19 episodes.  
 20 Q. We can see from records -- I won't put these ones up  
 21 on the screen -- that in about October 1979, your mum  
 22 was invited to be taught how to administer factor to  
 23 you and to Paul.  
 24 A. That's correct, yes.  
 25 Q. And the records also show that over the following

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1 a ridiculous question. It shouldn't come down to  
 2 cost; it should come down to safety. I just presumed  
 3 that he would give me the safest option. So I said to  
 4 him, "Well, I've always trusted you in the past so  
 5 I trust you now."  
 6 Q. There was an occasion during your childhood when you  
 7 went on an organised holiday to Wales --  
 8 A. Yes.  
 9 Q. -- for boys with haemophilia, and your parents were  
 10 told by Professor Ludlam not to allow you to use any  
 11 factor products locally in Wales.  
 12 A. Yes, that's correct. He actually said if I had  
 13 a bleeding episode not to take any treatment, to  
 14 actually wait until we come home and suffer the bleed  
 15 rather than take any other factor.  
 16 Q. You were treated at the Royal Infirmary in Edinburgh  
 17 in an adult unit.  
 18 A. Yes.  
 19 Q. There wasn't a bespoke haemophilia care facility for  
 20 children.  
 21 A. No, there wasn't, no.  
 22 Q. So you saw, a lot of the time, older haemophiliac  
 23 patients.  
 24 A. Yes, unfortunately I did, yes.  
 25 Q. You saw them becoming ill as the years went on.

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1 years, you received Factor IX concentrates on a very  
 2 frequent basis, prophylactically, twice weekly.  
 3 A. That's correct, twice weekly.  
 4 Q. As far as you're aware, was any advice or information  
 5 or warning provided to you or to your parents about  
 6 any risks of infection associated with the Factor IX  
 7 products?  
 8 A. None at all. They were assured all the time that it  
 9 was perfectly safe.  
 10 Q. Do you know whether any alternatives to this  
 11 twice-weekly prophylactic Factor IX treatment were  
 12 discussed with your parents?  
 13 A. None whatsoever. They were basically told to put  
 14 their trust in Professor Ludlam, and they did that,  
 15 but no alternatives, even though they were there, not  
 16 to our knowledge, were ever given.  
 17 Q. You, I think, Myles, have a recollection at some stage  
 18 of being shown two different Factor IX products by  
 19 Professor Ludlam and told that one was more expensive  
 20 than the other.  
 21 A. That's correct, yes.  
 22 Q. Can you remember how that made you feel?  
 23 A. I was actually in shock when he asked me. I thought  
 24 it was a trick question. I thought a person of his  
 25 intellect, you know, would not ask a patient such

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1 A. I seen things that no child should ever have seen.  
 2 I seen a lot of young men die, and I was only ten  
 3 years old. There was one specific boy that I grew  
 4 very fond of because he was very friendly and he was  
 5 a haemophiliac like myself, and he was like a big  
 6 brother figure, sort of, you know? And they had him  
 7 on a side ward because he had HIV. He never got any  
 8 visitors because his family were all strict Catholics  
 9 and the Professor Ludlam wouldn't admit that he had  
 10 received HIV through his treatment, so they were  
 11 convinced he led a life not to their liking and they  
 12 disowned him. So he was very lonely, and he became my  
 13 friend.

14 One night I'd been watching the TV when I was  
 15 lying on the bed in the hospital, and I looked next to  
 16 his room and I saw him crying for his mum, like I'd  
 17 done on many nights. And he died. His poor head went  
 18 down, his hand went to the side, and I seen all the  
 19 life drain out of this potential young man. And  
 20 nobody looked at him or gave any attention to him, so  
 21 I went over to him and I gave him a hug. And I said,  
 22 "You're with the angels now, you'll be okay".

23 And then I heard this trolley clattering down  
 24 the corridor, so I ran back to my bed, because the  
 25 nurses would get angry with me if I got out of my bed,

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and I seen two men coming down with this big steel trolley, and they were singing, "Another one bites the dust".

They picked up this poor young man's body, they slapped it on the tray, and they go, "Mind you don't touch him, mind your gloves are on, it's a disease, you don't want to touch him", and they slammed the door shut -- they caught his hand in the door, actually, I just remember that now, and I heard like a cracking noise. I can only presume it was one of the bones in his hand. They closed it shut and they started whistling merrily going up again.

But I seen a lot of things like that, I seen a lot of things. But that's the one that always sticks out because he became my friend, and no human being deserves that, no, no.

Q. You would spend time talking to some of the older patients. You were still a child yourself.

A. Yes.

Q. And you would be told things by older patients about American blood or blood being taken from Russian corpses.

A. Yes.

Q. That must have been, whether it's correct or not, very frightening information for a child to receive.

45

20 April 1984, and the positive result for hepatitis B.

If we can have 2168003, please, Henry.

We can see here a letter sent from the Royal Infirmary of Edinburgh to your GP. Diagnosis: hepatitis B positive. There had been an incident with you cutting your finger at school. It says:

"As you know, he has recently become hepatitis B positive."

Then describes you as a sensible, slightly obsessive child, very careful to bleed down the sink and to mop up after him, and refers to your brother being vaccinated and both parents receiving immunoglobulin.

What can you recall about this episode where you had hepatitis B?

A. I just remember there was a phone call and my mum and dad were panicking, "Something wrong with Myles", and they took me up to the hospital. It's a wee bit hazy, as you say, it's quite a while ago, but my mum and dad were very distressed, because, "What is this? What has my son got? What treatments are going to be available? What are they going to do to help him?" I just remember being put in a bed and they were

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A. Well, that's the thing. Nobody ever spoke to me.

They always made out, "Oh, we'll tell your mum and dad everything", which I found out later wasn't the case, and I'd ask questions and I'd just get palmed off. So whenever any of the older haemophiliacs talked to you, you listened, because they've lived with this, you know, all their lives, and you would trust them before the doctors, because they didn't talk to you, they didn't want to talk to you. Especially Professor Ludlam, he wasn't a very forthcoming chap at all.

To be honest with you, I felt like an object when I was in the hospital. I didn't feel like a human being.

Q. In 1984, you were told you had been infected with hepatitis B.

A. Yes.

Q. You were about 12 at that time.

A. Uh-huh.

Q. Had you and your parents been aware that you were being tested for hepatitis B?

A. No.

Q. We'll just have a look at a couple of documents to date this. First of all, Henry, 2168002, please.

We can see there, there is a date of April 1984,

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obsessing about what I'd done with my blood, what had happened to me, where exactly I'd been, but, as I say, I was sort of trained to clean up my own blood after me. It was a strange feeling.

They didn't talk to me much about it, because I was feeling really ill, I was in a pretty bad way, but even then there was no explanations given to my mum and dad as to how I got this virus. It was, you know, "Oh, this has just been an unfortunate event, we don't know exactly how it's happened."

After that, it was the start of me not being as well as I'd been prior, you know. I just felt my health started to slide after it. It was very distressing for my mum and dad, and it seemed like it was the first page in a mad book that we weren't going to want to read very much. That was the start.

Q. You say in your statement that when your parents would ask questions of Professor Ludlam, the answers they got your parents felt were rather vague.

A. Vague to say the least, yeah. I would actually go as far as to say he dismissed them. They were -- the questions they were asking bore no relevance to what he wanted or what he needed, so he didn't give them answers. And they make out that they reassured them and all that. I can remember my dad coming home with

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1 a leaflet in his hand. I said, "How did you get on,  
2 Dad?" and he goes (**demonstrated**).  
3 **Q.** We'll come on to that, because I think that's when you  
4 had your hepatitis C diagnosis a number of years  
5 later.  
6 **A.** Mm-hm.  
7 **Q.** Your parents were told in relation to the hepatitis B,  
8 I think, but please correct me if I'm wrong, that your  
9 infection could've come from the first time you had  
10 Factor IX concentrate.  
11 **A.** That's correct, yes.  
12 **Q.** Do you know whether they were told that at the time or  
13 was that later?  
14 **MYLES HUTCHINSON:** Do you think it was --  
15 **PAUL HUTCHISON:** Later.  
16 **MYLES HUTCHISON:** It was later?  
17 **PAUL HUTCHINSON:** Aye.  
18 **MYLES HUTCHINSON:** That was for the hepatitis B?  
19 **MS RICHARDS:** Your statement suggests that it may have  
20 been in relation to both the hepatitis B and hepatitis  
21 C, but they were told at some stage.  
22 **MYLES HUTCHINSON:** Yes, that's correct. They say that at  
23 some stage there was a non-A, non-B that they knew  
24 about for years. Well, try and prove that. But  
25 they'd known about for years and that was related to

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1 recall about that?  
2 **A.** Yes, I just -- well, I asked, because back then the  
3 factor we got was in big 50 ml syringes, and they were  
4 taking blood out of me in these giant syringes, and  
5 they were taking maybe four or five at the time, and  
6 why do they need so much blood? And I asked, "Why do  
7 I have to keep getting so much blood taken?" And the  
8 nurse said, "Oh, it's nothing to worry about, it's  
9 just looking for anomalies, et cetera, it's nothing  
10 for you to concern yourself with", so ...  
11 **Q.** You describe in your statement Professor Ludlam  
12 referring to you as "pups".  
13 **A.** Yes, I thought it was a term of endearment.  
14 I actually -- I was -- you know, I was -- you know,  
15 when I was walking up the ward, they'd say, "Here's  
16 the young pup", and I was -- "All right, Professor",  
17 because I looked up to him, I'll be honest, I did. I  
18 admired him. I thought he was this great figure that  
19 was helping me, who was giving me a chance at a normal  
20 life. So when he called me a pup, I thought it was --  
21 you know, he genuinely felt that way about me as well,  
22 it was affection. But I found out later that that  
23 might not have been the case.  
24 **Q.** You found out later that there's a term of previously  
25 untreated patient.

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1 the different viruses and that.  
2 **Q.** As you say, this was the start of you beginning to  
3 feel unwell.  
4 **A.** Yeah.  
5 **Q.** And you describe in your statement how from in  
6 particular the age of 13 or 14 you would feel  
7 fatigued, you had a strange feeling in your stomach,  
8 aching joints, flu-like symptoms.  
9 **A.** Yes.  
10 **Q.** You also recall seeing biohazard stickers on your  
11 medical files.  
12 **A.** That's correct, yes.  
13 **Q.** Now, I wanted to ask you a little about the view you  
14 express in your statement, Myles, that you've been the  
15 subject of being tested or researched without your  
16 knowledge and consent.  
17 **A.** That's correct, yes.  
18 **Q.** That's your firm view.  
19 **A.** Yes, definitely.  
20 **Q.** You say in your statement that often during your  
21 childhood and teenager years, bloods would be taken  
22 without you being told what the tests were for.  
23 **A.** That's correct, they took blood all the time.  
24 **Q.** And you've referred in your statement to being told  
25 something about testing for anomalies. What can you

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1 **A.** That's correct.  
2 **Q.** As an abbreviation.  
3 **A.** That's what I heard. Or previously uninfected,  
4 I heard that as well, but ...  
5 **Q.** You also recall on a number of occasions there being  
6 clinicians prodding you around the stomach area.  
7 **A.** Yes, that's correct.  
8 **Q.** Which subsequently you've thought may have been  
9 examinations of the liver area, and that this happened  
10 from childhood onwards.  
11 **A.** Yes, from when I was about 13 right up until basically  
12 I got told I got hepatitis -- or, actually, sorry, the  
13 first time I reacted, they checked my stomach every  
14 time I went to the hospital and prodded about just  
15 under my ribs round about the liver area, and they  
16 kept saying, "Do you feel anything there?" "No, no,  
17 fine." Then one day I went, "Oh, that's painful", and  
18 that day they stopped doing it.  
19 **Q.** What you've said in your statement is you feel in  
20 retrospect it was likely they knew there was something  
21 wrong, but they were waiting on symptoms emerging.  
22 **A.** Oh, definitely. That's what I felt, that --  
23 I wondered why they kept prodding my stomach. I mean,  
24 I'm a haemophiliac, it's mostly my joints, my muscles,  
25 things like that, and they kept prodding about my

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1 stomach. Why are they obsessed -- and they didn't  
2 check my joints as much, which you'd expect, they kept  
3 prodding my stomach. When they stopped doing it,  
4 I went "Oh, what's that?" Definitely it was -- it was  
5 like they were just waiting to see if something would  
6 happen.

7 They had previous knowledge of what was in my  
8 bloodstream and they were waiting to see if it came to  
9 fruition, which it did, unfortunately.

10 Q. You have a concern that you and Paul were regarded as  
11 interesting subjects for research.

12 A. Yes, that's correct.

13 Q. Because you were brothers --

14 A. Mm-hm.

15 Q. -- you had the same condition, and it occurred  
16 spontaneously in both of you.

17 A. That's correct, yes.

18 Q. It's your understanding from things that were said to  
19 you that you were regarded, the two of you, as being  
20 like twins genetically, even though you are not in  
21 fact twins.

22 A. Well, we're actually told that we're genetically  
23 identical, even though we're not twins. We're  
24 actually more identical than identical twins. But the  
25 features had, you know, differences but we're actually

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1 Q. We'll come on to it when I ask Paul some questions in  
2 a while. But it may have been that there was -- there  
3 could've been a good reason for giving Paul  
4 a pseudonym, so his colleagues couldn't see his  
5 medical records.

6 A. Well, it makes perfect sense for Paul, if he's working  
7 there, to keep confidentiality for him. But why would  
8 they do it with me? There's no reason for them to  
9 give me a pseudonym. Is it a fear that I might ask  
10 for a look at my medical records, and they could quite  
11 easily give me Myles Hutchison's records, but this  
12 other chap, I won't get to see his file, will I?

13 Q. Were you told you were being given a pseudonym of  
14 Robert Marr?

15 A. No.

16 Q. You have a recollection, as I understand it, of going  
17 to clinic appointments, and there would be two lots of  
18 files on the table or the desk or by the bed; there  
19 would be a file with your name on, and a file with  
20 Robert Marr's name on.

21 A. That's correct.

22 Q. You didn't know why.

23 A. I thought this was a chap that always got appointments  
24 at the same time as me and decided not to go.  
25 I thought, "He's awfully rude, this chap!" But this

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1 genetically identical inside. So I suppose if you  
2 were wanting to do any tests or research, we'd be  
3 perfect, we'd be like gold dust, basically, because it  
4 only happens one in a billion, I think, something like  
5 that.

6 Q. Then there was a time -- this is a little later on,  
7 but still I think relevant to your concern that you've  
8 been the subject of research or studies without your  
9 consent -- there was a time later on when the two of  
10 you were allocated pseudonyms by Professor Ludlam.

11 A. Correct, yes.

12 Q. We'll look at the document, 2168022.

13 It's from Professor Ludlam, it's addressed to  
14 the department of clinical biochemistry and headed  
15 "Strictly confidential", and it says this:

16 "For the purpose of clinical chemistry  
17 investigations, I have arranged the following.  
18 Paul Hutchison will be known in future as Alex Austin.  
19 Myles Hutchison will subsequently be known as Robert  
20 Marr. Neither brother knows the new pseudonym of the  
21 other. Thank you for archiving both individuals'  
22 previous results under their new pseudonyms."

23 Now, your brother, Paul, was working in the  
24 Royal Infirmary at the time.

25 A. That's correct, yes.

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1 file was always there, so ... obviously, you know, it  
2 was me, but not to my knowledge.

3 Q. You have a concern that there may be medical records  
4 or studies or tests that were undertaken in respect of  
5 you, but which have been filed under the name of  
6 Robert Marr and which you've never seen.

7 A. That's correct, yes.

8 Q. You also remember being sent to hospital for  
9 injections, and, when you were about 17, having  
10 injections from some large hexagonal device with lots  
11 of needles. That's how you describe it in your  
12 statement. What can you tell us about that?

13 A. Yes. I got a phone call, which happened now and again  
14 at my school, they would tell me I had to go up to the  
15 hospital to get blood tests or get treatment,  
16 something like that, and this one time I went up, they  
17 said, "Oh, we need to take some bloods off you, and  
18 then -- to stop you having to get BCGs, things like  
19 that, because we don't want you to get that at the  
20 school, we have to do this". They brought out this  
21 hexagonal thing, it looked a bit of a flat-top comb,  
22 you know, that sort of shape. It had over a dozen  
23 needles in it. They pushed it into my arm, and it was  
24 quite painful, actually, it was really painful, and  
25 when they pulled it away, it felt like it was

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1 a ripping sensation, like it was taking something with  
2 it. And I thought, this really weird, why do I have  
3 all these needles?

4 I presumed in my innocence that it was  
5 an alternative to getting the BCG, so I didn't  
6 question it. But then later on, when I spoke about  
7 it, nobody had ever heard of this before, and it left  
8 some unanswered questions to say the least.

9 **Q.** You've said in your statement you weren't told what  
10 this was for, despite asking.

11 **A.** No. All I was -- when I asked, all they said was  
12 it's -- "Instead of you getting your BCGs at school,  
13 things like that, we'll deal with you here, and this  
14 means you can get it all done at once."

15 **Q.** We'll look at a couple of the records, Myles.  
16 2168023, please.

17 We can see this is a document in relation to  
18 you, and it's headed "Hepatitis study". It's from  
19 1993.

20 If we have then, Henry, 2168024, we can see  
21 another document with the same heading, "Hepatitis  
22 study".

23 Were you aware of being in any respect the  
24 subject of any kind of hepatitis study?

25 **A.** I was never informed or told of any study to my

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1 it's a few years previously, and it's from the dean of  
2 dental studies, and it says this:

3 "Thank you for your letter of November 6 ..."

4 It's addressed -- sorry, I should say -- to your  
5 GP, I think.

6 "... in which you state your concerns about the  
7 way that two patients of yours who have a congenital  
8 bleeding diathesis have recently been treated in the  
9 dental hospital. I have every sympathy with your  
10 views and personally feel that at times we are almost  
11 overreacting to the problem of dental treatment of  
12 high-risk patients."

13 Pausing there, the two patients in question are  
14 you and your brother.

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

16 **Q.** And you have a clear recollection, as I understand it,  
17 of going for dental treatment in circumstances that  
18 prompted this letter.

19 **A.** That's correct.

20 **Q.** What can you remember?

21 **A.** It was horrendous. My dad -- it was Dad that took us?

22 **PAUL HUTCHINSON:** Yes, it was.

23 **MYLES HUTCHISON:** My dad took us up to the dental hospital  
24 we went to because with haemophilia, you know, they  
25 wouldn't let us have anything done at a normal

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1 knowledge. Not that -- no, no, if ever I was getting  
2 blood tests, I presumed it was normal blood tests,  
3 regular ones that we get, and I was never told I was  
4 in a particular study, no.

5 **Q.** Henry, could we have 2168015.

6 We can see this is an entry from your medical  
7 records, and it's the top entry we're interested in.

8 We can see Dr Ludlam's name at the top and the  
9 date appears to be January 1991.

10 If we go to the second entry under that date, it  
11 says:

12 "He is HIV and hep B negative, but should be  
13 treated as a risk of infection."

14 Do you know why in 1991 you were identified as  
15 someone who should be treated as a risk of infection,  
16 even though you were HIV and hep B negative?

17 **A.** No.

18 **Q.** You think that's an entry made by Dr Ludlam himself.  
19 You've got a recollection I think of him making  
20 entries with a particular kind of fountain pen.

21 **A.** Yes, it was a fountain pen he always used, and  
22 I always thought typical doctor's writing, you can  
23 hardly make it out, but that looks very much like his.

24 **Q.** Could we have up on screen, please, 2168021, Henry.

25 This a letter -- this from November 1986, so

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1 dentist, and we were waiting to get seen and all of  
2 a sudden we were taken to this room covered in plastic  
3 and the people that were going to do our dental care  
4 had big plastic suits on, actual hazmat suits.

5 **PAUL HUTCHISON:** Like firemen.

6 **MYLES HUTCHISON:** We were like, "What's going on?" And my  
7 dad was getting real angry. "The boys are nervous as  
8 it is, they're going to the dentist, no one likes the  
9 dentist really."

10 We went in and I can remember crying because  
11 they were doing this, you know, the usual things to my  
12 mouth, but I was scared because they were all covered  
13 in plastic. My dad was furious about it and I think  
14 he --

15 **PAUL HUTCHISON:** He just took us out.

16 **MYLES HUTCHISON:** He just pulled us out and said, "That's  
17 enough". I think by -- Dr Kuenssberg there is because  
18 my dad kicked up a fuss with the GP about the way we  
19 were treated, and I think that was him reaching out to  
20 say, "Why are you treating these boys like they are  
21 a virus? We've not said they've got anything wrong  
22 with them that they should have to be treated this  
23 way". Unless there was knowledge of us having  
24 something that they needed that much attention.  
25 Obviously my mum and dad weren't aware and we weren't,

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1 so it was horrendous. It was terrible.  
 2 **Q.** You were about 14 at the time, Myles. Paul would've  
 3 been about 12.  
 4 **A.** Yes.  
 5 **Q.** It's late 1986. Neither of you had ever tested  
 6 positive for HIV, and you weren't aware, either of  
 7 you, of having been diagnosed with any other infection  
 8 at this time.  
 9 **A.** That's correct. We didn't have any knowledge.  
 10 **Q.** We can just see the letter continues:  
 11 "I would like to explain the current procedure  
 12 in the dental hospital. A closed surgery has now been  
 13 set aside solely for the treatment of high-risk  
 14 patients, and in this surgery all precautions are  
 15 taken for the prevention of transmission of infection,  
 16 with particular reference to HIV and hepatitis B  
 17 virus. This involves staff being masked, gowned,  
 18 gloved and with plastic sheets on all working  
 19 surfaces.  
 20 "A problem that then arises is the  
 21 identification of high-risk patients. Dr Ludlam has  
 22 advised us that all haemophilia patients should be  
 23 regarded as high-risk patients, and he does not wish  
 24 us to investigate in any way which of these patients  
 25 are HIV antibody positive or negative. It is because

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1 "Pah" is just a total disregard for what professionals  
 2 are trying to tell him.  
 3 **Q.** It remains a matter of concern to you, Myles, you say  
 4 in your statement --  
 5 **A.** Yes.  
 6 **Q.** -- that there may still be samples of your blood at  
 7 the Royal Infirmary that could be used for research or  
 8 testing without your knowledge and consent.  
 9 **A.** That's correct, yes.  
 10 **MS RICHARDS:** Paul, can I turn to you and ask you some  
 11 questions. We've established you're a year and 10  
 12 months younger than Myles. You also have haemophilia  
 13 B diagnosed when you were a baby.  
 14 **PAUL HUTCHISON:** Yes.  
 15 **Q.** You recall in your statement having factor treatment  
 16 at home with your mum injecting you from the age of  
 17 about 6 or 7.  
 18 **A.** That's right, aye.  
 19 **Q.** You've described in your statement going to the  
 20 Royal Infirmary and you say this:  
 21 "We always cried having to go there. The people  
 22 were older and we kept seeing them disappearing, which  
 23 can be scary for children."  
 24 **A.** Yes.  
 25 **Q.** You have similar memories to Myles.

