

1 **Wednesday, 9 October 2019**  
 2 **(10.01 am)**  
 3 **SIR BRIAN LANGSTAFF:** Our first two witnesses today are  
 4 Louise and Trevor, are they?  
 5 **MS RICHARDS:** Yes, sir.  
 6 **SIR BRIAN LANGSTAFF:** Louise and Trevor, please.  
 7 **LOUISE MARSDEN, sworn**  
 8 **TREVOR MARSDEN, sworn**  
 9 **Questioned by MS RICHARDS**  
 10 **MS RICHARDS:** Trevor, you have haemophilia B.  
 11 **TREVOR:** Yes.  
 12 **MS RICHARDS:** And that's a blood clotting disorder with  
 13 a deficiency of Factor IX.  
 14 **TREVOR:** Correct, yes.  
 15 **MS RICHARDS:** Up until you were 18 years old your  
 16 haemophilia treatment was under the care of Dr Jones  
 17 at the Royal Victoria Hospital in Belfast.  
 18 **TREVOR:** That's correct, yes.  
 19 **MS RICHARDS:** And then from the age of 18 responsibility  
 20 for your treatment transferred to Dr Elizabeth Mayne  
 21 still at the Royal Victoria Hospital in Belfast.  
 22 **TREVOR:** That's correct, yes.  
 23 **MS RICHARDS:** Prior to you receiving Factor IX products in  
 24 the mid-1970s onwards, how was your haemophilia  
 25 treated when you were a child and teenager?

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1 treated there for jaundice.  
 2 **MS RICHARDS:** Trevor were you given any warnings or advice  
 3 or information about there being any risks of  
 4 infection associated with the Factor IX products?  
 5 **TREVOR:** Absolutely not.  
 6 **MS RICHARDS:** As far as you were aware, were you ever  
 7 given any choice about which treatment to receive?  
 8 **TREVOR:** No.  
 9 **MS RICHARDS:** Let me ask you both, and whichever of you  
 10 wants to please do feel I free to answer this, about  
 11 a meeting that was called by Dr Mayne in the 1980s to  
 12 talk about HIV.  
 13 Louise, in your second statement you thought it  
 14 might have been 1983 but I think you now think it's  
 15 more likely to have been 1985.  
 16 **LOUISE:** Yes, I do believe that it was the meeting in  
 17 1985. Trevor and I both attended the meeting. It  
 18 took place very bizarrely, I'm going to call it  
 19 a lecture theatre in the Royal Victoria Hospital in  
 20 Belfast and Dr Elizabeth Mayne took the meeting and it  
 21 was basically a meeting to give haemophiliacs and  
 22 their spouses information regarding what was very  
 23 topical, HIV/AIDS.  
 24 Trevor and I both attended. I remember very  
 25 vividly having to sit on desks. It was a bit

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1 **TREVOR:** Well, living on the farm it was treated by, if  
 2 I got hurt on the farm, I went straight to -- my Mum  
 3 took me straight to the hospital and I was treated  
 4 there and that was the Royal Victoria Hospital.  
 5 **MS RICHARDS:** You didn't require treatment on a regular  
 6 basis. It would be when you injured yourself working  
 7 in a very physically active way on the family farm?  
 8 **TREVOR:** That's correct, yes.  
 9 **MS RICHARDS:** Your medical records show that certainly by  
 10 1975 you were receiving Factor IX products.  
 11 **TREVOR:** I was getting hurt a lot, yes, on the farm.  
 12 **MS RICHARDS:** There are records which you have exhibited  
 13 to your witness statement which show that you had an  
 14 ankle injury in 1976, you went to the hospital for  
 15 treatment and you were given Factor IX products in  
 16 1976 and 1977.  
 17 **TREVOR:** That's correct.  
 18 **MS RICHARDS:** Louise, you have referred in your statement  
 19 to Trevor having become jaundiced in around 1976.  
 20 What do you know about that?  
 21 **LOUISE:** What I had been told was that following Trevor's  
 22 treatment for the sprained ankle where he first  
 23 received Factor IX, he then was diagnosed with having  
 24 jaundice and he was transferred from the Royal  
 25 Victoria Hospital to Purdysburn Fever Hospital and was

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1 dishevelled. We were told that all of the  
 2 haemophiliacs would be tested for HIV. That was  
 3 a given. We weren't asked. I'm quite sure and  
 4 certain in my recollection we were told.  
 5 Dr Mayne stated that the choice that the  
 6 haemophiliacs would have would be whether or not they  
 7 wanted to know the result of the tests and she said  
 8 she would ask everyone individually and that's exactly  
 9 what happened. She went round the room. Trevor was  
 10 sitting as we are and she asked Trevor did he want to  
 11 know. Her secretary recorded what people said and  
 12 Trevor said, no, he did not want to know the result of  
 13 his test.  
 14 She then passed over me to the next gentleman to  
 15 my left and I then -- I view this in my mind's eye,  
 16 I have a very vivid recollection of it, I then put my  
 17 hand up and said, a bit like Oliver, "I have  
 18 a problem. I want to know". I said, "Why would you  
 19 not want to know?" I said, "Trevor and I have two  
 20 children". At the time our eldest was three and the  
 21 other girl was 18 months and I said, "I want to know",  
 22 and one of the reasons why my recollection is very  
 23 vivid because I ruminated about it on the way home in  
 24 the car, even though I was known to Dr Mayne, she  
 25 turned to her secretary and said, "Put that down,