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1 of this advice that all haemophilia patients now  
 2 attending the dental hospital are treated as high-risk  
 3 patients.  
 4 "I would hope that in the not too distant future  
 5 a compromise can be reached in which the personal  
 6 feelings of these unfortunate patients can be met and  
 7 at the same time the most appropriate method of dental  
 8 treatment can be carried out.  
 9 "I am taking the liberty of copying this  
 10 correspondence to Dr Ludlam."  
 11 We see that at the bottom.  
 12 Now, this document has come from the medical  
 13 records you've received from the Royal Infirmary.  
 14 **A.** Yes, that's correct.  
 15 **Q.** The copy of the medical records that you have received  
 16 has this word "Pah!" -- if we could highlight that  
 17 please, Henry, if that's possible -- at the bottom  
 18 written on it.  
 19 **A.** Yes.  
 20 **Q.** You have a view as to who you think wrote that.  
 21 **A.** Oh, I know who wrote that. That's Professor Ludlam.  
 22 That's his P. I've seen it so many times. He's  
 23 obviously -- you know, he doesn't like being  
 24 questioned, his authority or knowledge or anyone  
 25 interfering in any way with what he requires, and the

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1 **A.** Yes, we used to go in -- you'd go in, there would be  
 2 the older chaps, and as you passed the door, I mean,  
 3 some of them could hardly walk, their limbs had been  
 4 in for operations and they were sorry looking, they  
 5 were down looking, and if you'd pass the treatment  
 6 door, if it was open, you'd see them sitting there,  
 7 and the only way I can describe my memory, seeing what  
 8 it was like, it was like a bunsen burner tube coming  
 9 out of their vein, and that was them getting their  
 10 treatment. But it was scary seeing this, in that we  
 11 were going to have to go and maybe get this ourselves.  
 12 So it was horrible, horrible visions we had in  
 13 the hospital. It was scary. Really scary, yeah.  
 14 **Q.** You started treating yourself at home from the age of  
 15 about 13 --  
 16 **A.** Yes.  
 17 **Q.** -- when you and Myles went on an adventure holiday for  
 18 haemophiliac boys. You say in your statement that you  
 19 had a bit of a fear of the nurse being the one to do  
 20 it, and you found it easier to find your veins than  
 21 the nurse.  
 22 **A.** Yes, it was the first time I injected myself when we  
 23 were in Wales at this activity holiday, because all  
 24 the children that were coming out were coming out  
 25 crying and it was making me feel worse, and

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1 I thought -- I spoke to Myles and I says, "Can -- what  
2 will I do?" The only other option was to try and do  
3 it myself. So I done it myself, with the fear of them  
4 making me cry, yeah, but at the time I actually got  
5 a bleed when we were out on an activity, and I didn't  
6 have enough treatment. My ankle was really swollen.  
7 I struggled to get my boot on at the time. But  
8 Dr Ludlam had told us under no circumstances to take  
9 English factor, to come back with a bleed if you had  
10 one.

11 So that's what happened. That was the end of  
12 the holiday for me. That was just -- I was sitting  
13 while everybody else went out because I refused the  
14 English factor when I was there.

15 Q. Do either of you remember what year that holiday was?  
16 A. I can't remember.

17 MYLES HUTCHISON: What age were you, about 14?  
18 PAUL HUTCHISON: Aye, must have been.

19 MYLES HUTCHISON: It must have been around 1986/1987.  
20 MS RICHARDS: Paul, you also recall Professor Ludlam  
21 referring to you and Myles as "pups", but also as "his  
22 boys".

23 PAUL HUTCHISON: Yeah.

24 Q. You've recalled in your statement you and Myles were  
25 very anxious when news of HIV, AIDS and its connection

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1 A. Yes. Every day after I came in from school, I would  
2 just put my bag down and go and lie on the settee, and  
3 that would be me for about an hour, two hours, and  
4 then I would get up feeling a bit better. But that  
5 was always the case. I never thought like it was for  
6 anything else. I thought just come in from school,  
7 you're tired. But obviously for other reasons now  
8 knowing that's why -- and I'm still like that, I still  
9 have to have a nap in the afternoon, and I feel guilty  
10 for doing it. I don't know why, but I do. I should  
11 be doing stuff, I should be working, whatever. But  
12 I still do that.

13 Q. And you, Paul, share Myles's concern that you've been  
14 the subject of tests or studies without your knowledge  
15 and consent.

16 A. Yes.

17 Q. We'll look at a small number of documents.  
18 Henry, these are 2167 documents, so 2167014,  
19 please.

20 This is a letter dated 7 May 1980. It's from  
21 Dr Ludlam to a consultant paediatrician at the Leith  
22 Hospital. That was the hospital where you received  
23 your care prior to your care being transferred to the  
24 Royal Infirmary.

25 A. Yes.

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1 with haemophiliac patients broke. You were always  
2 worrying that you had HIV because of everything you  
3 were reading in the press.

4 A. That's right.

5 Q. And you remember difficulties at school as well.

6 A. Yes. We were treated so differently. People would  
7 come up to us, and the teachers made it knowledge that  
8 we had haemophilia, and other children would come up  
9 to me and ask, "If I cut you, will you bleed to  
10 death?" And they did actually try and do it in the  
11 science class with a scalpel or whatever. Called AIDS  
12 scum, junkies, gay boys, everything like that. There  
13 was even stuff written -- when we stayed in Edinburgh,  
14 there was stuff written down on the ground, AIDS scum,  
15 to my brother, his nickname Mitch at the time, and to  
16 myself, and people -- you thought -- I ended up  
17 walking about at school sort of just yourself as  
18 a loner because I couldn't actually make specific  
19 friends because people were -- people were strange  
20 towards us.

21 Q. You too, Paul, remember in your teens feeling tired,  
22 having to lie down when you got home from school,  
23 having what you thought at the time were a lot of  
24 colds or flu-like symptoms, aches and pains, brain fog  
25 not being as energetic as other kids.

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1 Q. We can see here it says:  
2 "Dear Dr Syme, I believe that until recently  
3 these two brothers with haemophilia were under your  
4 care. Each year, as you will know, we have to compile  
5 statistics for the amount of treatment used in  
6 patients with congenital bleeding disorders. These  
7 then form part of the national statistics that are  
8 meticulously collected by the Oxford Haemophilia  
9 Centre on behalf of the Haemophilia Centre directors.  
10 I am currently collecting the treatment records for  
11 1979 and I should be most grateful if you could let me  
12 know the total number of packs of cryo and units of  
13 Factor [it says VIII but you would've been receiving  
14 Factor IX concentrate] given to both these patients.  
15 I am sorry to trouble you with this small matter."

16 Now, as I understand it, you don't have  
17 necessarily an objection to statistical information  
18 being collected, but you don't think that your parents  
19 knew that this information was being collected.

20 A. My parents had no knowledge of that at all. Neither  
21 did I, yeah.

22 Q. You have a concern that this was Dr Ludlam not simply  
23 providing information about his own treatment, but  
24 looking to see what kind of treatment you'd been  
25 receiving previously.

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1 A. Yes.

2 Q. Could we have 2167020, please.

3 The date of this document's unclear, but it's

4 from your records, Paul, and it has on the right-hand

5 side the word "AIDS", then it's unclear whether what's

6 written there is "skin" or whether it's part of the

7 word "stud", "study", or whether it's something else.

8 But do you know why there should be any reference to

9 AIDS, whether it's study or another word, in your

10 medical records?

11 A. None at all, because I didn't have HIV, AIDS.

12 Q. And 2167021, please.

13 Now, this is a very difficult document to read,

14 and all we can decipher from it is that it's from

15 Dr Ludlam and it's addressed to Dr McClelland, who was

16 a director of the blood transfusion -- or the blood

17 service. It appears to be about you. That's about

18 all that can be read.

19 Do you have any knowledge as to why that might

20 be in your records or why there might be

21 correspondence about you?

22 A. No knowledge whatsoever why Professor Ludlam would be

23 in contact with Dr McClelland, no.

24 Q. Then 2167022, please --

25 SIR BRIAN LANGSTAFF: Just before you leave that, does it

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1 that the development ..."

2 MS RICHARDS: "... that he developed ..."

3 SIR BRIAN LANGSTAFF: Thank you.

4 So that's dated 1984?

5 MS RICHARDS: It looks like it. But, again ... yes, on

6 the screen -- June 1984. 20-something of June 1984.

7 SIR BRIAN LANGSTAFF: So there looks to be a reference to

8 this gentleman having -- it looks like possibly

9 contracted hepatitis B in 1984.

10 MS RICHARDS: Although it was Myles who contracted

11 hepatitis B in 1984. You hadn't, Paul.

12 PAUL HUTCHISON: No, that's correct. Unless they haven't

13 told me!

14 MS RICHARDS: 2167022, then.

15 This a letter June 1992. It's addressed to

16 Dr Ludlam. It's from Professor Gianelli, professor at

17 molecular genetics at the United Medical and Dental

18 Schools of Guy's and St Thomas' Hospital in London.

19 It refers to a mutation in you and sets out what that

20 is.

21 Do you have any idea what that relates to?

22 A. No idea.

23 Q. Were you ever told at the time that there was some

24 form of dialogue or discussion about this?

25 A. No, never.

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1 help to put yellow over it? It says reference to

2 hepatitis --

3 MS RICHARDS: Yes. There is a reference to hepatitis in

4 the second line. We've not been able, even with

5 yellow highlighting, to clearly work out what is being

6 said. This is the copy as provided to Paul or his

7 legal representatives.

8 SIR BRIAN LANGSTAFF: Yes.

9 MS RICHARDS: But other than hepatitis -- it looks like it

10 might be hepatitis B, but ...

11 SIR BRIAN LANGSTAFF: It looks like "The latest

12 [something] of hepatitis B infection".

13 MYLES HUTCHISON: It does look like "hepatitis".

14 PAUL HUTCHISON: Mm-hm.

15 MS RICHARDS: Then you have --

16 SIR BRIAN LANGSTAFF: Thank you.

17 MS RICHARDS: -- something "let you know" in the first

18 line.

19 SIR BRIAN LANGSTAFF: "... that the above gentleman with

20 [something or other] is the latest [something] of

21 hepatitis B infection."

22 Latest victim? I don't know. It's not

23 "victim", but it's something. Then --

24 MYLES HUTCHISON: Hepatitis B infection.

25 SIR BRIAN LANGSTAFF: "I have just [something] identified

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1 Q. You also recall the device that Myles has described

2 with the multiple needles.

3 A. Yes.

4 Q. Did you know what that was for?

5 A. No, I didn't have any idea. We went up together for

6 that, and all I can remember was it was really painful

7 when they done it. I didn't know what it was for. We

8 always put our trust in Dr Ludlam, and what he said we

9 always thought was for the benefit of us, so we done

10 the things, but I didn't have any idea what it was for

11 though.

12 Q. You've learnt from your medical records that you were

13 tested on a number of occasions for hepatitis B from

14 the mid-1980s onwards. Were you told that at the

15 time?

16 A. No.

17 Q. Henry could we have 2167006, please.

18 This is just an example from your records. It

19 is one of a number of examples, but we see the

20 biohazard sticker or the "Risk of infection" or the

21 stamp or sticker on there, and that's a feature of

22 your records.

23 A. Yes.

24 Q. Stamped, "Risk of infection".

25 If we have then 2167007, please.

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1 This is a letter from a consultant surgeon to  
 2 a clinical assistant to Dr Ludlam. It's  
 3 dated April 1993. It's asking about a procedure, the  
 4 details of which are not relevant for present  
 5 purposes, but it says this in the last paragraph:  
 6 "Incidentally, I would be grateful if you would  
 7 let me know whether or not Mr Hutchison is still to be  
 8 regarded as a high-risk patient from the point of view  
 9 of taking special precautions in theatre and  
 10 subsequently. It is important that we know this so  
 11 that his case may be appropriately scheduled on one of  
 12 our lists."

13 Just pausing there, you weren't I think aware at  
 14 the time that you were regarded as a high-risk  
 15 patient.

16 **A.** The only thing I knew was I was to be taken first  
 17 thing in the morning to get the procedure done. Then  
 18 it got changed all of a sudden, that I was last into  
 19 the theatre to get it done. So looking back now,  
 20 I can only imagine it's because they thought I was  
 21 a high risk and they didn't want to put anybody else  
 22 at risk.

23 **Q.** Then we can see in the bottom right-hand corner  
 24 a handwritten entry. If we could have the bottom of  
 25 the page, please, Henry, and if you could highlight

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1 1993. Is that what you remember?  
 2 **A.** Yes, it was around about that time, that's correct.  
 3 I was actually -- I received a phone call from the  
 4 hospital and they asked me to come up because they  
 5 needed to speak to me about something, and I went up  
 6 the next day and I sat down and they told me, "I'm  
 7 sorry to tell you, Myles, but you've been infected  
 8 with hepatitis, but I wouldn't worry too much, it's  
 9 not that big a deal. You might get flu-like symptoms,  
 10 things like that, feel a bit tired", which was a wee  
 11 bit funny to me because I'd been feeling that since  
 12 I was about 12 years old, but they didn't make a big  
 13 fuss.

14 I said, "It's meant to be quite dangerous,  
 15 because I've had hepatitis B and that's a killer, you  
 16 know, it's killed people", and they said, "Oh, no,  
 17 it's nothing to worry about, you don't need to do  
 18 anything special or anything like that, but we feel  
 19 obliged we should tell you about it."

20 **Q.** We'll look at a couple of documents.

21 Henry, could we have 2168004. So we're on to  
 22 2168 now, please. Thank you.

23 We can see the date of this is 23 September 1993  
 24 at the top, date of admission, date of discharge:  
 25 24 September 1993. It's a discharge summary.

75

1 those handwritten words on the right-hand side. It  
 2 says:

3 "Paul was tested negative some years ago.  
 4 His ..."

5 Then a word is crossed out, which looks to me as  
 6 though it might be "sexual", but it's not clear, it's  
 7 crossed out:

8 "... behaviour since would not lead me to  
 9 believe he was/is now anything other than normal  
 10 Edinburgh risk."

11 The word "risk" has been cut off on this, but  
 12 the original says "normal Edinburgh risk".

13 Do you have any idea what the phrase "normal  
 14 Edinburgh risk" refers to?

15 **A.** No. My first knowledge of that was seeing my medical  
 16 records there, but I don't have a clue what it was  
 17 about.

18 **MS RICHARDS:** Myles, I want to turn back to you and ask  
 19 you how you learnt you've been infected with  
 20 hepatitis C.

21 You now know you have hepatitis C genotype 3  
 22 from Factor IX products that were administered to you.

23 **MYLES HUTCHISON:** That's correct, yes.

24 **Q.** It appears from your records that you and your parents  
 25 were told of that diagnosis in around the autumn of

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1 If we go down towards the bottom of the page,  
 2 please, we can see in the paragraph headed  
 3 "Management", five lines down it talks about you being  
 4 very reluctant to stay in hospital and it says this:

5 "Partly this was because discussion regarding  
 6 his hepatitis C status had been instituted with him.  
 7 His wife was a little upset to discover that he was in  
 8 fact hepatitis C positive and he was anxious to be at  
 9 home with her to reassure her."

10 That helps us try and date when you were told,  
 11 sometime in September 1993 you think.

12 **A.** Mm, that's correct.

13 **Q.** If we have up on screen 2168005, we can see here then  
 14 a letter the following month, 26 October 1993, from  
 15 one of Dr Ludlam's clinical assistants to your GP.

16 It says in the second paragraph:

17 "I am very sorry to hear that  
 18 Mr and Mrs Hutchison have been so worried about  
 19 hepatitis C."

20 It refers to both of you in fact having  
 21 appointments to be seen by Dr Hayes in November who  
 22 will be able to answer questions, and encloses a copy  
 23 of "an information leaflet we have made up for  
 24 patients which you may find of some help", so that was  
 25 being sent to your GP.

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1 A. Yes.

2 Q. Prior to being told that you were hepatitis C positive

3 in the autumn of 1993, had you been made aware that

4 you were being tested for hepatitis C?

5 A. No, not at all.

6 Q. Now, if we could have up on screen, please, Henry,

7 2168016, and could you highlight the bottom half of

8 the page, please.

9 What we can see from this, Myles, if we look at

10 the date -- the date is July of 1992. Again, it's

11 actually clearer on the hard copy than on the screen.

12 Date received -- this is the sample -- 6 July 1992.

13 Date reported: 10 July 1992.

14 We see it says:

15 "Final report. Enzyme immunoassay for antibody

16 to hepatitis C virus: positive. Confirmatory assay

17 for antibody to hepatitis C virus: positive."

18 So these positive test results for July 1992

19 appear in your records, but you don't think you were

20 told of your diagnosis until over a year later

21 in September of 1993.

22 A. That's correct. They mustn't have felt obliged at

23 that time to tell me.

24 Q. Can you recall what, if any, information you were

25 given about the prognosis for your hepatitis C

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1 at some length with your GP?

2 A. I went to my GP because I was scared, because I had

3 received so little information. And as I knew that it

4 was a blood-borne virus, I was worried I could hurt my

5 wife or anyone around me, because I like to think I'm

6 a decent person and I wouldn't intentionally hurt

7 anyone. So I went to my GP to get advice from him,

8 and his advice was actually: don't trust Dr Ludlam.

9 Q. Do you recall anything about this appointment

10 in December 1993? The doctor says that they hoped to

11 do their best to be informative and generally

12 reassuring. Do you recall whether you were reassured

13 or had the information you thought you required?

14 A. Not at all, no. Once again, like my mum and dad

15 before me, I was fobbed off. I was told I was

16 worrying about nothing. The main thing was to keep it

17 to myself and any questions that I had, "There's a wee

18 leaflet, read that tonight", you know? Same as they

19 done to my dad years earlier with the hepatitis B.

20 They gave him a leaflet and unlike -- unfortunately

21 I didn't listen to his advice -- I wonder why? -- and

22 I spoke to my wife, and that was the start of a lot of

23 other problems, but ....

24 Q. We'll come on to the family life later.

25 If we could have 2168019, please, Henry.

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1 infection?

2 A. I was told that I might get some flu-like symptoms, be

3 a bit more tired than usual, but it wasn't such a big

4 deal. But I was warned that I shouldn't tell people

5 about my infection. He even said, "It may be an idea

6 not to tell your wife". But the information was

7 minimal. It was sort of palmed off. The main thing

8 I took from it was I should keep it to myself and it

9 won't be as bad for me.

10 Q. We'll look at some of the correspondence that

11 followed. Could we have 2168018, please, Henry.

12 This is now December of 1993. It's from the

13 clinical assistant to Dr Ludlam, again to your GP, and

14 it says:

15 "I am writing to let you know that Myles was

16 seen by me in the haemophilia and haemostasis centre

17 today with his wife. The consultation was mainly

18 regarding his concerns about hepatitis C, which have

19 been discussed, as you are aware, with Dr Ludlam and

20 Dr Hayes in the recent past, and I understand that you

21 have also discussed this at some length with him.

22 I did my best to be informative and generally

23 reassuring relating to hepatitis C, its consequences

24 and treatment."

25 First of all, can you recall having a discussion

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1 This is a letter of 21 November 1994, so this is

2 later on in the following year, and we can see if we

3 go down to the large paragraph, please, Henry, picking

4 it up about six lines down, it says:

5 "Earlier this year, investigations were carried

6 out to assess the degree of liver damage secondary to

7 hepatitis C. An endoscopy was performed in February

8 which was normal."

9 Then it refers to a liver biopsy being carried

10 out in February which showed mild chronic hepatitis

11 but no evidence of cirrhosis.

12 "The features were consistent with chronic

13 infection of hepatitis C. Liver function tests have

14 been abnormal for some time, and most recent ALT is

15 413 units per litre. We are currently treating many

16 of our patients who have hepatitis C with interferon.

17 Myles will probably start treatment with interferon

18 sometime in the next few months."

19 There are two things I wanted to ask you about

20 relating to this letter, Myles.

21 The first is the reference to liver function

22 tests having been abnormal for some time. Had you

23 been told that your liver function tests had been

24 abnormal for some time?

25 A. On one occasion I remember being told that some of my

80



1 blood tests came back and they were a bit concerned  
 2 about them, but they never went into any great detail,  
 3 they just said, "We're going to take some more blood  
 4 now and run tests again". But they didn't mention my  
 5 liver function specifically, no. I was just told that  
 6 some of my readings were abnormal, which it says  
 7 there, but they didn't specifically state it was my  
 8 liver. They just told me they wanted to redo the  
 9 tests.

10 Q. Then we can see the reference to a liver biopsy  
 11 carried out in February of 1994.

12 A. Mm.

13 Q. What can you recall about the biopsy and how you ended  
 14 up having it?

15 A. The biopsy, that was the biggest mistake of my life,  
 16 to be honest. I was talking to Professor Ludlam and  
 17 he said, "Myles, it would be a lot easier for us to  
 18 judge how bad, you know, your liver has been affected  
 19 by hepatitis if we took a small biopsy". And  
 20 I said -- he said, "It's not a bad procedure, it will  
 21 just be a short thing, we'll get a wee piece of tissue  
 22 and then we'll get back to you about the results and  
 23 stuff". I said, "If I got this done, would you have  
 24 to do it with my brother?" He said, "Not really, no,  
 25 because, you know, your brother and you are, you know,

81

1 It's at 2168020. It's dated 1 November 1994. It's  
 2 from your mother to Dr Ludlam.

3 A. Yes.

4 Q. It says this, and this is an important letter to you  
 5 and you wanted, for your mum's sake, us to go through  
 6 it.

7 A. Yes, I do, please, yes.

8 Q. "Dear Dr Ludlam.

9 "Since Myles and Paul were born, I have  
 10 naturally worried about them. I could write a book  
 11 with experiences, both good and bad, that I have had  
 12 over the years. When they were children, I thought  
 13 that bleeds were my main worry. As you know, some  
 14 bleeds are very painful and cause my boys great  
 15 distress. Unlike today, mothers were not allowed to  
 16 stay at the ward overnight with their children, and  
 17 every night I had to leave them was torture.

18 "I thought as they got older and a little wiser,  
 19 things would ease, that they perhaps wouldn't get so  
 20 many bleeds. Then along came AIDS and the terrible  
 21 fear that they would be infected. Unlike a lot of  
 22 unfortunate haemophiliacs, they, thank God, were  
 23 clear.

24 "Now we have hepatitis C, and are worrying about  
 25 long-term effects, such as liver disease and cancer.

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1 virtually identical, the same sort of results would be  
 2 had."

3 So I went in a couple of weeks later, and while  
 4 I was getting the liver biopsy I woke up, and I seen  
 5 my own internal organs on a screen next to me, and  
 6 I shouted to the chap that was doing it, "I'm awake  
 7 and that's blooming sore". He was prodding about  
 8 trying to obviously get into the liver tissue to take  
 9 the sample. And it wasn't the same chap that had  
 10 started doing the procedure, it was a different chap,  
 11 and I -- maybe it was an anaesthetist, maybe I'm  
 12 confused, but it looked to me as though the  
 13 anaesthetist had already done his job and the guy that  
 14 was doing it came in. And then I just remember  
 15 getting that white stuff banged into me until I passed  
 16 out again.

17 When I went back to my doctor after it and I was  
 18 talking about getting more pain in my stomach, he  
 19 said, "You shouldn't have had a liver biopsy if you've  
 20 got hepatitis, it's going to really damage your liver,  
 21 your cirrhosis is going to" -- it might have been mild  
 22 at the start, but after the biopsy my cirrhosis went  
 23 through the roof. So it was basically  
 24 Professor Ludlam's advice destroyed my liver.

25 Q. We have a letter from your mum from around this time.

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1 We are told that interferon has a 20 to 25 per cent  
 2 chance of producing normal liver function tests, but  
 3 like everything else, it also has side-effects.

4 "I think that you and your staff do a wonderful  
 5 job and are very dedicated people, but sometimes you  
 6 forget the human factor. John Smith and Harry Bloggs  
 7 are sons, husbands and fathers, and their emotional  
 8 wellbeing is as important as their physical health.

9 "My sons are trying to live normal lives, but  
 10 are finding it very difficult. I want them to do  
 11 anything that will be helpful to them and increase  
 12 their chances of a long and fruitful life, but I am  
 13 afraid to advise them in case the treatment causes  
 14 other illness and makes their life even more  
 15 difficult.

16 "I feel that hepatitis C, the illness and the  
 17 side-effects that stem from treatment with interferon,  
 18 have not been fully explained to them, and that if  
 19 they could see a little light at the end of the  
 20 tunnel, they could look forward to a future which they  
 21 are convinced they don't have. I know that you can't  
 22 make any guarantee about their future health, but  
 23 a little reassurance would go a long way.

24 "They are only starting their lives and I want  
 25 them to be happy, and it is breaking my heart to see

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1 them hurting so much. The pain they are suffering  
2 emotionally just now is far worse than any bleed they  
3 have ever had.

4 "I love my sons. They are my life. Could you  
5 please talk to them."

6 One of the reasons it's important to you to have  
7 that letter read out is because of the role your mum  
8 has played in both your lives.

9 A. Yes.

10 Q. And one of you I think says in your statement that she  
11 has blamed herself because she was the one  
12 administering the injections.

13 **PAUL HUTCHISON:** All her life she's blamed herself. Out  
14 of the blue, she'll phone us if she hears anything on  
15 the telly and she'll start crying, saying she's sorry.  
16 From the first injection she gave us, she's blamed  
17 herself for giving Myles and I what's wrong with us,  
18 so much so her [redacted] has been terrible, and it's  
19 broke my mum, everything that went on. And my dad of  
20 course.

21 **MYLES HUTCHISON:** My mum was trying to protect her  
22 children. She just wanted answers. She just wanted  
23 to try to give us the same future that any reasonable  
24 parent would want for her children, and she was denied  
25 basic knowledge or choices. She put so much faith in

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1 paragraph to having received a letter from your mum  
2 expressing some anxieties about hepatitis and its  
3 treatment. Dr Ludlam says this:

4 "I met with Mr and Mrs Hutchison this morning.  
5 We had a fairly full discussion. I explained to them  
6 about hepatitis C and its potential treatment with  
7 interferon. They both seemed more reassured after our  
8 talk. I gave them a copy of the Haemophilia Society  
9 booklet on hepatitis and also the local information  
10 leaflet we devised."

11 If we just leave this up on screen for a moment,  
12 please, Henry.

13 We can see there Dr Ludlam describing it as  
14 a fairly full discussion, providing an explanation and  
15 reassurance.

16 Do you know what your parents' recollection or  
17 experience of that meeting was?

18 A. Nothing like that. They were in a room with  
19 Professor Ludlam, who was very agitated he was having  
20 to do it, and he says, "Have you any questions?" He  
21 was very vague with my mum and dad. He said, "Look,  
22 you're worrying over much -- over nothing. They will  
23 be fine, you know. Here's a leaflet. Look through  
24 that. I'm very busy. I've got to do things", and  
25 that was it. It wasn't reassuring -- he's not

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1 people and they let her down so badly. And even  
2 though she didn't personally -- well, she did, she  
3 injected it, and that's the problem. She did inject  
4 us with it. But she had no knowledge at all that she  
5 was hurting us. She thought -- she used to practise  
6 on her own arms with needles before she started giving  
7 us it. She had blood running down her own arms  
8 because she didn't want to hurt us. She practised on  
9 her own veins. She would do anything for her boys.  
10 And you can't take away, she did give us it, but only  
11 because she didn't have the knowledge to make  
12 an informed choice.

13 **PAUL HUTCHISON:** She thought it was going to help us.

14 **MYLES HUTCHISON:** She was just looking after her kids,  
15 that was all she was doing, but she'll never see it  
16 like that, and we know that.

17 **MS RICHARDS:** We can see from the letter that in  
18 November 1994 she felt that she and you had not been  
19 given sufficient information about hepatitis C and the  
20 pros and cons of treatment.

21 We can see if we have up on screen, please,  
22 2168006, Dr Ludlam did meet with your parents after he  
23 received the letter. It's dated 18 November 1994.  
24 It's addressed to the social work department at the  
25 Royal Infirmary, and it refers in the opening

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1 a reassuring man. He's not the type of man that gives  
2 reassurance to anyone.

3 But all my mum and dad wanted, like any parent,  
4 was some information, some knowledge on how they could  
5 help us. But all he did was palm them off yet again.  
6 He gave them a leaflet and when my dad came home  
7 I said, "How did you get on, Dad?" and he had  
8 a leaflet.

9 **PAUL HUTCHISON:** There was no point. It involved a social  
10 worker as well, Geraldine Brown, and she never even  
11 got in contact with my mum and dad.

12 **MS RICHARDS:** Then we see in the paragraph below it says  
13 this:

14 "We also went on to discuss the rather more  
15 general issues that are causing the family concern.  
16 As you know, both Paul and Myles are off work because  
17 of 'depression' and you were seeing them both  
18 individual."

19 That probably should be "individually".

20 You express the concern in your statement,  
21 Myles, that this observation about depression is  
22 regarding the depression as something separate from,  
23 unrelated to, the diagnosis of hepatitis C.

24 **MYLES HUTCHINSON:** Yes.

25 Q. Whereas you view it -- you both view, as I understand

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1 it -- your depression that you were experiencing as  
 2 intimately connected with the diagnosis of  
 3 hepatitis C.  
 4 **A.** Definitely. I mean, we were both happy kids. We had  
 5 a good mum and dad. We had every reason to be happy.  
 6 We had people that cared for us, we had a loving  
 7 family. Yes, you've got problems, anyone can get  
 8 depression, I understand that. But it wasn't, you  
 9 know, until our teens at the Royal Infirmary that we  
 10 started to not be as happy as normal kids anymore, and  
 11 I'm convinced that the hepatitis and me also the hep  
 12 B, the things in my body that were hurting me did  
 13 cause depression. The physical pain caused mental  
 14 pain as well. And the same with my brother. It was  
 15 a pain no one can see, so you couldn't put a name to  
 16 it, but we felt it and it affected our minds.

17 But there was no thought attached to it  
 18 whatsoever that the problems that we'd had and  
 19 infections we contracted could cause depression.  
 20 I don't know, they must think, oh, haemophiliacs are  
 21 supermen or something that can just struggle aside  
 22 their feelings. But when you're feeling as low as you  
 23 felt with that, and then you get treated with things  
 24 like interferon, depression is very easy.

25 **MS RICHARDS:** Before we talk about interferon, Paul,

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1 wished it had just been himself that got it.  
 2 **Q.** You said in your statement that Professor Ludlam said  
 3 something to the effect that they knew you had had  
 4 non-A, non-B hepatitis --  
 5 **A.** Yes, that's right.  
 6 **Q.** -- for some time.  
 7 **A.** Yes.  
 8 **Q.** But you weren't aware of that.  
 9 **A.** I wasn't aware of this, no.  
 10 **Q.** You were told by Professor Ludlam, I understand, not  
 11 to tell the people you were working with at the  
 12 Royal Infirmary.  
 13 **A.** Yes. He said, "Under no circumstances tell anybody  
 14 you work with in the clinical biochemistry labs that  
 15 you've got hepatitis C."  
 16 **Q.** You were also told by Professor Ludlam either at that  
 17 meeting or subsequently about the possibility of  
 18 passing hepatitis C through sex, saliva or blood; is  
 19 that right?  
 20 **A.** Yes, that right.  
 21 **Q.** You say in your statement to this day it still worries  
 22 you.  
 23 **A.** Yes, it does. Even though I'm supposedly clear of the  
 24 hep C virus, but they say it is dormant, it's at such  
 25 a low level. I still believe it's in my system.

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1 I wanted to ask you about how you were informed that  
 2 you had hepatitis C. You were working at this time as  
 3 a clinical biochemistry assistant in the  
 4 Royal Infirmary.

5 **PAUL HUTCHISON:** That's right, aye.

6 **Q.** You were about 19 or 20. You've got a recollection of  
 7 being told by Professor Ludlam that you had tested  
 8 positive for hepatitis C.

9 **A.** Yes. After I found out about my brother obviously  
 10 I went up to see my brother, and I was devastated for  
 11 Myles when he was told he'd got hep C, in tears  
 12 wishing it was me that had got it, because at this  
 13 stage I didn't know I had it. I got a phone call to  
 14 go up a couple of days later to see Professor Ludlam.  
 15 He sat me down and he says, "I have to inform you  
 16 you've also got hepatitis C. We don't know much about  
 17 it," he says, "but there's a possibility you'll die of  
 18 liver cancer."

19 He said, "Have you got any questions at this  
 20 stage?" I just stared. I was in shock anyway. And  
 21 that was -- he says, "We'll provide leaflets and we'll  
 22 get more information", and that was it.

23 Then I left in a daze and I went down to the  
 24 ward where Myles was, and we cried. When we -- when  
 25 I told Myles I had it as well, he was the same. He

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1 I still think it's there. What was the --?

2 **Q.** Well, it was about the information that was given  
 3 about the fear of transmission and that still worrying  
 4 you.

5 **A.** Yeah. I mean, I still to this day think -- if I cut  
 6 myself in the house, I had -- I got blood on the  
 7 handle of the door. My wee lass says, "There's blood  
 8 on the door" and I jumped up, "Don't touch it". Even  
 9 to this day, even though I'm supposedly not going to  
 10 infect any of my family members, it worries me sick  
 11 that there's a possibility that I could give my kids  
 12 or my wife hep C.

13 **Q.** Again, we're just going to look at a few of the  
 14 records relating to your hepatitis C diagnosis, Paul.  
 15 Henry, could we have 2167008, please.

16 We can see this is dated, top right-hand corner,  
 17 January of 1993, and if we go further down the page,  
 18 we see the January 1993 date there:

19 "First report enzyme immunoassay for antibody to  
 20 hepatitis B virus positive. Results of confirmatory  
 21 testing to follow."

22 So there appears to be a positive result, at  
 23 least a preliminary positive result, in January of  
 24 1993, but you weren't told until September of 1993; is  
 25 that right?

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1 A. That's right, uh-huh.  
 2 Q. If we have up on screen 2167009, this is a letter,  
 3 24 September 1993, to your GP from a clinical  
 4 assistant to Dr Ludlam. It refers to you "attending  
 5 at the Haemophilia Centre today where we discussed  
 6 hepatitis C". It refers to hepatitis C antibodies and  
 7 that you have slightly abnormal liver function tests,  
 8 and it says this:  
 9 "Hepatitis C was discussed at some length with  
 10 Paul and he was given an information sheet to take  
 11 away with him."  
 12 If we then have up on screen, please, 2167010,  
 13 we can see a letter dated October of 1993. Again, it  
 14 just gives us some insight into how your parents were  
 15 feeling. It's from the GP. It says:  
 16 "I have had a meeting with the parents of my  
 17 patients Paul and Myles Hutchison. They are worried  
 18 and perplexed by this new terror of hepatitis C. Paul  
 19 specifically is increasingly rejectionist of all  
 20 advice as he has been witness to all the story of HIV  
 21 and hepatitis B."  
 22 That was, as I understand it, Paul, from your  
 23 statement, the beginning of something which continues  
 24 to this day, where you are very concerned about  
 25 putting any trust in doctors and taking any form of

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1 You had interferon in 1995. You were in your  
 2 early to mid-twenties. What can you recall about that  
 3 experience and any side-effects that you suffered?  
 4 **MYLES HUTCHISON:** It wasn't the best, to say the least.  
 5 I went to the hospital and they said, "We're going to  
 6 give you this to take, injections, you might feel, you  
 7 know, the usual flu symptoms, but you should be fine  
 8 about going to your work and things like that."  
 9 I started taking the injections, but I couldn't  
 10 keep doing it. I think I was only on it for about six  
 11 weeks, maybe, because my behaviour was changing.  
 12 I was irrational, I was becoming moody, becoming more  
 13 aggressive as a person, which really isn't in my  
 14 nature. I'm not aggressive by nature. And I started  
 15 to feel terrible, shaky. It was like the worst  
 16 hangover mixed with the worst cold you've ever had.  
 17 My joints were sore. It was just horrendous. So  
 18 I had to stop.  
 19 I said, "I'm sorry, I can't do this", and I went  
 20 up to the hospital, took the treatment back, and --  
 21 but after it, it was -- the feelings were still there.  
 22 Even though I stopped taking it, they seemed to go on  
 23 and on and on, and I actually felt like it made things  
 24 worse. I actually felt ten times worse after it.  
 25 Even six months after it, I still didn't feel as well

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1 treatment.  
 2 A. Yes, I don't trust them whatsoever. I think  
 3 everything tells me it's all lies they're telling,  
 4 I feel.  
 5 Q. Could we have on screen, please, Henry, 2167011.  
 6 This is 16 December 1993. It refers to you  
 7 having been seen in a joint liver haemophilia clinic  
 8 and says this:  
 9 "As you know, we discussed with him whether  
 10 further investigation should be undertaken. While he  
 11 is antibody positive, he is PCR negative, and his  
 12 liver function tests at the moment are only mildly  
 13 abnormal. However, on reviewing his case history, his  
 14 transaminases in the mid and late 1980s were  
 15 persistently over 100. I therefore think that we  
 16 cannot be absolutely sure that he has entirely  
 17 quiescent disease or what stage it is at."  
 18 Do you recall whether you were told about the  
 19 persistent results over 100 in the mid to late 1980s?  
 20 A. I was never told this.  
 21 **MS RICHARDS:** We can see from this in December 1993 it  
 22 records you as being PCR negative.  
 23 I am going to ask you both now about the  
 24 treatment you received for your hepatitis C.  
 25 Myles, you first.

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1 as I did before I started taking it.  
 2 Q. You've said in your statement it's around this time  
 3 that your mental health started to go downhill and  
 4 there were two occasions when you tried to kill  
 5 yourself.  
 6 A. That's correct, yes.  
 7 Q. Can you tell us about that to the extent that you  
 8 would like to.  
 9 A. Well, I stopped being the person that a lot of people  
 10 knew. As I said, my moods changed, I became  
 11 aggressive, I drank too much, I became a more selfish  
 12 person. I had a wife that was not the understanding  
 13 type, let's say. She expected life to be a smooth,  
 14 easy ride, but it wasn't possible with everything that  
 15 was going on with me, and my head just went down.  
 16 I went to a dark, dark place where I hope I never find  
 17 myself again.  
 18 The first time I got into my car and I drove  
 19 into another car without a seat belt on, hoping that  
 20 I'd go through the windscreen and it would end me.  
 21 I don't know how I survived that, but I did.  
 22 Then my marriage split up. I lost my house, my  
 23 job, everything, and I was back with my mum and dad,  
 24 and I couldn't cope. I just -- I'd lost everything.  
 25 My pride was gone, I just -- so I went down to Granton

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1 Harbour in Edinburgh and I jumped off the pier.  
2 Instead of dying, I tore the muscle in my leg on the  
3 rocks at the bottom, and luckily someone seen me there  
4 and the police came and got me, and they took me home.  
5 I don't know why, they took me to my mum and dad's,  
6 who automatically phoned the hospital and I got taken  
7 up there. It's pretty hard to explain how you got  
8 a bleed when you jumped off a pier. It's obvious you  
9 weren't just trying to go swimming because the tide  
10 was out.

11 So, yeah, I -- that's a couple of times. Other  
12 times I thought about taking pills and doing other  
13 things, injecting air into my veins to try and cause  
14 a haemorrhage. I've thought of lots of ways to kill  
15 myself, and it's not a normal thing for any human  
16 being to have to think. I'm just glad it never  
17 happened, but -- it never worked, sorry. But, yeah,  
18 I have been to the darkest place. I hope I'll never  
19 go back.

20 Q. You've said in your statement you were scared of what  
21 was inside you.

22 A. Yeah.

23 Q. What did you mean by that? The hepatitis or  
24 psychologically what was inside you, or both?

25 A. I was scared of both. I don't know -- my brother

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1 me through it. I also had my wee kid, my wee daughter  
2 there, and I had something to fight for. I wanted to  
3 get through this. But I was warned a few times that  
4 it was getting dangerous when I was taking it. My  
5 results were coming back and I was getting very ill.  
6 It was really hurting me. They told me to half the  
7 amounts I was taking, but I was determined to get rid  
8 of this horrible thing inside me, so I kept taking the  
9 full amount.

10 For six months I basically just clung on to one  
11 side of the wall to get through it, because the place  
12 that I'd been before in my mind, the dark place,  
13 I seen the bright light with my wee kid's face and  
14 I kept walking towards that instead of there again.  
15 I felt that's the nearest I came since, you know,  
16 where I tried to hurt myself, to being there again.  
17 It's a horrible, horrible treatment.

18 If it wasn't for what you think it's going to  
19 do, nobody in their right mind would take it. But as  
20 I'm sure a lot of people here will know, you're that  
21 desperate to get some good back in your life, to get  
22 something out of you, to feel a wee bit better, that  
23 you've got a chance at being happy again and not feel  
24 so ill, you'll do almost anything.

25 And I did it, I went through it, and they told

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1 sometimes says this. Sometimes in my body when I wake  
2 up I feel like I've got fire ants going through my  
3 skin, under my veins. I just feel so sore and so  
4 tired and my body -- I feel like -- I know I'm a big  
5 chap, but it's like trying to move a -- well, I'm not  
6 quite there yet, but I feel it's just such an effort  
7 to move. And mentally it just drags -- I've just been  
8 that badly damaged, it's -- sorry, I've lost myself  
9 there.

10 Q. No, you've answered it perfectly, thank you.

11 In 2003, you were advised by Professor Hayes to  
12 attempt treatment again because of the risk to your  
13 liver.

14 A. That's correct, yes.

15 Q. And so on the second occasion you had interferon and  
16 Ribavirin for six months.

17 A. Yes.

18 Q. You've described that in very vivid terms in your  
19 statement as hell on Earth. You thought you were  
20 going off your head. You were in a dark place. What  
21 can you tell us about it?

22 A. What I could tell you is that that place I was hoping  
23 to never be in again very nearly came back. Luckily  
24 the second time I was on interferon, I had my current  
25 wife, who is a lovely person, very supportive, to help

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1 me it was cleared, which I then found out, you know,  
2 a matter for great conjecture because it's not clear,  
3 it's still in my body, it's lying there dormant, and  
4 I've got this constant fear that it'll start again.  
5 Because I want to be here now, I have got something to  
6 live for, I've got my wee kids and got my lovely wife,  
7 you know, my brother and my family. I've got a lot to  
8 live for, but I'm genuinely scared about how long I've  
9 got.

10 Q. You've said in your statement although that course of  
11 treatment was, you were told, successful, and the  
12 description that was given to you was that the  
13 hepatitis C was now dormant, you still suffer many of  
14 the effects of being infected, and you say, "It  
15 doesn't seem that I'm clear of anything".

16 A. No. All the same pains, all the same things I hoped  
17 would disappear when I done this treatment, that's why  
18 I did it. I hoped to feel a bit better, play with my  
19 kids more, do more. Just didn't seem like anything  
20 changed. If anything, my mental health had been  
21 damaged again. The only thing that I got out was  
22 I seen a wee glimpse into the dark place I'd been  
23 before, and it reminded me to watch what I was doing.  
24 That's all I got. But I certainly didn't feel any  
25 better.

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1 Q. You put it this way in your statement, Myles. You  
2 talk about having gone through the two courses of  
3 treatment and the detriment to your physical and  
4 mental health. You say that the spark in you has  
5 gone.  
6 A. Yeah.  
7 Q. You feel a different person.  
8 A. Yeah. It's just like, you know, anyone, when you're  
9 growing up, you're young, you've got ambitions, you  
10 see life, you see this big opportunity to be somebody,  
11 make a difference to other people's life, you know, be  
12 somebody or not. You don't have to be famous or rich  
13 or -- just be somebody that people want to remember.  
14 Somebody that they go, "Yeah, nice person", you know.  
15 I tried my hardest. I was the boy that would  
16 help a wee lady come off the bus and you got messages  
17 to her house and that. My mates would make fun of me  
18 and things like that, but I wanted to be that guy.  
19 And I just feel that the spark that we're born with  
20 inside us and it grows depending on our lives, it just  
21 got totally wiped out. Now I'm lucky that I've got  
22 some lovely wee sparks around me that I call my  
23 family, and I try and feed off of their dreams and  
24 hopes and that and try to help them now, because  
25 I feel my hopes and dreams are gone.

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1 want to be here anymore. I couldn't take it anymore.  
2 I'd had enough.  
3 My mum and dad, they wouldn't leave me in the  
4 house in case I tried to commit suicide or whatever,  
5 because that's how -- that's how I felt. I didn't  
6 want to live anymore.  
7 Q. You had mood swings, depression. Physically you had  
8 problems with hearing, vision, sore head,  
9 co-ordination problems.  
10 A. Yes.  
11 Q. Could we have up on screen, please, Henry, 2167012.  
12 We can see this is a letter from October of  
13 1995, and it says this:  
14 "I was pleased to see Paul at the Haemophilia  
15 Centre this morning. As you know, he stopped  
16 interferon on 13 September because he was finding the  
17 side-effects intolerable. However, shortly after he  
18 stopped we had the results of his HCV RNA quantified  
19 by PCR, which show that he had become negative in May,  
20 just before he commenced interferon, and was also  
21 negative in the most recent sample, which was at the  
22 end of August. I explained to Paul that even when his  
23 PCR was positive, the level of viraemia was fairly  
24 low and as it had become undetectable, this was a very  
25 good sign. However, we will have to monitor him

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1 MS RICHARDS: Paul, you had treatment for interferon in  
2 1995.

3 PAUL HUTCHISON: That's right.

4 Q. But your medical records record that you were hesitant  
5 about it. You managed to stay on it for four months  
6 rather than the full six months.

7 A. Mm, that's right, but the side -- I was working in the  
8 Royal Infirmary at the time as a clinical biochemist,  
9 and Professor Ludlam said to me, "You'll be able to  
10 continue working whilst on interferon", because I'd  
11 only been in the job for just about a year and I was  
12 wary obviously about starting a new treatment, because  
13 I didn't know the side-effects, you didn't know what  
14 was going to happen.

15 I started it and the side-effects were  
16 horrendous. I was getting bleeds in my abdomen where  
17 I was putting the actual interferon, so I was getting  
18 bleeds as well as taking interferon. There were --  
19 my -- it was a lot worse than the flu. I would be in  
20 the house shaking. My body -- I couldn't even walk to  
21 the shops for a paper because my vision was blurry.  
22 It was horrendous. So much so, I gave up. I took  
23 it -- I went like for the four months, but I was that  
24 sore and tired, and I was just similar to my brother,  
25 I just -- I was in a really dark place and I didn't

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1 closely as it is of course possible for his PCR to  
2 become positive again."

3 So we've seen from earlier correspondence you  
4 were PCR negative December 1993. We see from this  
5 that they discovered after you'd stopped the treatment  
6 you had been PCR negative before you started.

7 A. That's right.

8 Q. We also see you've been told here that although  
9 undetectable it could become positive again.

10 A. That's right.

11 Q. That's the fear that's haunted you ever since.

12 A. Yeah, I mean, when I had the interferon, I lost my  
13 job. I thought I'd get a lot more support working in  
14 the Royal Infirmary through it, but I ended up losing  
15 my job because of being off with depression. And that  
16 just made me even worse, losing my job. It made me  
17 feel worthless. It was just -- it was -- what was  
18 the -- sorry. I've lost my train of thought there.

19 Q. The fear that you've had ever since that the  
20 hepatitis C is still with you.

21 A. Yeah. I mean, it doesn't matter, I've seen  
22 Professor Hayes and they've told me, "It's fine,  
23 you've got nothing to worry about". It doesn't matter  
24 what he says. I don't believe him at all. I don't  
25 trust him. I don't trust anybody at the Royal.

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I've seen the psychologist for over a year and a half at the Royal Infirmary, and I eventually said to her "I think" -- she said, "When do you want to see me again?" I said, "I think we should just call it a day now". I says, "You can't fix me, I'm broken. It's in here, it's in my DNA", and nothing that anybody can say will change the fact that I still think I'm going to die of liver cancer. In my mind, that will still happen some time, or that I could infect my family or something.

**Q.** We can see from some of the correspondence in your medical records that you have returned to the doctors over the years and your concerns remain. We'll have 2167002, please. If you could highlight the first paragraph, please.

This is November of 1996, so this is a year on from the interferon treatment. It records you attending the Haemophilia Centre with your mum. You and your mum had a number of questions relating to hepatitis C. You wanted to know if you should have a laparoscopy and possible liver biopsy.

"Dr Hayes explained that previously he had had slightly abnormal liver function tests, but following his short course of interferon treatment, which he took between June and September 1995, his liver

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says:

"While he was here, we had a long discussion about hepatitis C. Paul has taken away some information leaflets regarding hepatitis C."

You must have a lot of leaflets, Paul, by now.

"I again explained to him that our last tests show that although he has antibodies against hepatitis C, the quantitative PCR test has consistently been negative for some years. I explained that there was a lower limit of viral detection in these tests and therefore if there was any virus present, it was at a very low level. We are unable to say that there is no virus present in the liver without performing PCR tests on the liver biopsy."

Then it says you don't need treatment because the aim of treatment is to make PCR tests negative.

Again, you still don't have the confident reassurance that it's definitely been eradicated.

**A.** I've still got the feelings that I'm -- a lot of pain, I'm tired all the time, and that obviously makes me feel that, well, it's still there, obviously, or I'd feel I'm coming back to normal.

**MS RICHARDS:** Myles, I wanted to ask you about being told of potential exposure to vCJD.

You were told in 2004 that you were at high risk

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function tests have been normal until September 1996, when his ALT was only very slightly outside the normal range."

And then it refers to it being likely you have a very low level of viraemia:

"... as we have only detected hepatitis C RNA by quantitative PCR on one occasion in October 1994."

It refers to samples between May and December 1995, negative.

And then it says this:

"It is difficult to know whether this means that he has cleared the virus or whether it is at too low a level to detect by our current methods."

That's your fear. You just don't know whether it's still there or not in your mind.

**A.** Yes, basically it said that, and it's at a level that it's undetectable. There's a certain test you can do to detect it, whatever, but it's still in my body, as far as I'm concerned, and after he said that, that's stuck with me, that something could then make it happen again to become active, and that's a really big fear of mine, that I'll leave my wife and kids.

**Q.** We can see if we have 2167003, please, Henry.

This is from March 2000, so it's some five years further on. If we go to the bottom of the page, it

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for public health purposes in terms of vCJD, but more than that, you were told that you've actually received a factor product from a batch that is implicated, a batch including a donation from a donor infected with vCJD.

**MYLES HUTCHISON:** That's correct. Professor Ludlam told me that unfortunately I had had over 40 treatments, which could be anything from 4,000 to 5,000 units of factor concentrate, from the factor derived from a man who had died directly -- they knew directly from variant CJD. So I was obviously very upset and I said, "Well, can you not test me for it? Is there a treatment?" Because we've seen all the fuss with mad cow disease. It was crazy. I thought: not another thing, this is getting beyond a joke. And I says, "Is there a test you can do?" He said, "Unfortunately the test is not very reliable and it's very expensive, so we're not doing it as such, but there's no point in us doing the test because there's no known treatment for it anyway". I said, "So where does that leave me?" He says, "Well, I'm sorry, it leaves you the way you were when you came in, only you know now that you might have vCJD."

**Q.** That's impacted upon the way in which you receive care. You're labelled again as high risk of infection

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1 in medical notes, you say.  
 2 A. Yes.  
 3 Q. And there was one occasion when you were due to have  
 4 an endoscopy and that didn't go ahead.  
 5 A. Yes. I was due to get several things. I've actually  
 6 been told by the surgeons they wanted to do surgery on  
 7 kidney stones, gallstones, things like that, and they  
 8 phoned the Royal to check for my clotting levels,  
 9 because it was usually (inaudible) that ended up, and  
 10 they just treated me like anyone else. Until my files  
 11 came through with a biohazard thing. Then they had to  
 12 make a phone call.

13 They said after speaking to the Royal they  
 14 weren't going to go forward with the surgery anymore,  
 15 they were just going to monitor it, because it was too  
 16 much of a high risk. And I said, "High risk to  
 17 myself?" They went, "No, high risk to others." And  
 18 I went, "Okay, so I'm being denied treatment because  
 19 of a yellow badge on my file?" They said,  
 20 "Unfortunately, yes."

21 I've heard stories about insurers not being  
 22 willing to cover hospitals for the cost of a bed  
 23 because it is very expensive, but they're obviously  
 24 worried about these viruses because these beds, you  
 25 know, they can surely be cleaned down, surely you

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1 table because of the cost of having to replace that  
 2 table."  
 3 A. That's correct, yes.  
 4 Q. You have experienced ongoing physical and mental  
 5 health problems ever since --  
 6 A. Yes.  
 7 Q. -- the events that we've been talking about.  
 8 In terms of your depression and mental health  
 9 problems, you remain concerned that they are regarded  
 10 as something separate from your infection and  
 11 treatment.

12 A. Yes. I definitely do think that they keep them  
 13 separate until you actually bring them up. For  
 14 example, I went to my GP a wee while back. Because  
 15 I knew I was going to be doing this and things,  
 16 I thought maybe I should get a wee bit of help dealing  
 17 with emotions coming out, what I'm going to have to  
 18 tell people, the things that I'm going to have to  
 19 share. So I went to my GP and I asked him to refer me  
 20 to someone for psychological counselling.

21 My doctor believes that I suffer from PTSD  
 22 because of the things I seen in hospital, the traumas  
 23 that I went through. Having my arms tied to the bed  
 24 in the hospital was one of the worst ones, but -- so  
 25 I went to a meeting and I says, "Look, I'm coming

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1 don't have to replace a whole bed because somebody has  
 2 been on top of it? But I've been denied -- sorry,  
 3 I went off on on a tangent a wee bit -- I've been  
 4 denied procedures definitely.

5 But the endoscopy, I refuse to get anything like  
 6 that done now because I've been told that the camera  
 7 they use is devoted just to me, but it's say  
 8 15/16 years old and it can't take a clear picture, so  
 9 it's pointless, basically. Because they won't use  
 10 a normal endoscopy for the NHS on me. Mine has a big  
 11 yellow badge around it, so I know which one is mine.  
 12 It is hanging up there and it's the same one I had  
 13 when I had a procedure when I was about 30, I think.  
 14 And they can't take pictures clearly because there's  
 15 new equipment, but they still insist on using it.

16 So there's no point in me getting the procedure,  
 17 because I'll just go through all the discomfort and  
 18 they can't get a proper reading.

19 Q. You put it this way in your statement, Myles. This is  
 20 your perspective on what the vCJD assessment means in  
 21 practical terms for you. You say this:

22 "I feel that I get the brush-off from doctors as  
 23 a result. There have been so many times that  
 24 surgeries have been mentioned but they end up not  
 25 happening. I feel they do not want my blood on the

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1 here, I'm asking for help, but I want no involvement  
 2 whatsoever with the Royal Infirmary Edinburgh. This  
 3 has to be something I know I'm talking to you about,  
 4 and it's got nothing to do with them. This has to be  
 5 about me and I don't want any" -- they always say it  
 6 goes back to my haemophilia. It's not about my  
 7 haemophilia. This is about my mental state and I want  
 8 it staying here. And she says, "Well, you've  
 9 definitely got the signs of severe PTSD and emotional  
 10 trauma problems and I'm going to refer you to  
 11 a specialist to give you some counselling."

12 Anyway, I was feeling quite good, you know, I'd  
 13 got a lot of things off my chest, I felt this is going  
 14 to help me, and coming here, you know, helped me as  
 15 well, just get all this away once and for all.

16 I came home one day and there was a letter lying  
 17 for me, and they said, "We've managed to get your  
 18 referral to the Royal Infirmary of Edinburgh  
 19 psychology team. We've passed all the notes and  
 20 relevant information you've provided to us", all the  
 21 things I basically told them I didn't want them to  
 22 know about, they sent all the notes to the Royal. And  
 23 I'm not going to the Royal, so I'm going to have to go  
 24 back to my doctor and ask them to try and find an  
 25 alternative.

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1 Because they say that it's got nothing to do  
2 with mental health, all these things that have  
3 happened, but it's funny how as soon as you have  
4 a problem, you get sucked right back under them again.  
5 **Q.** You say in your statement that for years you hated  
6 yourself.  
7 **A.** Yes.  
8 **Q.** You've become over the years more socially withdrawn,  
9 and you worry about how long you're going to be around  
10 for your kids.  
11 **A.** Yes, of course I do. It's -- I became a father, you  
12 know. It's a lot different from being an individual  
13 to just think about yourself. I've been blessed with  
14 my two gorgeous kids, you know. I love them with  
15 every element of my being. I had a good teacher in my  
16 mum. I think everyone could see how caring she was  
17 just by the things she tried to do, and it destroyed  
18 her. And I'm trying to learn how to be a good dad,  
19 because I think you learn every day a bit more how to  
20 be a dad.  
21 I have recurring nightmares of me lying on my  
22 deathbed, saying goodbye to my kids, and that's part  
23 of the PTSD. I have to cut my nails right down  
24 because I scratch my head that bad that I cut myself.  
25 And it's the same dream all over and over again, just

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1 similar.  
2 **PAUL HUTCHISON:** Yes.  
3 **Q.** Your depression's never gone away.  
4 **A.** No.  
5 **Q.** You describe yourself as someone who is largely  
6 withdrawn. You don't go out much. You feel tired and  
7 very cold a lot of the time. You always have to have  
8 the heating on.  
9 **A.** Mm-hm.  
10 **Q.** You say that sometimes your kids call you Mr Angry.  
11 **A.** Yes.  
12 **Q.** And you suffer from anxiety.  
13 **A.** Yes.  
14 **Q.** You've got long-lasting fears about your health.  
15 **A.** That's right.  
16 **Q.** We can just see that from a couple more documents.  
17 Could we have 2167017, please.  
18 This is 2006, and we can just see it at the  
19 bottom of the page. It says this:  
20 "I think it is also important to note that Paul  
21 clearly has had long-lasting fears regarding his  
22 death. He has been haemophiliac since birth,  
23 contracted hepatitis C from the blood products, and  
24 this led him to feel angry and distrustful of the  
25 health service. He fears that the hepatitis C may

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1 telling my kids I'm sorry, I want to be with them but  
2 I can't. I wake up panicking and I'm just so thankful  
3 that I'm here. I check they're in their bed and --  
4 you know, every single night. And I just think: one  
5 of these mornings, I'll not wake up. And I want to --  
6 I want to be there for my daughter's wedding, my  
7 brother -- my son's wedding, sorry -- you're not  
8 getting married again! -- my son's wedding. I just  
9 want to be their dad.

10 I just want to be a good husband to my wife.  
11 I want to be the person that she fell in love with.  
12 She's even noticed, you know, changes in me with all  
13 these memories coming back. But luckily she's the  
14 type of person that loves me enough to see the bad in  
15 me as well as the good and let me get this out of me,  
16 let me get help for this. Because she says the person  
17 that she fell in love with is a diamond, a gentleman,  
18 as she puts it. And that's why I asked for help. But  
19 I feel I asked for help and they put me right back to  
20 them again that caused it all.

21 **Q.** You still experience similar physical symptoms to  
22 those you've experienced for a number of years, joint  
23 pain and fatigue in particular.

24 **A.** Yes, that's correct.

25 **MS RICHARDS:** Paul, the picture for you I think is very

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1 become active again, and also he has concerns about  
2 CJD. When his wife accuses him of being  
3 a hypochondriac, he responds by thinking that he has  
4 entirely justifiable health concerns."

5 We've seen the basis for your fears that your  
6 hepatitis C may become active again.

7 It says here you have concerns about CJD.

8 If we just have up, please, 2167015. We can see  
9 October 2004, second paragraph of this letter, that  
10 you're regarded as falling into the at-risk group of  
11 vCJD for public health purposes. It is said that if  
12 any surgical procedures are considered, advice should  
13 be sought from infection control regarding any  
14 instruments.

15 If we have 2167016, please. If we can see the  
16 third paragraph, again, this is October 2004:

17 "He was keen to know whether he had received any  
18 implicated batches and he was advised that he had.  
19 I explained that we think that the risk of  
20 transmission is very low. There have been no known  
21 cases of vCJD in the haemophilia population as a  
22 whole, which is reassuring as some of the implicated  
23 batches were used as long ago as the 1980s."

24 You are in a similar position to your brother.  
25 You've been told you've received implicated batches.

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1 A. Yes.

2 Q. You've been told the risk is low that you yourself

3 will develop vCJD, but you have that fear.

4 A. Yes. Like my brother, I was to go for a colonoscopy.

5 I went for one about 15 years ago, it was, and --

6 about a year ago I went to the Royal Infirmary for

7 another colonoscopy, and they put me on the table and

8 couldn't get a vein, so I had butterflies in my hand

9 and my arms, and the chap that done the procedure he

10 started to do it and then realised that the camera

11 wasn't taking pictures. And he spoke to the nurse and

12 she says, "Oh, this gentleman's high risk for vCJD,

13 it's the camera that we used on him 15 years ago.

14 We're not to use a new one on him". He says, "Why

15 not?" She says, "Oh, the expense, because it has to

16 get destroyed."

17 Q. If we have up on screen, please, 2167018, we can see

18 how your concerns continue to affect you. Second

19 paragraph please, Henry.

20 It says this:

21 "He explained that he was told he had received

22 contaminated blood products when he was 19 years old,

23 resulting in him contracting hepatitis C. He

24 described this as a very distressing time in his life

25 as he was uncertain if the diagnosis would impact on

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1 haven't been able to tolerate what would be the normal

2 product for you.

3 A. That's right. It's just recently that I got the

4 man-made stuff. The other one I took I had an

5 allergic reaction to it, and for months and months

6 I wanted them to retry in case it was just something

7 that was wrong with me on that day, but they refused

8 in case I had any side-effects again to do it. So

9 I had to keep taking the Scottish blood plasma. I

10 think I was the only one in Edinburgh that was on it

11 still. It got to the stage where I was that scared

12 that I'd get something else from it that I stopped

13 taking my prophylaxis. So I wasn't taking anything at

14 all. But then when I was getting a bleed, I was

15 having to take -- it was a Catch 22 situation.

16 I ended up taking more of the stuff against my wishes.

17 And this went on for quite a while, taking it,

18 and I even phoned the hospital, the chap, I said -- it

19 was Barry at the hospital, he phoned the house,

20 "You've got to use this factor left here at the

21 hospital", and this was at the time when I was

22 refusing to take it because I was worrying. He says,

23 "There's 20 bottles here, you'll have to take them".

24 I said, "I'm not taking it, I don't want to put myself

25 at risk anymore". He said, "No, you will bloody take

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1 his life expectancy. He avoided intimacy and

2 relationships due to worry about infecting others. He

3 described a sense of shame, isolation and stigma

4 attached to the illness as other people would

5 associate it with promiscuity and drug use.

6 "We explained that treatment with interferon

7 cleared the infection, but he believes it is lying

8 dormant and could reappear in the future. He

9 remembers the treatment as very challenging,

10 describing lowered mood, increased fatigue and

11 increased suicidal thoughts at the time."

12 That is as recently as 2016 you were having that

13 discussion.

14 And then if we have 2167019, please, Henry.

15 This is 2017, and we'll just look at the second

16 paragraph, please.

17 It says:

18 "Paul highlighted specific beliefs and fears

19 about plasma-derived products which acted as a barrier

20 to his prophylaxis adherence."

21 Then it goes on to talk about discussing

22 possible alternative treatment options and a new

23 treatment being trialled with you.

24 You have had particular difficulties in relation

25 to your treatment for your haemophilia because you

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1 it. You realise how much it cost?"

2 Q. You, like Myles, have a loss of trust in the medical

3 profession.

4 A. Totally.

5 Q. And in particular in relation to the Haemophilia

6 Centre at the Royal Infirmary.

7 A. Even though I complain about the staff, it was

8 Ludlam's driftwood essays (?), I called them, the ones

9 that had been there all through the hep C stuff,

10 they're no longer there, but I still have no trust

11 going up to the hospital at all. I feel -- even when

12 I was seeing the psychologist, so much of what I told

13 her, she says she'd have to tell them. But I wanted

14 to speak to her in total confidence. I didn't want

15 them to know anything, so much so I held back on what

16 I told her, because I knew it was maybe going back to

17 the staff there.

18 MS RICHARDS: You both feel that what you need is some

19 form of different alternative provision of services

20 unrelated to the Haemophilia Centre in Edinburgh.

21 MYLES HUTCHISON: Definitely. We think most people who

22 have suffered like this, they need somebody

23 independent of any treatment they've had in the past.

24 We need somebody to look at it with a clean slate and,

25 you know, assess you as to what they see, not by

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1 looking at your biohazard files and what other people  
 2 have said. You need someone to take you freshly on  
 3 and listen to you. Just, you know, somebody totally  
 4 independent of the problem that you've had.

5 **PAUL HUTCHISON:** Because they just fob you off, you feel,  
 6 that's what they do. And you see a lot less of them  
 7 now because it's on deliveries. I haven't had  
 8 an appointment now for over a year. It used to be  
 9 every six months. So I think they've washed their  
 10 hands of me.

11 **MS RICHARDS:** Myles, you've touched already on the effect  
 12 that what you've described had on your family life and  
 13 private life. Your first marriage ended. You have  
 14 your happy second marriage.

15 **MYLES HUTCHISON:** Mm-hm.

16 **Q.** But you talk about having a fear of infecting your  
 17 wife and your daughter worrying about you a lot.

18 **A.** Yes, my darling wee girl, she's a very bright and  
 19 intelligent, lovely girl, but unfortunately this all  
 20 came out. It was good for us but not so good for my  
 21 wee girl, because like a lot of girls with their dad,  
 22 she worships the ground I walk on and she worries  
 23 about me. She missed her exams and everything  
 24 [redacted]. [Redacted] she was that scared at not  
 25 being in the house when I'm around that she would miss

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1 that.

2 And I actually really enjoyed human company, you  
 3 know, it was nice to talk to people that you don't  
 4 have to talk to, that are around you all the time. We  
 5 all enjoy that, and I miss it an awful lot. I liked,  
 6 if I was doing my job, I was able to help somebody or  
 7 make somebody's day a bit easier. It always made me  
 8 feel good about myself. And I've lost all that, you  
 9 know, it's gone.

10 **Q.** In terms of your job, you worked in the civil service  
 11 from November 1989 onwards.

12 **A.** Yes.

13 **Q.** But that employment came to an end in 2002 because of  
 14 your ill health?

15 **A.** Yes, that's correct.

16 **Q.** You say in your statement that's contributed to a loss  
 17 of self-respect and feelings of worthlessness.

18 **A.** Yes, it has, because we all know how society judges  
 19 people. We make out it doesn't, but it does. I took  
 20 pride in going to my work, getting my pay at the end  
 21 of the month, paying all my bills and seeing all my  
 22 brown letters and going: is it worth it? But at least  
 23 you know you've done it, you contribute to the society  
 24 you live in, you're a part of the cog -- a cog in the  
 25 wheel as such. But now I'm -- my brother worries

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1 me if something happened. She is so scared of losing  
 2 her dad because she hears all this, and that's why  
 3 I've held back in the past saying things, because  
 4 I didn't want them to get hurt or, you know, worry  
 5 about me.

6 I've reassured them I don't plan on going  
 7 anywhere. I love them and I'll be with them as long  
 8 as God permits. But it's definitely taken its toll.

9 [Redacted]. He always worries about his dad if  
 10 I'm not about. And my wee daughter, yes, she missed  
 11 her exams and she's suffered a lot.

12 **Q.** Your wife had to give up her work -- she worked as  
 13 a care assistant --

14 **A.** Yes.

15 **Q.** -- to help support you.

16 Other than your wife and your brother, you say  
 17 you don't really have any friends with whom you  
 18 socialise.

19 **A.** Not really, no. Facebook -- like everyone, we've got  
 20 friends, but the people that I used to call friends  
 21 and, you know, maybe socialise with, they're all gone.  
 22 They're all -- a lot of the friends I thought were  
 23 friends weren't really friends when I look back on it.  
 24 But, yeah, I've lost all that, and my best friends are  
 25 my family. They're my best friend. And I've lost all

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1 about it as well. People look at you and think, "He's  
 2 never at his work, he's always in his house, another  
 3 scrounger, another blooming sponger". I wouldn't mind  
 4 if they were chucking money at us, but that's not the  
 5 case.

6 **Q.** You receive disability benefits. We'll come on to  
 7 a recent development in that respect. But you've said  
 8 in your statement that you struggle financially as  
 9 a family. You've mentioned in the past, when you did  
 10 get some money from the Skipton Fund, you took the  
 11 kids to Disneyland Paris, but you couldn't afford  
 12 travel insurance for yourself.

13 **A.** No, I got a crazy quote. It was silly money.  
 14 Hundreds and hundreds of pounds. And even then I had  
 15 certain conditions on it. So I'm afraid I just had to  
 16 take a gamble. I didn't want to disappoint the kids,  
 17 and I went with just my NHS cover that you always  
 18 take.

19 **Q.** There has been a recent development in terms of the  
 20 PIP assessment by the DWP.

21 **A.** Mm-hm.

22 **Q.** What can you tell us about that?

23 **A.** I was on the higher rates of DLA because of all my  
 24 problems with my joints, et cetera, and I had my  
 25 Motability car. Obviously this PIPs came in and asked

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me to go for an assessment after I sent in an application. I went to the assessment, and it was a young chap, I don't know what his -- my wife actually asked him, "What is your medical, you know, qualification?" And he says, "I'm a healthcare professional". That was his answer.

Anyway, he wanted to examine my legs and I said, "No point, my legs are knackered, you'll not like what you see", and he started making me move my arms about silly ways and that. Anyway, the next day I ended up with a bleed because of it. That was fun. We were in there for hours and hours.

I got my assessment back and they took my car off me, so I don't know how they expect me to get to appointments for the hospital and that.

**Q.** You were on the high level.

**A.** I was on the highest rate, yes.

**Q.** You were assessed down to standard.

**A.** Yes.

**Q.** And that's going to mean the loss of your Motability car.

**A.** Yes.

**Q.** That's what you rely upon to get out to visit your mum, to take kids to school and the like.

**A.** Everything I do relies on the car, because I can walk

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

**Q.** You've seen a copy of an email. We don't, I'm afraid, have a copy I can display on the screen, so I'll just read out the relevant bits that you've drawn to my attention. It is from James Wolfe, director, disability and housing support, addressed to Diana Johnson. I'll just read the bits relevant to the issue that you've raised, Myles.

It says:

"The department, along with PIP assessment providers and stakeholders, has implemented new guidance on haemophilia and haemarthropathy to ensure health professionals assess such cases appropriately."

Then it says this:

"The severe conditions guidance in ESA and PIP ensures that claimants who currently receive the highest level of PIP entitlement ..."

Which you were receiving.

**A.** Yes.

**Q.** "... or are in the ESA support group and whose needs are unlikely to improve are placed on ongoing awards, preventing unnecessary reviews.

"Claimants affected by contaminated blood who meet these requirements will be entitled to an ongoing award."

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short distances and I am fine, but I start to get sharp pains up my legs and back, and I rely on the car. It's my lifeline to the world because I became a house-dad and my wife worked because of my illness. I said I'll be the one, because I'm too ill and I'll be the dad. I loved it. Best thing I've ever done. The hardest job I've ever had but the best job I've ever had. The car's my only way to get to appointments, things like that.

Because to be honest with you, even being here now, my brother and I were both bags of nerves, because we've lost the ability to be out in public, do things ourselves. It's amazing how quickly you get stuck in a way being in the house, and the car is a lifeline, you can go here or there.

They've also cut my support money down because my wife looks after me now. I don't know how that works out. She doesn't work, so she's there to help me with things, so I don't have to be able to do it. The questions were ridiculous.

**Q.** You're concerned, amongst other things, that the stance that has been taken in relation to your assessment contravenes assurances that have been given by the DWP to Diana Johnson MP as co-chair of the APPG?

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**A.** That's correct.

**Q.** You don't think that's happened in your case.

**A.** Not at all. I shouldn't have even been assessed, because I am in the support group for ESA, I already went through the humiliation of being asked a million questions that aren't even relevant, and I should've just been enrolled right onto the new benefit. They're not following their own guidelines.

There's actually -- there was a helpline in that -- a helpline, and I phoned the helpline, and it doesn't exist. It says, "This line is not in order". I phoned it about a dozen times. Then I waited -- anyone that phones PIP, it takes you about 40 minutes to talk to someone. I went back again on the phone and they said, "We've never heard of this". Eventually I spoke to a manager. Luckily my experience working at an office got me somewhere eventually. She says, "Oh, we're going to have a look at your claim again anyway, and I'll put this statement from Mr Wolfe down and hopefully somebody that knows something about it will see it". So it's in the lap of the gods now. I don't know what's going on.

**Q.** Myles, the final thing I wanted to ask you about before I turn again to Paul was just about the

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observations that you've made in your witness statement about the Scottish Infected Blood Support Scheme.

You've said in some respects things are better with the current arrangements than they have been previously. But you identified two concerns you continued to have. Firstly, the disparity with what was provided to those who lived in the Republic of Ireland continues to anger you.

**A.** Mm-hm.

**Q.** Secondly, you say that there's now nowhere to go to make specific applications, there's no fallback emergency provision, as there used to be with the Caxton Fund.

**A.** That's correct, yes. I believe that we all, as British people, should get the same money. I mean, it's ridiculous what they've done, some things, one is getting less than another and then they flip it around again. In Scotland it looked like we were getting a big, big hand up, but -- we used to get payments for the cold weather, things like that, your kids' uniforms paid, for you could apply for all these different things. Me myself, I got a new house at the beginning, and it was a council house, so if you've not got a fence you have to find one. So I'd asked

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right thing because they've just evaded the question. You know, governments all have promised they'll do this, that and the next thing and none of them have, none of them have kept their word. Politicians have been elected saying they'll do this, the local MPs, and I just feel we've been left to rot.

**MS RICHARDS:** Paul, you too had to stop working because of your ill-health.

**PAUL HUTCHISON:** Yes.

**Q.** You have, and your family, have struggled financially.

**A.** That's right, aye.

**Q.** You talk about, in your statement, feeling worthless, people look at you, they wonder why you're not working because they can't see what's wrong.

**A.** Yes. It's an invisible disability, and it's -- when I go out the door and my wife gets annoyed with me because when I go outside if somebody looks at me I'm paranoid at people that know me or see me, going to your car, "How have you got a car like that? Oh, he doesn't even work. Lazy so and so [whatever], scrounger off the state." And I've worked since I was 15 years old and brought up that way, I always wanted to work, and since I've stopped working I feel worthless, I've lost my identity altogether and I'm just a number sort of thing feeling.

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them for help, and it was expensive, but they done the job like that for me, they got it all done for me.

In Scotland now if you're getting any form of support you can't apply for anything. If you're on stage 1 or stage 2 that has been totally wiped out, you have to be a poor soul that's getting nothing to be able to apply for things. And although we're getting a lot more money than we used to get, which is great, it's still -- it's still average wage, it's not as if they're giving us the world. We have not got access to credit the way other people have because we don't work, so we have to have somewhere to go to for that and it's just not there. We can't even ask for a loan from SIBS or anything like that. I think we should all be on the same thing.

In Ireland, it's strange as it's so close, but they dealt with it fairly and right from the beginning, it was like we've infected you, you'll get a lump sum and ongoing support. And they're still getting well more than anyone in this island, they're getting a lot more. And I just feel we've been -- I think -- it's going to sound very cynical but I think it feels like they're just waiting as long as they can until there's none of us left to worry about, and it will be a hell of a lot cheaper than doing the

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**Q.** In terms of the impact upon your family life, you say that one of your regrets is you haven't been able to play with your children as much as you would like because you have just been too tired.

**A.** Aye, that's right.

**Q.** You worry about your wife being -- becoming infected.

**A.** Mm-hm.

**Q.** And your children, like Myles's, worry about you.

**A.** Yes.

**Q.** You've described in your statement, Paul, comments that you have from a dentist on one occasion. Can you recall that?

**A.** Sorry?

**Q.** Comments that you had from a dentist on one occasion.

**A.** Er ...

**Q.** A dentist making a comment about throwing away the instruments after treating you. If you don't remember it, don't worry.

**(Pause)**

**A.** That's right, because of the hepatitis C they would have to get -- destroy the -- the actual instruments that they'd used on me. And how much it cost again. Similar.

**MS RICHARDS:** Those are the questions I have for you both, but I'm going to ask Mr O'Neill and Mr Dawson if

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1 there's anything further they'd like to ask.  
 2 **(Pause)**  
 3 There's just a few points.  
 4 First of all, Myles we talked about the  
 5 hexagonal device.  
 6 **MYLES HUTCHINSON:** Yes.  
 7 **Q.** And I understand from Mr Dawson that was used on you  
 8 not once but twice; is that right?  
 9 **A.** As I remember, yes.  
 10 **Q.** And then there was a particular concern you have about  
 11 missing medical records; is that right?  
 12 **A.** Yeah, a big, big concern. When I got my notes, most  
 13 folk would think, for God's sake, it was a massive box  
 14 with reams of documents. But I thought that looks  
 15 awful wee, because whenever I was in the hospital  
 16 there was a blooming trolley that used to come with  
 17 "Hutchison/Hutchison", it was all me. And that, and  
 18 the box I received was about that (Indicates). And  
 19 all the time from when I was a teenager right until  
 20 a certain point they're gone, years and years. And  
 21 being a haemophiliac you'd think the previous history  
 22 would be very relevant, you know, you wouldn't destroy  
 23 notes. But I do know that notes were destroyed in  
 24 an inappropriate manner.  
 25 I went to the Old Royal Infirmary for an

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1 **Q.** And was that in the early 1990s.  
 2 **A.** Yes.  
 3 **MS RICHARDS:** Paul, were either of your parents ever  
 4 offered any counselling or psychological support or  
 5 practical support?  
 6 **PAUL HUTCHISON:** None at all. They were just left -- left  
 7 to their own devices.  
 8 **Q.** And there is in your records, Paul, a reference at one  
 9 stage to you being offered an SNBTS product that  
 10 wasn't made from Scottish donations --  
 11 **A.** That's right.  
 12 **Q.** -- but from donations elsewhere; can you remember  
 13 that?  
 14 **A.** Obviously the stock, whatever they had, they didn't  
 15 have anything left, but they gave me this stuff, and  
 16 I took it home. And I actually phoned my brother  
 17 because I had started mixing it, and it was just full  
 18 of like floaters inside it and parts of the rubber  
 19 seal had all fell inside it as well. And I actually  
 20 got you to look at the bottle (To Myles). So I didn't  
 21 take it because it's just looked --  
 22 **MYLES HUTCHISON:** Dodgy. And when you phoned the hospital  
 23 they expected you to inject it.  
 24 **PAUL HUTCHISON:** Aye.  
 25 **MS RICHARDS:** Those are the questions that I have.

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1 appointment and I became very friendly with the  
 2 receptionist, and she said to me, "Myles, I shouldn't  
 3 tell you this, but I have to, my conscience is getting  
 4 me." She goes, "I know one of the nurses is up the  
 5 stairs just now and they're up to something." And  
 6 I went, "What?" She goes, "They're destroying your  
 7 notes." I said, "Maybe it's just the old ones they're  
 8 getting rid of." She goes, "No, these are notes you  
 9 have to keep in your records."  
 10 Anyway, I went and seen the nurse when I went  
 11 through for my usual gallons of blood test, and  
 12 I says, "Why were you destroying my notes? The  
 13 receptionist said." And she goes "Well, she should  
 14 mind her own business in the first place." And she  
 15 goes, "They are getting transferred onto CDR" -- you  
 16 know, at the time it was CDs, I think -- "... and they  
 17 are not relevant, it's just notes we keep aside for  
 18 the doctors' comments, things like that." And I says,  
 19 "All right, so there's not going to be a big space in  
 20 my files or anything?" She goes, "No, no, no, no,  
 21 it's nothing like that."  
 22 And so when I got my medical files I wasn't  
 23 surprised when there was a massive gap, because it was  
 24 happening right in front of me, basically, while I was  
 25 attending the Old Royal Infirmary.

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1 Is there anything that either of you would like  
 2 add?  
 3 **MYLES HUTCHISON:** Yes, we'd both like to say something, if  
 4 that's okay.  
 5 **MS RICHARDS:** Yes, of course.  
 6 **PAUL HUTCHISON:** Just -- I'll start off.  
 7 Sir Brian, can I start by thanking you for  
 8 sharing such an important inquiry and being so  
 9 compassionate throughout the oral hearings. We are  
 10 here today fighting for the bereaved, the living and  
 11 families that have been torn apart through this  
 12 horrific disease that has caused so much hurt and pain  
 13 to all. All we want is answers to why it happened and  
 14 why we were treated as guinea pigs. My medical  
 15 records were destroyed, and know why haemophilia  
 16 centres no longer seem to want anything to do with us.  
 17 Is this because they have run out of tests to do on  
 18 us? Or is it because they are running scared as they  
 19 have been found out?  
 20 All my life I have been treated differently. At  
 21 school, when the AIDS adverts started, that's when  
 22 I got hit hard, along with my brother, getting called  
 23 gay, scum or junkie, or people writing things about us  
 24 on walls, et cetera. Even family members, who I will  
 25 not name, wouldn't cuddle us or kiss us. I wouldn't

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1 have minded, but we didn't have AIDS. We wondered why  
2 we were being treated in this way. So much so until  
3 this day I still panic if I cut myself and my children  
4 and wife getting anything on them, and in my mind  
5 infecting the people I love more than life itself.

6 People made me feel dirty and diseased. Then we  
7 were hit with hep C and vCJD, this made me more wary  
8 of having relationships as I would have to explain  
9 everything and hope they wouldn't stop wanting to see  
10 me.

11 I started Interferon, which I was told I would  
12 get flu symptoms and be able to continue my employment  
13 at the Royal Infirmary of Edinburgh, clinical  
14 biochemistry lab. Unfortunately, they were  
15 horrendous, I became so depressed I wanted to kill  
16 myself as I had had enough.

17 My poor mum and dad would not leave me alone in  
18 case I tried to commit suicide. I lasted a course  
19 before I was refusing any more, that's when they told  
20 me it's dormant, they said it was inactive but in the  
21 future it may become active again and chances were  
22 I would die of liver cancer. "You can go home now",  
23 they said. No support whatsoever, or treatment for my  
24 brother and myself and my parents. All that was given  
25 to us was it was a horrible death.

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1 to you, you're very compassionate and a gentleman and  
2 I really appreciate you giving us this opportunity to  
3 speak.

4 I am just one of the many who have been affected  
5 by this disgraceful blood stain on this great  
6 country's history. But what happened to me and others  
7 like me should never have been. For decades we have  
8 been let down by government after government, and told  
9 what happened to us was unfortunate, but never any  
10 blame really accepted.

11 As a child I watched young men die knowing I was  
12 the same and wondering when it would be my turn.  
13 Before I was 30 I had lost a wife, a home, a job and  
14 my dignity. But instead of being told why I was like  
15 this, I was left to feel it was all my fault and I was  
16 a failure. I struggled with the guilt of still being  
17 alive when so many I knew died, and I felt that others  
18 who had died deserved a life I had failed so miserably  
19 in. So much so that I tried to take my own life on  
20 more than one occasion, coming very close more than  
21 once.

22 But I was blessed and, against odds, I found  
23 love once again where I met, like my brother, love of  
24 my life -- I think we'll go for points - and was  
25 blessed with two beautiful children. And although we

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1 So much so, after seeing a liver specialist that  
2 told me I'm clear, I said, "I don't believe you." And  
3 seeing a psychologist for over a year to one day sit  
4 with her and say, "I'm broken. It's embedded in my  
5 mind and my DNA, I'll always feel worthless and  
6 diseased and like I'm living on borrowed time.  
7 There's nothing you can say that will change this."

8 Fortunately, I met my true love of my life,  
9 Elizabeth, the same girl that knocked me back at my  
10 brother's work party when I was 18; but I was to get  
11 another chance many years later in life when I got  
12 employment where she worked alongside my brother.  
13 I asked her out and this time she said yes and the  
14 rest is history. She gave me two beautiful children,  
15 [redacted], who I love ... sorry ... who I love to  
16 infinity and beyond. I was that worried about dying  
17 that I forgot how to live.

18 Sir Brian, I hope and pray everyone involved  
19 gets answers and the closure we need to start living  
20 our lives before it's too late. It's already too late  
21 for so many, so please deal with this as quickly and  
22 efficiently as possible.

23 Thank you from the bottom of my heart.

24 **MYLES HUTCHISON:** Sir Brian, like my brother I'd like to  
25 thank you so much. I've had the pleasure of speaking

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1 struggled with money, due to my inability to work, we  
2 were blessed with love and a true feeling of what  
3 a family should be.

4 So many young people have died not having the  
5 gift of finding love and having a family who should  
6 have, so for this I am truly grateful.

7 I am telling you my story as much for those who  
8 can't as myself, and believe in doing so I am  
9 honouring their memory. I still feel guilt for being  
10 alive, I can't help it.

11 Every night, when I lie in bed, I wonder how  
12 much time I have left and have a recurring nightmare  
13 of lying on my deathbed saying goodbye to my wife and  
14 kids. I wake up every morning in pain, both mentally  
15 and physically, and struggle to be the man I want to  
16 be. I have struggled with intimacy because I feel I  
17 am a danger to those I love; my medical files make  
18 sure of that with the biohazard warnings. The truth  
19 is we were lied to, and information we were entitled  
20 to know about our own bodies was withheld by those who  
21 were meant to protect us. People talk about proof of  
22 wrongdoing: we, and those who are not here, are the  
23 proof.

24 How can so many tell the same story without it  
25 being true? We were let down, and still are, by the

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1 NHS and the governments that are meant to serve us.  
2 In the past months I have witnessed true heroism by  
3 the affected, their parents, spouses and children who  
4 have had the courage to tell their stories no matter  
5 how painful. You are all heroes and have acted with  
6 a dignity and grace that shames those who wish to  
7 silence us.

8 But you will never silence us, for once we are  
9 all gone, those who love us will take up the fight  
10 until justice is served.

11 You know who you are, and I pray, come the day  
12 of your judgment by our Lord, you finally feel the  
13 pain you have caused. You may have used the system to  
14 evade justice, but you can't avoid your own fate.

15 We have been left to struggle financially for  
16 decades and have never been compensated for the loss  
17 of earnings and ability to own a home that we have had  
18 taken from us, even though those who did this have  
19 enjoyed high paid careers and homes of their choosing.

20 So for my final comment, I wish to stand up for  
21 those who cannot and address those who are here  
22 representing the government.

23 We are never going to give up, and I shall  
24 personally fight for justice until my dying breath.  
25 Those of us who are still alive deserve to live out

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1 given us a dismal tale of the slow loss of trust in  
2 the medical profession which has passed on to others  
3 of its after effects on you personally, on your  
4 families, on your parents, particularly your mother,  
5 as testified to by that incredibly moving, beautiful  
6 letter, which was read out in full. Leaving her  
7 trapped by the fears of what is possibly yet to come  
8 and by a feeling that you have lost all value.  
9 Although plainly you haven't because you have found  
10 value, each of you, in your marriages, and it's  
11 amazing that, even in that, you are, as it were,  
12 almost two peas in a pod, you both have two children  
13 and you both say very similar things about your new  
14 loves.

15 But can I just say this in particular, picking  
16 up something you said, Myles, if I may. You said at  
17 one stage that you'd lost -- you weren't the same  
18 person you were, you were no longer the person that  
19 would help the wee lady off the bus or help someone  
20 with the messages. Well, what you have done today, as  
21 I think you recognised in what you said at the end, is  
22 you have stood up, literally, for others. The  
23 evidence you have given is important, it's  
24 particularly important because the two of you have  
25 such shared experiences, one reinforcing the other and

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1 the rest of our lives comfortably and with dignity, as  
2 do those left behind to pick up the pieces of a broken  
3 life. I implore you to tell the government that the  
4 time has come to admit fault and give us the  
5 compensation we deserve, now, just as so many other  
6 countries such as Ireland have and go some way to  
7 putting things right. Don't tell us there is no  
8 money, because we pay billions in foreign aid because  
9 it is the right thing to do, so surely this is the  
10 right thing to do? It is, after all, our money, and  
11 all the taxpayers' of this country.

12 I stand on the shoulders of the dead and it  
13 breaks my heart every day. I thank you all for  
14 listening to me.

15 Thank you, Sir Brian.

16 **SIR BRIAN LANGSTAFF:** I've one question for you, Myles.  
17 Have you ever asked for the medical records of Robert  
18 Marr?

19 **MYLES HUTCHISON:** No.

20 **SIR BRIAN LANGSTAFF:** I suppose I should ask the same  
21 question of you.

22 **PAUL HUTCHISON:** No.

23 **SIR BRIAN LANGSTAFF:** In what I may describe -- and you  
24 know what I mean -- the straight, frank way that some  
25 Edinburgh people speak, which I know well, you have

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1 paralleling the other. It is very valuable indeed,  
2 and I have been privileged to listen to it.

3 So you have, in what you've been doing, been  
4 helping, even though you may think that you no longer  
5 are that sort of person. In my eyes, you are.

6 And I hope that your wish, saying that coming  
7 here would get this away once and for all, may prove  
8 to be the truth.

9 But thank you both. I'm sorry, Paul, for  
10 leaving you out of a specific mention, but I think --  
11 I see the two of you almost as two sides of the same  
12 coin, as it were, and I hope you don't mind my doing  
13 that.

14 **PAUL HUTCHISON:** No, that's fine.

15 **SIR BRIAN LANGSTAFF:** Thank you again for doing that.

16 **MYLES HUTCHISON:** Thank you, Sir Brian.

17 **SIR BRIAN LANGSTAFF:** We'll take a break now until  
18 3 o'clock.

19 **MS RICHARDS:** Sir, the live stream will be off after  
20 lunch.

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

22 (2.00 pm)

23 (Luncheon adjournment)

24 (3.00 pm)

25 **SIR BRIAN LANGSTAFF:** Now, our next two witnesses, who

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1 will give evidence together, are both anonymous.  
2 Each, therefore, has an order, and I shall read out  
3 both orders.

4 The first is in respect of witness 2590, who  
5 will be known as Mrs AU. I order that the name and  
6 address of witness W2590 -- that's Mrs AU to you and  
7 me -- and any other identifying information, such as  
8 the names of her husband and children, as well as the  
9 witness's image or a description of their appearance,  
10 cannot be disclosed or published in any form unless  
11 express permission is given by me or by the solicitor  
12 to the inquiry acting on my behalf.

13 Witness W2590 must be referred to only as  
14 Mrs AU.

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

20 The second witness is witness W0671. She will  
21 be known as Miss AV.

22 The name and address of witness W0671 and any  
23 other identifying information, such as the names of  
24 her family, as well as the witness's image or  
25 a description of their appearance, cannot be disclosed

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1 Miss AV.

2 **SIR BRIAN LANGSTAFF:** You are Miss, she's Mrs.

3 **MRS AU:** I'm Mrs.

4 **MISS AV:** I'm nervous.

5 **MS FRASER BUTLIN:** We'll take it nice and slowly, so don't  
6 worry. You were just 9 months old.

7 **MISS AV:** Mm-hm.

8 **MS FRASER BUTLIN:** You were being carried down the stairs  
9 by your childminder, when she fell.

10 **MISS AV:** Mm.

11 **MS FRASER BUTLIN:** Mrs AU, what do you remember of what  
12 happened next?

13 **MRS AU:** I was at work and I got home about 5 o'clock that  
14 night to -- we didn't have mobile phones then, so my  
15 landline rang, and it was my husband in a phone box  
16 somewhere phoning. And I'll never forget his words  
17 were -- you're going to laugh, but it's horrible --  
18 "Hold onto your knickers, you'll never believe what's  
19 happened". It's just like -- he just went into panic  
20 mode, couldn't cope, couldn't deal. So I had to rush  
21 to Royal Berkshire Hospital, which obviously now I  
22 know clearly where it is, but at the time I had no  
23 idea. I know it was a Friday night. It was rush hour  
24 traffic. I remember trying to get there, going the  
25 wrong way about five times, beating the inside of the

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1 or published in any form, unless express permission is  
2 given by me or by the solicitor to the inquiry acting  
3 on my behalf.

4 Witness W0671 must be referred to only as  
5 Miss AV.

6 The order remains in force for the duration of  
7 the Inquiry and at all times thereafter, unless  
8 otherwise ordered, and I may vary or revoke the order  
9 by making a further order during the course of the  
10 Inquiry.

11 Could we please have Mrs AU and Miss AV.

12 **MRS AU and MISS AV (affirmed)**

13 **Questioned by MS FRASER BUTLIN**

14 **MS FRASER BUTLIN:** You're both here to talk about your  
15 infections with hepatitis B, and you are mum and  
16 daughter.

17 You are going to try and not use each other's  
18 names or names of others in the family, but that might  
19 be quite tricky, and so if they slip, we're not going  
20 to worry and they will simply be redacted later, but  
21 they will obviously fall within the restriction order  
22 and mustn't be referred to outside of the room.

23 In 1995, Miss AV, you were just 9 months old.

24 **MISS AV:** Is that me?

25 **MS FRASER BUTLIN:** That's you, absolutely. You are

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1 windscreen because I was stuck in traffic, until  
2 I finally arrived at accident and emergency, threw the  
3 car outside. Arrived at accident and emergency. Sort  
4 of like waited in a queue -- it's bizarre -- I waited  
5 in a queue to be seen at A&E, because you just go into  
6 a really weird place, and then I said who I was and  
7 they ushered me into the resuscitation room, where  
8 I found [redacted], who was 9 months old, strapped to  
9 a resus table, basically, and she was strapped down so  
10 she couldn't move.

11 One of the bizarre things I remember is that she  
12 just had some front teeth, and there's a little gap in  
13 them, and I remember what she was wearing and the gap  
14 in the teeth. It's bizarre what you remember. Then  
15 the nightmare just started, really.

16 **Q.** She had had a bleed inside her skull and four major  
17 and eight minor fractures.

18 **A.** Yeah, so an eggshell break, four majors, eight minors.  
19 She had quite a few bleeds. She had -- her head was  
20 massive, but a lot of the bleeds were outside the  
21 skull, so the one they were concerned about was in her  
22 skull, in between her skull and the back of her neck,  
23 which is where they were really concerned. But, yeah,  
24 she was in a really bad way.

25 **Q.** You were warned she was going to die, and if she

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1 didn't die, she would be severely brain damaged.  
 2 **A.** More than four doctors told us that, yeah. She didn't  
 3 die. You get taken -- everyone watches Casualty and  
 4 things like that, but it's actually true; they have  
 5 a little room where they take you to deliver bad news.  
 6 We were told by every single doctor that she would  
 7 die, or if she didn't die, if we were in that  
 8 1 per cent chance, that she should need 24-hour care  
 9 and we should prepare ourselves for that. My response  
 10 was to tell the doctors -- I don't know, I just went  
 11 into a weird mode -- to tell them to eff off,  
 12 basically, and get me a proper doctor, because I just  
 13 wouldn't accept what they were -- I went into fight  
 14 mode and I wouldn't accept what they were telling me.  
 15 But more than four doctors told us she was going to  
 16 die, and if she didn't die, she would be brain damaged  
 17 severely.  
 18 **Q.** She was in intensive care for a period and you  
 19 remember her being given clear plasma.  
 20 **A.** Yeah, so part of what I learnt about myself then -- it  
 21 was -- I was -- I can't remember how old I was, like  
 22 31 or 30 or 31, and I think we find out who we are  
 23 when we get tested in bad times in our life, what sort  
 24 of person we are, and when she was in the resus room,  
 25 just going back to the resus room, they said to me

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1 gone through them, but we'll come back to some of the  
 2 documents in a moment.  
 3 And then when you were 4 you were playing at  
 4 a friend's house.  
 5 **MISS AV:** Yes.  
 6 **MS FRASER BUTLIN:** Mrs AU, you got a phone call. What  
 7 happened?  
 8 **MRS AU:** So --  
 9 **MISS AV:** Sorry, it's not funny, but --  
 10 **MRS AU:** So, again, there was another head injury really  
 11 for [redacted]. Again, I was at work, which gives me  
 12 immense guilt, which is ultimately why I started to  
 13 work from home and started my own business. But she  
 14 was playing with a friend, jumping around on the  
 15 sofa -- were you practising backflips? Oh, apparently  
 16 practising backflips. And there was a pen down the  
 17 back of the sofa. We've all got pens and chocolates  
 18 and 10ps and what have you, and apparently a pen went  
 19 in [redacted]'s head. It went under the skin, but  
 20 with head things, there was just loads and loads of  
 21 blood. So I screamed again to the hospital. I found  
 22 [redacted] when I got there running around, absolutely  
 23 fine, but blood all over her. So she was like, "I'm  
 24 fine, mum, I'm fine", but she had blood all over her.  
 25 So I pick her up, and I'm like, "Oh, my baby,

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1 that she was a Glasgow coma score of 4, and I asked  
 2 them what that meant and 15 is alive and 3 is dead, so  
 3 she only responded to one vital sign.

4 Then what that taught me is I wanted to know  
 5 everything that was happening to her while she was  
 6 there, and that was my way of trying to keep control  
 7 of the situation and hopefully of her and it not  
 8 spiralling and me not being in control.

9 As a result I didn't leave her side for the  
 10 whole time she was in hospital. I stayed with her  
 11 every minute.

12 When she was in intensive care, I didn't leave  
 13 her, so I know everything that was happening.  
 14 Everything they did, I asked them what they were  
 15 doing. Everything they did for her, I said, "Explain  
 16 that to me". So I know that she had saline drips and  
 17 plasma drips and metal shunts in her hands as well.  
 18 But I remember asking them and I remember them telling  
 19 me clearly what it was they were doing.

20 **Q.** Were you given any advice or warnings about any of the  
 21 risks involved in receiving that plasma?

22 **A.** No.

23 **MS FRASER BUTLIN:** Miss AV, you've obtained your own  
 24 medical records and there's no record of you having  
 25 received any transfusions at that stage when you've

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1 this has happened" -- in my head I'm like, "This has  
 2 happened again, I wasn't there for you", kissing her  
 3 and cuddling her, and -- I say licking her.  
 4 I remember distinctly going, "Look, it's fine" and  
 5 kissing her and licking her, and that's what  
 6 I remember happening, then taking her home and  
 7 managing to get through another scrape, we thought.

8 **MS FRASER BUTLIN:** Six weeks later you were attending  
 9 a work event and became unwell. You initially thought  
 10 it was sort of food poisoning or something you'd  
 11 eaten, but then it continued on.

12 **MRS AU:** Yes, I was actually at work, and I felt fine,  
 13 absolutely felt fine, when two minutes -- I'd had  
 14 a sausage roll. As soon as I'd had this sausage roll,  
 15 I had to go throw up. As soon as I'd thrown up,  
 16 I felt absolutely fine again. I was like, "Oh, great,  
 17 I don't know that was". So about half an hour later I  
 18 thought I'd have some more food. I had something else  
 19 that contained fat and as soon as I ate it again  
 20 I threw up. And that was the -- you know -- but then  
 21 I felt fine. As soon as I -- I had a couple of days  
 22 just throwing up constantly and then I went fine  
 23 again.

24 **Q.** Then you went to visit family that weekend but felt  
 25 very off, and you turned yellow by the Sunday of that

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1 weekend.

2 **A.** Yeah, which was just bizarre. So I come from up north

3 and I went to see family, and I felt really weird.

4 I was going out and so much so -- I went out with

5 family and I didn't have any alcohol, I didn't feel

6 right, I drove. And I woke up the next morning.

7 I remember I had lilac contact lenses at the time, and

8 I woke up looking like an Oompa Loompa. I woke up

9 bright orange with purple lenses. It was just the

10 most horrific look.

11 My nana actually ran a doctor's surgery and she

12 was like, "Right, there is something seriously,

13 seriously wrong". So I drove back home. I felt fine,

14 I was just bright orange. I actually phoned

15 out-of-hours GP that night and he said, "There is

16 something seriously wrong, you must go to the hospital

17 and see your doctor immediately". That's when I

18 was -- yeah.

19 **Q.** You had a series of blood tests and were found to be

20 positive for hepatitis B.

21 **A.** Yes.

22 **Q.** You told your husband about the result of the blood

23 test, and what was his reaction?

24 **A.** I had to tell him on the Sunday night that him and the

25 kids were getting tested on the Monday. Not great.

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1 So I went to see him and he couldn't really help

2 because he didn't know. He'd never encountered anyone

3 else with hepatitis B, he didn't really know what to

4 do and what to say.

5 **Q.** You were given some information about the risks to

6 others and the rest of the family were inoculated.

7 **A.** Mm.

8 **Q.** They also arranged for an investigation into how you,

9 Miss AV, had been infected. What were your feelings

10 about that at the time as her mum?

11 **A.** How I felt about the investigation?

12 **Q.** Yes.

13 **A.** Well, partly we wanted to find out what had happened

14 and all that sort of stuff really. So we understood

15 it, but we were assured that it would be completely

16 confidential.

17 **Q.** We'll come back to that in a moment. But the local

18 authority then tested everyone around you, including

19 children at the nursery, family members, childminder,

20 and we have some of the letters about the

21 investigation that we're just going to have a look at.

22 0671003, please.

23 It's a letter from September 1998, and we can

24 see in the second paragraph:

25 "In the process of screening her family, we

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1 So it was -- he assumed that I'd been sleeping around

2 or having an affair or certainly done something,

3 because the understanding about hepatitis B is -- it's

4 still not great, but then it was even less, so he just

5 assumed it was a sexually transmitted disease and what

6 had I been up to, basically.

7 **Q.** The whole family were then tested.

8 **A.** Yes.

9 **MS FRASER BUTLIN:** And at that point you also tested

10 positive, Miss AV?

11 **MISS AV:** (Nodded)

12 **MS FRASER BUTLIN:** What were you told about hepatitis B at

13 that stage?

14 **MRS AU:** Not a lot, actually. The internet had just been

15 going, I don't know for how long for, and every time

16 I went to see my doctor --

17 **Q.** Sorry, can you just slow down slightly. Our

18 transcribers are taking a note.

19 **A.** Oh, sorry.

20 **SIR BRIAN LANGSTAFF:** We will take all the time we need.

21 **A.** Sorry. I'm a bit nervous and a bit shaky.

22 So you asked me --?

23 **Q.** I was asking you what you were told about hepatitis B.

24 **A.** Our doctor didn't know very much at all really. It

25 appeared that I and the internet knew more than him.

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1 discovered that [Miss AV] was positive for hepatitis B

2 surface antigen and hepatitis B S antigen. I enclose

3 a copy of her immunology results which suggest that

4 she's a chronic carrier."

5 Then the next paragraph:

6 "I have been working with Dr Linda Booth,

7 consultant in communicable diseases at Basingstoke,

8 and the only conclusion we can come to is that Miss AV

9 has contracted hepatitis B from her nursery, either

10 from another child or from a carer. As a result,

11 Dr Booth has initiated screening of all the children

12 present at the local nursery and of those children who

13 were there when [Miss AV] was there too. In addition,

14 she has also screened all the carers."

15 And then we have 004, please, in the November.

16 In the first paragraph:

17 "Thank you for asking me to see this girl, who

18 has been found to be a hepatitis B carrier after her

19 mother presented with jaundice in July and was found

20 to have acute hepatitis B.

21 "As you mention in your letter, it seems likely

22 that her mother contracted the hepatitis B from

23 [Miss AV], but extensive contact tracing has failed to

24 identify the source of [Miss AV's] infection."

25 But at the end of the investigation at that

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1 time, you were -- you recall being told something very  
 2 specific; what was that?  
 3 **A.** We received a letter that I very clearly remember.  
 4 Unfortunately we don't have that copy now because  
 5 we've -- my marriage since broke up and we've moved  
 6 house so many times. But the conclusion of the letter  
 7 was, despite the extensive testing, they've not been  
 8 able to -- the only -- sorry, the only conclusion they  
 9 can have is that it was a direct result of her medical  
 10 intervention she received at the hospital, and they  
 11 understand if we wished to take it further. But  
 12 that's now conveniently not in her medical notes  
 13 unfortunately either.  
 14 **Q.** So you have a recollection of the letter, but now that  
 15 you've got the records, that letter is no longer  
 16 there.  
 17 **A.** It's not there, yeah.  
 18 **MS FRASER BUTLIN:** But, Miss AV, you remained concerned  
 19 and a bit questioning throughout your teenage years  
 20 about exactly how you had contracted hepatitis B and  
 21 asked further questions about it in 2012.  
 22 **MISS AV:** Mm-hm.  
 23 **Q.** You've provided us with a letter from King's Hospital,  
 24 which mentions your questions. It's 0671016, please.  
 25 Thank you.

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1 but the original investigation by the local authority  
 2 was meant to be kept confidential, but you discovered  
 3 that your daughter's name had been provided to people.  
 4 **MRS AU:** At least two of the parents and also one of the  
 5 carers that was actually looking after [redacted]  
 6 after hours, they all came up to me in our little  
 7 village, so I would imagine that everyone was told  
 8 which child it had been.  
 9 **Q.** What was the effect of that on you and on your  
 10 daughter?  
 11 **A.** We immediately retreated from that nursery, changed  
 12 our nanny, changed our carers, just became a lot more  
 13 reclusive, really. We lived in a small village that  
 14 we couldn't just manoeuvre in anymore as well, really.  
 15 We just felt that everyone was talking about us. It  
 16 was like the latest gossip.  
 17 **Q.** And you've particularly mentioned that people did ask  
 18 you what was going on, why she had a sexually  
 19 transmitted disease --  
 20 **A.** Yes.  
 21 **Q.** -- at such a young age.  
 22 **A.** Yes, yes, and they actually referred to it as, yes,  
 23 a sexually transmitted disease.  
 24 **Q.** You were both then referred up to King's, and you've  
 25 described being given a little bit more information

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1 We can see in the middle of the page a reference  
 2 to you now being 17 years old and having been reviewed  
 3 in the liver clinic.  
 4 In fact, could we take that straight down,  
 5 please.  
 6 Sorry, there's a difficulty.  
 7 There's a reference to you having questions  
 8 regarding how you came to be infected. But there's no  
 9 response to that letter in your medical records, is  
 10 there, and as far as you're aware, questions were  
 11 asked but there was no answer at that stage?  
 12 **A.** Mm-hm.  
 13 **Q.** But then we do have a letter from 2014 when you went  
 14 to the adult hepatitis clinic, in which it is recorded  
 15 that you had been treated at 9 months for brain injury  
 16 and multiple facial fractures, and that you appeared  
 17 to have received HBV infected blood product at that  
 18 stage.  
 19 **A.** Mm-hm.  
 20 **Q.** So it wasn't until 2014 that --  
 21 **A.** They confirmed.  
 22 **Q.** -- you had something in your hands that confirmed that  
 23 that's how you had been infected.  
 24 **A.** Mm-hm.  
 25 **MS FRASER BUTLIN:** Mrs AU, you alluded to it a moment ago

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1 about hepatitis B when you were there, but that it was  
 2 still quite limited.  
 3 **A.** Is this to me? Erm -- it seems -- even from the  
 4 beginning, they didn't really know what to do with us,  
 5 and I know that the first clinical trial [redacted]  
 6 was put on, I think it was the first in the UK, so  
 7 I feel like through the whole process we've been  
 8 learning with them. So I don't think they knew that  
 9 much more than we did, even at that point.  
 10 **Q.** In terms of your treatment, first -- we'll talk about  
 11 your daughter's in a moment -- what were you told  
 12 about what you required in relation to the hepatitis B  
 13 in terms of medication?  
 14 **A.** I got like effectively like a plaster to put over it,  
 15 really. They can't -- or they didn't try and do  
 16 anything for me other than giving me -- I couldn't  
 17 eat. I couldn't eat anything. I would just want to  
 18 be sick so -- and I lost huge amounts of weight. So  
 19 they gave me drugs, I think they were chemo -- anti  
 20 chemo sickness drugs to at least allow me to not be  
 21 sick when I did eat and that was it. The rest of it  
 22 was, "Well, we'll just keep checking you to see if you  
 23 clear it", and that was it, and just time, really.  
 24 **Q.** What was the effect on you for at least the first  
 25 year?

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1 A. Huge. So a lot of people in this room will understand  
2 about ALT scores and your liver. Your liver is meant  
3 to be around about 40 and [redacted] -- or, sorry, my  
4 daughter had some bloods taken once, and the  
5 phlebotomist said that you start-- her brother had  
6 died when his ALT went to 450, and she said that's  
7 when people -- that tends to be like the danger level  
8 for -- you know, you live or you die if it gets that  
9 bad, and mine was 1,060. So I was just like a walking  
10 skeleton. I couldn't get out of bed some days. Some  
11 days I had great days, other days I just couldn't get  
12 out of bed. I would just sleep.

13 I had two small children. I had a husband that  
14 I had managed to convince that I wasn't having  
15 an affair, so we were happy. I was trying to hold  
16 down a job. I'd gone to a local marketing agency, so  
17 I was trying to hold down a job. Just taking it  
18 day-by-day, really. Just taking it day-by-day until  
19 I -- you know ... I managed to clear it, luckily.  
20 I managed to clear it.

21 Q. You decided you did need to tell your employer that  
22 you were unwell, but you didn't want to explain you  
23 had hepatitis B, so what did you tell them?

24 A. I told them I had hepatitis A, because I had been on  
25 a work trip, and I know that hepatitis A you can get

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1 body defence mechanism (the immune system) is still  
2 immature and unable to fight the infection. Older  
3 children and adults are more frequently able to clear  
4 the virus, producing antibodies against it."

5 You only covered that quite recently.

6 MISS AV: Mm-hm.

7 Q. At the time, that wasn't your or your mum's  
8 understanding, that this would be something that would  
9 be lifelong.

10 A. No.

11 Q. When you were 11, you then had pegylated interferon.

12 A. Mm-hm.

13 Q. And you struggled to cope with that, so the dose was  
14 reduced.

15 A. Yes.

16 Q. What do you remember of that?

17 A. Was that my second injections? My dad did those in my  
18 legs, I think. What do I remember of it?

19 Q. Yes, what do you remember of the treatment?

20 A. Erm, none of them have been ideal, health-wise. They  
21 just completely savage you. They're not great. But  
22 I'd already had one when I was -- the one when I was  
23 5, so it wasn't -- it was later in life and now when  
24 I'm on treatments that I get more scared now. Does  
25 that make any sense? When I was younger it was all

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1 from food, so it just seemed to fit in nicely with,  
2 like, some sort of like back story that I could spin.

3 Immediately -- it was really weird. Immediately  
4 I -- immediately I had these tablets to take, they  
5 were on my desk and my boss came in, he picked them up  
6 and he went straight onto the internet and looked at  
7 what they were. He was that intrusive. He actually  
8 said, "Oh, yeah, they are what you say they are". He  
9 actually didn't even believe -- he was just like  
10 looking at my stuff and -- yeah, awful.

11 Q. Your liver was checked at the time of the infection,  
12 but have you had any follow-up since then?

13 A. No.

14 MS FRASER BUTLIN: Miss AV, in terms of your treatment,  
15 when you were 5, you had lamivudine and interferon for  
16 52 weeks. You didn't respond to that treatment, and  
17 since obtaining your medical records, you've  
18 discovered an information sheet about hepatitis B, but  
19 for you it's put some pieces into place.

20 It's 067018, please, and it's the second  
21 paragraph:

22 "When the hepatitis B virus infection is  
23 acquired at birth or during the first year of life,  
24 the child is likely to continue to carry the virus  
25 lifelong, possibly because in very young children the

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1 right, it wasn't too --

2 Q. They had to drop the dose of the interferon, though,  
3 didn't they?

4 A. Yes.

5 Q. Because your white cells had dropped completely.

6 A. Yes.

7 Q. Then at 14 you had entecavir and pegylated interferon  
8 again.

9 A. Yes.

10 Q. What were you told about that treatment?

11 A. By?

12 Q. By the doctors when you were given it. I think you  
13 were told it was sort of really the last shot at --

14 A. The last chance trial. Yes, it was the last set of  
15 medication that could potentially clear it. Obviously  
16 medical science has gone a bit further than that now,  
17 but, yeah, that was the last shot.

18 Q. But, again, the interferon element had to be stopped  
19 after about six doses.

20 A. Mm-hm.

21 Q. Because you were becoming very anaemic and very  
22 poorly.

23 A. Mm-hm.

24 Q. Again, what do you remember of that time in terms of  
25 how you felt?

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1 A. I think that period of time -- did you say I was 14 on  
2 that one? That's when it started going a bit -- a bit  
3 downhill from there, really.  
4 Q. It wasn't successful.  
5 A. No, unfortunately.  
6 Q. You've recorded that it felt really terrible because  
7 you put so much hope in the treatment.  
8 A. Yes.  
9 Q. You continued with the entecavir through until you  
10 were 16.  
11 A. Yes.  
12 Q. But then unfortunately you were still a non-responder.  
13 A. Yes, I failed that one.  
14 Q. Then you were put on management treatment of tenofovir  
15 and entecavir.  
16 A. Yes.  
17 Q. You're still on management treatment.  
18 A. Yes.  
19 Q. What are the effects of it on you physically?  
20 A. I mean, the first three years weren't good at all.  
21 I don't know how old I would've been. Probably just  
22 after 16, I think.  
23 Q. In your statement it says that at 16 you changed over  
24 to management treatment.  
25 A. Yes. Yes, the first three years were pretty rough.

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1 with your mental health.  
2 A. Mm-hm.  
3 Q. That wasn't helped by how you were treated by your  
4 peers at school.  
5 A. Mm-hm.  
6 Q. If we start there, how did they come to find out that  
7 you had hepatitis B?  
8 A. I made the terrible -- it sounds weird -- I made the  
9 terrible mistake of telling my best friend, and I just  
10 made the assumption, because we had been best friends  
11 for seven years, that it wouldn't go anywhere else.  
12 But it did, and it spread quite quickly, as you can  
13 imagine, because kids are mean.  
14 Q. And what happened once others knew about it?  
15 A. With regard to what? Generally?  
16 Q. You've said in your statement that they bullied you.  
17 A. Yes, yes, school was horrendous, yes.  
18 Q. Do you want to tell us anything more of what was  
19 happening at school?  
20 A. Erm ...  
21 Q. In terms of what they were saying to you.  
22 A. The problem is it's not -- it's not understood.  
23 I don't think particularly at that age it's that easy  
24 to understand because obviously someone's -- someone  
25 is -- they -- how do I word it? An STD is something

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1 They're quite -- they're really aggressive drugs, they  
2 are quite symptomatic, but naturally over time you  
3 just -- it's been so long now, I don't really --  
4 I still get my headaches and I still do feel sick and  
5 I'm tired all the time, but it's not as severe as it  
6 was in the beginning. I stopped going to school and  
7 things like that.  
8 Q. You've recently been diagnosed with polycystic ovarian  
9 syndrome, and you've wondered whether there's a link  
10 between that and your hepatitis B.  
11 A. Yes. They can't say that it was a direct link because  
12 there isn't enough versions of this same situation at  
13 that age and being on that particular trial. There's  
14 not a big enough sample size to kind of say it was  
15 a direct cause. But my consultant at London said  
16 because of the aggression of the treatment, with  
17 someone who was just experiencing menstrual cycle, the  
18 combination was a bit of a dodgy mix, basically.  
19 Q. The combination of going through puberty and having  
20 the --  
21 A. Treatment.  
22 Q. -- treatment at the same time, they've questioned  
23 whether that's caused ongoing gynaecological issues.  
24 A. Yes.  
25 Q. In your teenage years, you struggled significantly

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1 that is dirty. It's explained to us in sex education  
2 as being caught with drug needles and sexual  
3 interaction and this, that and the other. So there  
4 was a lot of different versions of events that people  
5 had of how I had it, and unfortunately you can't  
6 correct everyone, so ... that was that, really.  
7 Q. There was just a lot of name-calling and  
8 unpleasantness towards you.  
9 A. Mm.  
10 Q. You missed a lot of school because of your physical  
11 ill-health.  
12 A. Yes.  
13 Q. Also because of your mental ill-health.  
14 A. Yes, I just stopped going.  
15 Q. Your mental state was very low and you began to drink  
16 and self-harm as a way of coping.  
17 A. Mm-hm.  
18 Q. Is there anything you want to tell us about that time  
19 in your life and what it was like?  
20 A. I had my arms stitched up or glued a few times. That  
21 was -- it wasn't actually too -- maybe I was about 18  
22 or 19 then. I still don't have an answer to why that  
23 happened, but I think -- I don't know, just extremely,  
24 extremely self-destructive, really, I guess.  
25 Q. In terms of psychological support, you had some

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1 counselling when you were in your early teens, and  
 2 I think the first occasion your mum had asked for you  
 3 to see a female counsellor, given your age and the  
 4 issues you were facing, but you were offered a male  
 5 counsellor.  
 6 A. Mm-hm.  
 7 Q. And then you did see a female counsellor for a few  
 8 sessions, but what did she say?  
 9 A. That -- I only saw her once.  
 10 Q. Oh, okay.  
 11 A. She discharged me after I think it was like 20 minutes  
 12 because I was a bit -- sorry, I was a bit mean, but  
 13 I just was really tired that day because I'd been at  
 14 hospital all day and then they had booked the session  
 15 for the end of the day and I was really tired  
 16 and I just wanted to go home, so I was just, "I'm all  
 17 right", so I could go home.  
 18 Q. So as far as she was concerned, there was nothing  
 19 wrong and she discharged you.  
 20 A. She discharged me, yes.  
 21 Q. Your quite significant mental health difficulties  
 22 continued and continue to an extent today, but they  
 23 particularly continued until you reached about 22, and  
 24 then you decided to try and turn your life around.  
 25 Can you tell us about that?

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1 No, my auntie works in sales for a ski company. One  
 2 of their nannies had dropped out at the beginning of  
 3 the season, so she asked if she could fly me out. So  
 4 then whilst I was in France, I realised the same thing  
 5 I realised whilst I was in Spain. So whilst I was in  
 6 France I reapplied for college to come back to  
 7 in September.  
 8 Q. You've come back, you've started basically from the  
 9 beginning.  
 10 A. Mm-hm.  
 11 Q. Retaking some GCSEs.  
 12 A. Mm.  
 13 Q. Doing an access course.  
 14 A. Mm-hm.  
 15 Q. Going on to a higher education course.  
 16 A. Yes.  
 17 Q. Now you're at university studying psychology.  
 18 A. Yes.  
 19 Q. You've said in your statement that things are much  
 20 better in terms of your mental health, but you still  
 21 struggle with anxiety and it's not entirely  
 22 straightforward.  
 23 A. Well, the problem is with the anxiety and depression  
 24 is I've tried a lot of things, and I've come to the  
 25 conclusion I don't like being on medication -- more

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1 A. Well, I stopped running away, because moving countries  
 2 does not fix anything. I didn't do well in school,  
 3 therefore didn't do well in college and just left both  
 4 of those. So I went back to college, redid those two  
 5 years, and now I'm in my third year of uni and will do  
 6 my Master's next year.  
 7 Q. In between all of that, you had had some GCSE results  
 8 that were very poor.  
 9 A. Mm-hm.  
 10 Q. You tried college. That hadn't worked. And you  
 11 decided to go abroad.  
 12 A. Yes.  
 13 Q. What did you do?  
 14 A. I worked in a bar. Did you mean job-wise?  
 15 Q. Yeah, where did you go, what did you do?  
 16 A. I went to Spain. I was meant to go for three months  
 17 and then I came back a year and a half later.  
 18 I'm so sorry! She hated me!  
 19 Q. You say in your statement although you like being away  
 20 from home, you hadn't tackled your issues, you just  
 21 moved them somewhere else with you.  
 22 A. Yeah.  
 23 Q. Then you decided to come home to try and sort things  
 24 out.  
 25 A. Yeah. Then I sort of accidentally moved to France.

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1 medication. I don't like talking to people because  
 2 I don't trust people, so I just keep moving, really.  
 3 So I don't -- it's not very tackled, really, as of  
 4 yet.  
 5 Q. You're now in a very supportive relationship.  
 6 A. Mm-hm.  
 7 Q. But going forwards, you've got concerns about having  
 8 children.  
 9 A. Mm-hm.  
 10 Q. If you want them in the future, can you tell us about  
 11 that?  
 12 A. If I want them? No, I do, I really want them. But  
 13 with the current treatment I'm on, it wouldn't mean it  
 14 would be 100 per cent -- it's not -- I don't know how  
 15 to word it.  
 16 So although it's undetectable in my blood  
 17 because of the medication that I've been on for a long  
 18 time, if I was to fall pregnant, there's still that  
 19 0.00-something chance that the baby could get hep B.  
 20 Also would not -- breast feeding is off limits, no-no,  
 21 can't do that. I can't even remember the reason for  
 22 that. But that's that.  
 23 But I wouldn't run the risk of having a child no  
 24 matter how small the risk was. I wouldn't want to  
 25 obviously do that to someone else, especially not my

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1 child. So I'm just going to put the baby idea away  
2 for a while.  
3 **Q.** Also because if you were trying to get pregnant, you'd  
4 have to come off the maintenance treatment that you're  
5 on.  
6 **A.** I think it would have to be with something else,  
7 I can't remember what my consultant said, but I'd have  
8 to be on it for a certain amount of time and stay at  
9 certain levels for it to be safe to have a baby.  
10 **Q.** You've just been told that there may be a new trial  
11 coming on board.  
12 **A.** Yes.  
13 **Q.** Can you tell us about that?  
14 **A.** I'd need to stay on what I'm on for another few years,  
15 I think, or a year. I need to stay undetected,  
16 basically, like underneath the level, and then I could  
17 maybe get rid of it.  
18 **Q.** But it's an entirely new treatment that is --  
19 **A.** Unfortunately it's an aggressive one again, so it's  
20 all the injections and the bloods and I have to stay  
21 on the treatment I'm already on as well and then take  
22 another oral medicine with all -- it's just a big  
23 combination, a little cocktail.  
24 **Q.** The piece of that jigsaw you're particularly worried  
25 about is the injections.

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1 **Q.** But the waiting time was too long, so you've had some  
2 privately.  
3 **A.** I had some privately, but I think the counselling  
4 around something like this, there's no help, people  
5 can't understand, because it's essentially a long-term  
6 illness, rather than you're definitely going to die,  
7 you know. We were told [redacted], when she was --  
8 when we were first diagnosed, we were told she would  
9 probably start dying about 25, you know, if she got  
10 cirrhosis and this sort of stuff. And as it turns  
11 out, as time and everything goes on, that changes and  
12 the prognosis is a lot better now. But, you know, you  
13 live with all of that, and it's just -- yeah,  
14 a rollercoaster, terrible, terrible.  
15 **MS FRASER BUTLIN:** Miss AV, you've talked about the  
16 difficulties in your relationship with your mum --  
17 **MISS AV:** Mm-hm.  
18 **Q.** -- because of your infection.  
19 **A.** Mm-hm.  
20 **Q.** Do you want to say anything about that? You don't  
21 have to.  
22 **A.** What do you want to hear? There's a lot.  
23 **Q.** I think you just wanted to say something around that  
24 it had been difficult.  
25 **A.** Yeah, because I spent a long time -- this -- okay, the

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1 **A.** Yeah.  
2 **Q.** Because you've had so many when you were little,  
3 that's something of a block now for you sort of  
4 mentally.  
5 **A.** Yes. I think the problem is it was always in a really  
6 big bulk. So every treatment you obviously -- your  
7 blood needs to be monitored at least once a week for  
8 you to be having injections once a week, and for you  
9 to be taking this, that and the other, so I think  
10 after about 16 I'd had enough of those, petrified.  
11 **MS FRASER BUTLIN:** Mrs AU, emotionally, what's been the  
12 effect of your infection and your daughter's infection  
13 on you?  
14 **MRS AU:** Huge. And it continues. It's just -- it's just  
15 awful. It's just a rollercoaster. I call it like  
16 there's good and bad days, especially leading up to  
17 this and giving evidence. I mean, I'm so proud of my  
18 daughter for being here, basically, because it just  
19 brings back so many memories. And then the emotions  
20 start again. Just horrific, really. It's just so  
21 devastating. Awful. Constant. It's just constant.  
22 And just a rollercoaster is all I can describe it as,  
23 really, for both of us and everyone in the family.  
24 **Q.** You asked for counselling from your GP for yourself.  
25 **A.** Yes.

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1 same with everybody else's stories today, you hear it  
2 and it sounds so bad that you think is that -- okay,  
3 obviously I believe it's true, because I'm in that  
4 position, but there were so many rumours and stories  
5 about me from kids and stuff at school, there was  
6 a lot of things about maybe -- there was rape, there  
7 was drugs, there was this, there was all sorts of  
8 stories. So after a while, after so many years,  
9 I started to question -- because some people had said,  
10 "Oh, her mum had given birth to her with it" and  
11 things like this, so it goes round and round and we  
12 started to fight quite badly, because if I got drunk  
13 or just generally, really, I'd blame her, I'd say she  
14 was irresponsible, she missed something. Why can't  
15 I see my doctor's notes? You know, all of these  
16 things, which wasn't right, but you know ... can't  
17 take it back now.

18 **MS FRASER BUTLIN:** Mrs AU, what was the effect of your  
19 infection on your relationship with your husband?

20 **MRS AU:** Oh, that wasn't great.

21 Yeah, I mean, he never really got over the fact  
22 that he thought I cheated on him, and of course the  
23 fact he thought that damaged us, because he should  
24 have known me better than that, really. So it wasn't  
25 the reason why we got divorced, but it definitely put

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1 a massive wedge between us.  
 2 **Q.** But then, now, what's the relationship like?  
 3 **A.** Yeah, we're -- we were separated for eight years, we  
 4 actually got divorced, and four years ago we  
 5 reconciled. So we live together now again. We're not  
 6 married, but we're together.  
 7 **Q.** You said you now get on well and are very different  
 8 people to the people you were back then.  
 9 **A.** Very different people, yeah, yeah.  
 10 **Q.** But that your husband still suffers from both your  
 11 diagnoses in terms of his worry and his anxiety about  
 12 both of you.  
 13 **A.** He just can't deal with it. We found out from very  
 14 early days, when my daughter had had her head injury,  
 15 that he feels like he should be there as the  
 16 protector, and when he can't, he can't deal with it.  
 17 So even today he was -- he could've been here, but  
 18 he's not. When we go -- we go to the hospital four  
 19 times -- I mean, when it's her trial, we'll go every  
 20 week for three months, then we'll go every month, and  
 21 he can come to all of those and never does because he  
 22 just can't deal with it. He can't deal with it. And  
 23 if we try and talk about it, he just wants to get off  
 24 the subject, because he just feels guilt that he  
 25 didn't stop it and can't help it.

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1 schemes don't cover hepatitis B.  
 2 **A.** No.  
 3 **Q.** You've also not been able to obtain any disability  
 4 benefits.  
 5 **A.** (Indicated dissent)  
 6 **Q.** Those are the questions I have for you. I'm just  
 7 going to turn to Mr Lock to see if there is anything  
 8 else he would like me to raise.  
 9 (Pause)  
 10 Mr Lock has just said that you wanted to say  
 11 something about the care you've received from the  
 12 consultants at King's throughout all the trials.  
 13 **A.** Yes. We've had a couple of bad therapist experiences  
 14 there but, bar that, the consultants we've had at  
 15 King's have been outstanding. I feel like they picked  
 16 up [redacted] when she was very young and have taken  
 17 her under their wing, and she's had clinical trial  
 18 opportunities that I don't believe others have had.  
 19 I think they connected with her in a way that is just  
 20 magical and I cannot fault them. I cannot fault them.  
 21 Her current consultant I feel is just outstanding.  
 22 We've really -- not that you can enjoy going to  
 23 hospital, not that she can enjoy doing that, but --  
 24 **MISS AV:** We did when we had to get drunk on the train.  
 25 **MRS AU:** Oh, that's a moment. But she is amazing. So the

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1 **Q.** You mentioned earlier, Mrs AU, that you ended up going  
 2 self-employed in order to give more support to your  
 3 daughter. Financially, you've said in your statement  
 4 that obviously had quite a significant impact on you.  
 5 **A.** Yeah, so I was -- I was like on a fast track. I was  
 6 fast track in a corporate world, then I was fast track  
 7 in a marketing agency world, what you'd probably  
 8 describe then as like a high-flyer. I was the wage  
 9 earner in the family, doing exceedingly well at a very  
 10 young age. I'd like to say with no degree, and --  
 11 I felt like I was busking it but getting away with it.  
 12 It was crazy.

But I just felt so much guilt, and I do to this  
 day, that, you know, I hired that nanny that fell down  
 the stairs; I wasn't there when the pen went in her  
 head; I wasn't there to look after her. So I feel  
 such guilt that I wasn't at home. So I thought  
 I couldn't -- I can't change that, but I can be around  
 more.

So I gave up my job and I started working from  
 home as a marketing agency girl, and just hoped I'd  
 get work. I didn't have a client, I just hoped I'd  
 get work, and I was lucky, and I worked from home.

**Q.** Throughout the time, you've not been able to apply for  
 any financial assistance because the trusts and

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1 consultants and the professor at the university have  
 2 been exceptional, and I can't fault them. They've  
 3 just been wonderful. And really nurturing and really  
 4 supportive of us emotionally. You know, the times  
 5 that we've gone in there and the pair of us will just  
 6 both start crying. We don't realise we're feeling  
 7 like that, but we're just in tears, or [redacted] will  
 8 come into a story that actually I didn't know. She'll  
 9 just sit there and listen. She's got a queue outside  
 10 the door, but she's just got endless time for the  
 11 emotional side as well as the physical time, and I  
 12 can't fault -- I think they're exemplary.  
 13 **MS FRASER BUTLIN:** Is there anything else either of you  
 14 would like to say to finish?  
 15 **MISS AV:** No.  
 16 **MRS AU:** I just -- did David want to hear the story? I  
 17 don't know if you did or didn't. No, we're good,  
 18 thank you.  
 19 **MS FRASER BUTLIN:** Sir.  
 20 **SIR BRIAN LANGSTAFF:** Well, Miss AV --  
 21 **MRS AU:** Oh, sorry, I did have something to say. I forgot  
 22 about my bit of paper. Is that all right? Sorry. So  
 23 nervous.  
 24 Right, okay.  
 25 I would just like to say a huge thank you to

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Sir Brian Langstaff and all his team and all our lawyers, in particular the incredibly helpful and supportive Sarah Westerby, without whom we wouldn't even have got this far, as revisiting things is hugely traumatic.

Just today, as I am typing out this statement -- which was Monday this week -- I have just received a text from my daughter which reads as follows:

"I knew there were going to be some dark truths, but I never predicted this. To know that a GP would have let a 4-year-old girl eventually die from hepatitis rather than let me have the interferon treatment has made me sick to my stomach. I feel robbed of my childhood and my life and nothing will ever make this okay. I feel confused, heartbroken and abused. That's what this feels like. It feels like constant abuse and there is no escape. Recently I even thought about how much easier this would have been if I had just died from it so I wouldn't have to suffer daily mentally. I can't wrap my head around this and I think I really need to pull out of this process because I honestly think it will kill me. I wasn't ready for this and I don't think I ever will be."

I think that text pretty much sums things up and

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been her and continues to be so. We share the closest bond and couldn't love each other any more. It is just not possible. But I just publicly wanted to share how proud of her I am, how she faces her struggles and of the woman she has become, a woman who after crashing out of college due to illness and depression is now in her third year of university and about to graduate in psychology, just so she can help others with similar illnesses to hers get the help she never got.

Hepatitis B and Royal Berkshire almost broke us, but it didn't, and for that we feel incredibly blessed. For us, the nightmare will never end, but if this inquiry can change the future, hopefully this will have been worth it.

So thank you again to Sir Brian Langstaff and everyone involved for your help in making this change happen.

Thank you.

**SIR BRIAN LANGSTAFF:** Well, Miss AV, I am -- I must thank you that, having tried to escape by going to Spain and then France, and despite your obvious reluctance to talk about the school days and what happened in the past, that you've brought yourself to come here.

You realise how important it is that you and

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the never-ending torture and ordeal that the infection has brought on our lives.

If King's College hadn't pushed for the interferon treatment when my daughter was 4, she probably could be dead or dying now of untreated hepatitis B. It will never end. It will always be like this. I only hope the conclusion, if there is one, is that hepatitis B will be recognised as a blood-borne virus and not a sexually transmitted disease, and that hepatitis B carriers are treated equally in terms of compensation from the government as hepatitis C and HIV currently are.

Huge thanks also goes to the very brave souls and sufferers who initially brought this case to attention. They must have had huge struggles getting heard, fobbed off repeatedly but they didn't give up.

Thank you to you very brave men and women, and rest in peace those who didn't get to see this inquiry taking place on your behalf as the disease took you before you got to see justice.

Finally, I would like to say thank you to my incredible daughter. She has had the worst start in life and still struggles to greet each day with dignity and a brave face. People sometimes ask me who my hero in life is, who has inspired me, and it has

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your mum should come and tell us about hepatitis B and the cross-infection that took place and the aftermath, and you've told us actually quite a lot by your very different responses to what happened. You, I think shutting it out a bit, perhaps, if I may say so; you on the other hand, Mrs AU, you're only too willing to want to deal with it by talking about it. So very different responses, but each of them, together, present to me a fascinating and compelling picture.

I'm sorry that it had to be hepatitis B that brought you here. But thank you.

**MRS AU:** Thank you.

**SIR BRIAN LANGSTAFF:** 10 o'clock tomorrow then.

**MS FRASER BUTLIN:** Yes, sir.

**SIR BRIAN LANGSTAFF:** What do we have tomorrow?

**MS FRASER BUTLIN:** We'll be hearing from two anonymous witnesses, followed by David Rankin and Mary Grindley.

**SIR BRIAN LANGSTAFF:** Thank you. So tomorrow, 10 o'clock. (4.00 pm)

(Adjourned until 10.00 am on Friday, 1 November 2019)

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1	I N D E X	
2	JRYNA BATTERS (sworn) .....	1
3	Questioned by MS FRASER BUTLIN .....	1
4	MYLES HUTCHISON and PAUL HUTCHISON (sworn) ...	40
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76/19 77/2 77/4 77/16 77/17 77/25 78/18 78/23 79/19 80/7 80/10 80/13 80/16 81/19 82/20 83/24 84/16 86/19 87/2 87/6 87/9 88/23 89/3 89/11 90/2 90/8 90/16 91/4 91/15 91/18 92/14 92/20 93/6 93/6 93/9 93/18 93/21 94/24 97/23 100/13 104/20 105/20 106/6 107/3 107/4 107/7 115/23 115/25 116/6 117/23 132/20 146/15 153/20 154/3 154/12 154/23 155/3 156/1 156/2 156/9 156/18 156/20 156/22 157/20 158/14 160/1 160/12 161/23 161/24 161/25 162/18 162/22 166/10 167/7 179/1 181/12 182/6 182/8 182/10 182/12 183/11 184/1 184/10 <b>hepatitis B</b> [2] 70/24 71/11 <b>hepatitis C</b> [63] 1/10 5/25 6/5 6/9 7/5 10/4 10/16 11/6 11/9 12/17 12/24 13/1 21/21 23/3 23/9 24/6 25/5 26/24 27/4 28/1 34/3 38/24 49/4 74/20 74/21 76/6 76/8 76/19 77/2 77/4 77/16 77/17 77/25 78/18 78/23 80/7 80/13 83/24 84/16 86/19 87/6 88/23 89/3 90/2 90/8 90/16 91/18 92/14 93/6 93/6 93/9 93/18 94/24 100/13 104/20 105/20 107/3 107/4 115/23 115/25 117/23 132/20 182/12 <b>her</b> [79] 23/16 24/6 24/8 24/13 27/16 76/9	76/9 85/13 85/18 85/21 85/24 86/1 86/6 86/7 86/9 86/9 86/14 101/17 105/3 113/18 120/13 120/14 120/16 121/23 122/2 122/11 122/12 134/14 138/4 138/13 143/6 145/8 145/24 148/16 148/19 148/21 148/22 148/22 149/19 150/5 150/7 150/9 150/10 150/13 150/15 150/17 151/23 151/24 151/25 152/2 152/3 152/3 152/5 152/5 152/6 155/10 155/25 156/3 156/9 156/18 156/22 157/9 157/12 161/5 169/9 176/10 176/10 176/13 177/14 177/19 178/15 178/16 179/17 179/19 179/21 183/1 183/4 183/4 183/7 <b>here</b> [31] 1/9 24/23 39/13 47/4 57/13 68/1 76/13 99/20 100/5 103/1 104/8 105/6 107/2 112/1 112/8 112/14 114/3 116/7 119/20 119/23 126/10 126/15 136/10 140/22 141/21 144/7 146/14 174/18 177/17 183/24 184/11 <b>Here's</b> [2] 51/15 87/23 <b>hero</b> [1] 182/25 <b>heroes</b> [1] 141/5 <b>heroism</b> [1] 141/2 <b>hers</b> [1] 183/9 <b>herself</b> [3] 85/11 85/13 85/17 <b>hesitant</b> [1] 102/4 <b>hexagonal</b> [3] 56/10 56/21 133/5 <b>high</b> [19] 13/20 13/22 59/12 61/13 61/21 61/23 62/2 73/8 73/14 73/21 107/25 108/25 109/16 109/16 109/17 117/12 125/16 141/19 178/8 <b>high-risk</b> [7] 13/20 59/12 61/13 61/21 61/23 62/2 73/8 <b>higher</b> [2] 124/23 171/15 <b>highest</b> [2] 125/17 127/17 <b>Highlands</b> [2] 27/17 27/23 <b>highlight</b> [4] 62/16
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(58) grew - highlight

<b>H</b>	139/6	101/25	172/24 181/18 183/4	38/23 96/10 96/11	97/25 104/24 104/24
<b>highlight...</b> [3] 73/25 77/7 105/14	<b>hit</b> [4] 27/8 27/20 136/22 137/7	<b>hoping</b> [2] 96/19 98/22	183/4 183/25	113/11 126/3 134/1	104/25 119/24 122/6
<b>highlighted</b> [2] 15/9 118/18	<b>HIV</b> [12] 44/7 44/10 58/12 58/16 61/6	<b>horrendous</b> [7] 59/21 61/1 95/17 102/16	<b>however</b> [4] 39/19	137/15	125/3 125/14 126/17
<b>highlighting</b> [1] 70/5	61/16 61/25 65/25	102/22 137/15 167/17	94/13 103/17 103/25	<b>I been</b> [1] 154/6	126/19 128/22 138/2
<b>him</b> [72] 2/16 2/17	66/2 69/11 93/20	<b>horrible</b> [8] 29/16	<b>hug</b> [1] 44/21	<b>I believe</b> [3] 68/2	152/17 154/15 160/8
2/22 3/14 3/16 3/19	182/12	64/12 64/12 99/8	<b>huge</b> [6] 160/18 161/1	129/15 176/3	165/21 166/3 167/23
7/23 8/5 11/11 26/19	<b>hm</b> [46] 4/9 4/13 8/17	99/17 99/17 137/25	174/14 180/25 182/13	<b>I broke</b> [1] 27/5	168/23 171/25 172/1
28/10 29/13 29/14	10/5 11/10 12/11	147/17	182/15	<b>I call</b> [2] 101/22	172/2 172/3 172/14
29/15 29/19 30/12	12/23 18/18 21/10	<b>horrific</b> [3] 136/12	<b>hugely</b> [1] 181/4	174/15	179/18 181/23
31/5 31/6 31/13 31/15	22/18 28/2 28/14	153/10 174/20	<b>huh</b> [3] 6/4 46/19 93/1	<b>I called</b> [1] 120/8	<b>I done</b> [2] 65/3 100/17
31/20 32/24 33/9 33/9	28/18 35/13 35/16	<b>hospital</b> [46] 2/16	<b>human</b> [5] 45/15	<b>I came</b> [4] 20/1 67/1	<b>I drove</b> [4] 2/16 96/18
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34/12 34/16 37/21	53/14 70/14 115/9	26/21 29/23 38/4 38/5	123/2	<b>I can</b> [9] 48/25 60/10	<b>I drunk</b> [1] 96/11
38/11 39/4 43/4 44/6	121/15 124/21 129/10	44/15 46/13 47/20	<b>humiliation</b> [1] 128/5	64/7 72/6 73/20	<b>I enclose</b> [1] 156/2
44/12 44/16 44/20	132/7 147/7 157/22	52/14 56/8 56/15 59/9	<b>hundreds</b> [2] 124/14	125/25 127/3 174/22	<b>I ended</b> [4] 66/16
44/20 44/21 44/21	158/12 158/19 158/24	59/23 61/12 62/2	124/14	178/18	104/14 119/16 125/10
45/6 45/7 47/13 47/24	163/6 163/12 164/20	64/13 67/22 67/22	<b>hurt</b> [7] 9/24 79/4 79/6	<b>I can't</b> [10] 65/16	<b>I even</b> [3] 16/21
51/17 51/18 55/7	164/23 167/2 167/5	71/18 75/24 76/4 95/5	86/8 99/16 122/4	95/19 114/2 140/10	119/18 181/18
58/19 60/19 63/2 76/6	168/17 169/6 170/9	95/20 97/6 111/22	136/12	149/21 172/21 173/7	<b>I eventually</b> [1] 105/2
78/21 79/7 79/20	171/10 171/14 172/6	111/24 119/18 119/19	<b>hurting</b> [4] 85/1 86/5	178/18 180/2 181/20	<b>I ever</b> [1] 181/23
93/11 94/9 103/25	172/9 175/17 175/19	119/21 120/11 125/15	89/12 99/6	<b>I cannot</b> [2] 179/20	<b>I explained</b> [4] 87/5
104/24 104/25 107/6	<b>hold</b> [3] 147/18	133/15 135/22 147/21	<b>husband</b> [8] 1/11	179/20	103/22 107/9 116/19
111/19 115/24 116/2	161/15 161/17	150/10 151/21 153/16	114/10 145/8 147/15	<b>I certainly</b> [1] 100/24	<b>I failed</b> [1] 165/13
117/13 117/14 117/23	<b>holding</b> [3] 31/11	157/10 157/23 169/14	153/22 161/13 176/19	<b>I cheated</b> [1] 176/22	<b>I feel</b> [19] 67/9 84/16
125/4 153/24 153/24	33/12 39/1	177/18 179/23	177/10	<b>I check</b> [1] 114/3	94/4 98/2 98/4 98/6
154/25 155/1 176/22	<b>holey</b> [1] 2/19	<b>hospitals</b> [1] 109/22	<b>husbands</b> [1] 84/7	<b>I climb</b> [1] 2/7	101/25 110/22 110/25
<b>himself</b> [5] 2/10 6/12	<b>holiday</b> [5] 43/7 64/17	<b>hour</b> [5] 9/19 67/3	<b>HUTCHISON</b> [12]	<b>I come</b> [1] 153/2	114/19 120/11 131/23
35/1 58/18 91/1	64/23 65/12 65/15	147/23 149/8 152/17	40/18 40/18 54/18	<b>I complain</b> [1] 120/7	140/16 160/7 178/16
<b>hired</b> [1] 178/14	<b>home</b> [41] 4/10 4/10	<b>hours</b> [9] 3/9 3/13	54/19 73/7 76/18 87/4	<b>I could</b> [9] 17/9 37/1	179/15 179/21 181/13
<b>his</b> [84] 2/9 2/10 2/11	19/4 24/22 29/4 29/14	9/14 39/1 67/3 125/12	93/17 133/17 133/17	79/4 92/11 98/22	181/15
2/14 2/14 2/22 3/2	29/22 29/25 30/23	125/12 153/15 159/6	185/4 185/4	105/9 162/2 169/17	<b>I felt</b> [17] 27/9 34/13
3/11 3/12 5/12 9/2	31/4 31/22 31/23	<b>house</b> [19] 4/7 5/6	<b>Hutchison's</b> [1] 55/11	173/16	34/14 34/14 46/12
9/11 25/12 25/23 26/8	31/25 32/4 33/11	16/23 19/13 36/21	<b>Hutchison/Hutchison</b>	<b>I couldn't</b> [11] 6/8	52/22 99/15 103/5
28/9 29/2 29/12 29/24	33/19 33/23 43/14	92/6 96/22 101/17	<b>[1]</b> 133/17	37/23 66/18 95/9	112/13 139/17 152/12
30/9 30/24 31/17	48/25 63/16 64/14	102/20 103/4 119/19	<b>hypochondriac</b> [1]	96/24 102/20 103/1	152/16 152/21 153/3
32/22 32/22 34/19	66/22 76/9 88/6 97/4	121/25 124/2 126/4	116/3	160/16 160/17 161/10	153/13 155/11 178/11
35/22 36/24 36/24	112/16 135/16 137/22	126/14 129/23 129/24	<b>I</b>	178/18	<b>I finally</b> [1] 148/2
37/16 39/2 42/24 44/8	139/13 141/17 147/13	151/4 157/6	<b>I actually</b> [11] 16/6	<b>I cut</b> [4] 66/9 92/5	<b>I forgot</b> [1] 180/21
44/10 44/16 44/16	151/13 152/6 153/13	<b>household</b> [2] 7/13	20/19 23/24 51/14	113/24 137/3	<b>I found</b> [6] 46/3 51/22
44/17 44/18 45/8	169/16 169/17 170/20	15/10	65/4 95/23 95/24	<b>I definitely</b> [1] 111/12	90/9 139/22 148/8
45/11 49/1 55/4 55/4	170/23 178/17 178/21	<b>housing</b> [1] 127/6	123/2 135/16 135/19	<b>I did</b> [14] 5/16 16/5	151/21
55/12 58/23 62/22	178/23	<b>how</b> [66] 8/2 9/17 9/25	153/14	21/17 23/25 35/19	<b>I gave</b> [4] 44/21 87/8
62/24 65/21 66/15	<b>home-schooled</b> [1]	11/1 14/22 20/24 21/6	<b>I again</b> [1] 107/6	43/24 51/17 78/22	102/22 178/20
68/23 70/6 73/11 74/4	4/10	24/1 30/16 30/19 34/7	<b>I already</b> [1] 128/4	96/1 96/21 99/25	<b>I get</b> [2] 110/22
76/6 76/7 78/17 78/18	<b>homes</b> [1] 141/19	41/22 42/22 48/8	<b>I also</b> [1] 99/1	100/18 160/21 180/21	163/24
79/8 79/21 82/13	<b>honest</b> [4] 46/12	48/10 49/1 50/5 56/11	<b>I always</b> [2] 58/22	<b>I didn't</b> [26] 19/17	<b>I go</b> [2] 131/16 131/17
94/11 94/13 94/13	51/17 81/16 126/10	74/19 81/13 81/18	131/22	20/23 21/21 21/22	<b>I got</b> [25] 30/20 35/18
103/18 103/22 104/1	<b>honestly</b> [1] 181/22	88/4 88/7 90/1 93/14	<b>I am</b> [10] 68/10 94/23	32/24 46/13 57/5 65/5	36/7 44/25 48/8 52/12
105/24 105/25 106/2	<b>honeymoon</b> [1] 1/15	96/21 97/7 100/8	126/1 128/4 139/4	69/11 72/10 79/21	52/12 56/13 81/23
115/21 116/2 117/24	<b>honouring</b> [1] 140/9	103/5 103/5 113/3	140/7 140/8 181/6	90/13 102/13 102/25	90/13 96/18 97/6
118/1 118/20 122/9	<b>hope</b> [9] 62/4 96/16	113/9 113/16 113/18	183/4 183/20	103/5 112/21 120/14	100/21 100/24 119/3
124/2 124/2 125/3	97/18 137/9 138/18	113/19 117/18 120/1	<b>I and</b> [1] 154/25	122/4 124/16 135/20	125/13 129/23 133/12
125/6 147/16 153/23	144/6 144/12 165/7	123/18 125/14 126/13	<b>I ask</b> [1] 55/1	150/9 150/12 153/5	134/22 136/22 138/11
161/6 177/11 177/11	182/7	126/17 131/19 132/22	<b>I asked</b> [9] 51/2 51/6	170/2 178/22 180/8	147/13 151/22 160/14
181/1	<b>hoped</b> [5] 79/10	138/17 140/11 140/24	57/11 111/19 114/18	<b>I do</b> [8] 27/8 35/5 65/2	176/12
<b>histories</b> [1] 9/8	100/16 100/18 178/21	141/5 149/21 154/15	114/19 138/13 150/1	67/10 113/11 125/25	<b>I grew</b> [1] 44/3
<b>history</b> [9] 12/20 13/8	178/22	155/8 155/11 157/20	150/14	133/23 178/13	<b>I guess</b> [1] 168/24
13/18 14/16 41/3	<b>hopefully</b> [3] 128/20	158/8 158/23 164/25	<b>I ate</b> [1] 152/19	<b>I don't</b> [41] 17/5 18/11	<b>I had</b> [48] 5/25 6/10
94/13 133/21 138/14	150/7 183/14	165/21 167/3 167/6	<b>I basically</b> [3] 20/18	21/19 26/19 26/20	10/21 10/22 19/19
	<b>hopes</b> [2] 101/24	167/25 168/5 172/14	99/10 112/21	37/20 37/21 38/4	20/8 23/1 23/25 23/25
			<b>I became</b> [8] 17/15	67/10 70/22 74/16	27/6 37/19 43/12 79/2
				89/20 94/2 96/21 97/5	79/17 83/17 90/13

(59) highlight... - I had



<b>I</b>	<b>I look [1]</b> 122/23 <b>I looked [1]</b> 51/17 <b>I lost [3]</b> 96/22 104/12 160/18 <b>I love [7]</b> 85/4 113/14 122/7 137/5 138/15 138/15 140/17 <b>I loved [1]</b> 126/6 <b>I made [2]</b> 167/8 167/8 <b>I managed [2]</b> 161/19 161/20 <b>I may [5]</b> 142/23 143/16 145/17 146/8 184/5 <b>I mean [16]</b> 17/5 18/14 21/17 23/1 23/25 31/18 34/18 64/2 89/4 104/12 104/21 142/24 165/20 174/17 176/21 177/19 <b>I met [3]</b> 87/4 138/8 139/23 <b>I might [2]</b> 55/9 78/2 <b>I miss [1]</b> 123/5 <b>I must [1]</b> 183/20 <b>I need [1]</b> 173/15 <b>I needed [1]</b> 19/9 <b>I never [3]</b> 67/5 96/16 181/10 <b>I only [1]</b> 169/9 <b>I order [1]</b> 145/5 <b>I passed [1]</b> 82/15 <b>I phoned [2]</b> 31/13 128/12 <b>I pick [1]</b> 151/25 <b>I picked [1]</b> 27/6 <b>I pray [1]</b> 141/11 <b>I presumed [2]</b> 57/4 58/2 <b>I ran [1]</b> 44/24 <b>I reacted [1]</b> 52/13 <b>I realised [4]</b> 19/25 21/6 171/4 171/5 <b>I really [4]</b> 38/23 139/2 172/12 181/21 <b>I reapplied [1]</b> 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(72) thankful - tight-knit



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