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1 Trevor doesn't want to know but Mrs Marsden wants to  
2 know".  
3 To me, it was the touch of sarcasm because she  
4 referred to me as Mrs Marsden rather than Louise.  
5 **MS RICHARDS:** In your statement, Louise, you've described  
6 how the meeting, in a sense, fell into two halves.  
7 There was an introductory part from Dr Mayne and then  
8 there was a point at which Dr Mayne left the room.  
9 **TREVOR:** Correct.  
10 **MS RICHARDS:** And the haemophiliac patients and their  
11 relatives who were in the room then discussed or there  
12 was some form of discussion about matters and then  
13 Dr Mayne came back in and it was at that point when  
14 she came back in that the questions were asked of  
15 feeds. Is that correct?  
16 **LOUISE:** That is correct, yes.  
17 **MS RICHARDS:** Just one point of detail because, as you  
18 know, I think it came up in evidence that was heard in  
19 Belfast, your recollection is that the doors to the  
20 room were not locked.  
21 **TREVOR:** No, they were not.  
22 **LOUISE:** They were definitely not locked.  
23 **TREVOR:** No.  
24 **MS RICHARDS:** I'll just, if I may, because we have  
25 a witness statement from Dr Mayne in response to your

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1 result. This was noted. Then the witness herself  
2 [you Louise] requested to be given the result. Her  
3 husband looked surprise and I think possible I raised  
4 my eyebrows."  
5 That's Dr Mayne's account.  
6 In terms of the actual test that was then later  
7 carried out, Trevor, can you recall any further  
8 discussion when you actually went and had the test for  
9 HIV or anything about the testing?  
10 **TREVOR:** No, I don't remember anything about, say, filling  
11 in a form or somebody asking me. It was just  
12 a routine thing. I went to get my bloods taken. When  
13 I was called up and that was it, so I take it it was  
14 just they took bloods and did it then.  
15 **MS RICHARDS:** Then how was it that you both came to learn  
16 the result of the HIV test?  
17 **LOUISE:** Trevor was -- it was a letter addressed to Trevor  
18 and in it the letter said, and I am paraphrasing,  
19 basically, "as per your instructions I am writing  
20 because your wife wanted to know and you didn't want  
21 to know", and informed us that, thank goodness, Trevor  
22 was HIV negative.  
23 **MS RICHARDS:** Now, that was we think 1985. You were told  
24 you were HIV negative.  
25 Was anything said to you at the time or in the

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1 statements, I will come back to some of what she says  
2 at a later stage of your evidence, but in relation to  
3 the particular issue of the meeting, Dr Mayne says  
4 this:  
5 "HIV testing was offered to all those who had  
6 been in receipt of blood factor concentrates."  
7 Then she refers to something in your evidence  
8 about her having said she was erring on the side of  
9 caution and Dr Mayne says this:  
10 "The witness is correct because in carrying out  
11 such widespread testing it probably was erring on the  
12 side of caution. However, at the time of actually  
13 testing, the patient was invited to give consent and  
14 if they had any difficulty in doing it the test was  
15 easily postponed until a future date or not carried  
16 out at all in accordance with the patient's wishes.  
17 Several patients postponed testing but none refused.  
18 It seemed only right and proper that they should be  
19 given the opportunity to know or not know the results.  
20 One of the secretaries took a note of the names of  
21 patients who did not wish to know the result. The  
22 witness's husband [so it is referring to your  
23 statement there, Louise. You are the witness she is  
24 referring to] decided that he did not want to be  
25 tested at the time and he did not wish to know the

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1 years that followed about any risk relating to  
2 hepatitis?  
3 **LOUISE:** Absolutely not to me at all and what's your  
4 recollection, Trevor?  
5 **TREVOR:** No, absolutely not, no.  
6 **MS RICHARDS:** Trevor, you began in the 1980s into the  
7 early '90s to experience severe fatigue. You had been  
8 a very, very physically active person all your life  
9 working on the farm but you began to notice that you  
10 were very easily tired.  
11 **TREVOR:** Yes, that's correct, yes.  
12 **MS RICHARDS:** But it was in 1996 that you attended  
13 a hospital appointment with Dr Mayne and possibly  
14 Dr McNulty present.  
15 **TREVOR:** That's correct, yes.  
16 **MS RICHARDS:** And you were given information about  
17 hepatitis C. What can you recall about that, Trevor?  
18 **TREVOR:** At that meeting, Dr McNulty obviously was  
19 present, Dr Mayne said that, "It's apparent that  
20 you've got hepatitis C", and obviously I'm always in  
21 a hurry to get back to the farm and really wasn't  
22 taking a lot in, and she went on about maybe I had to  
23 take precautions with Louise, that was sexually, with  
24 you know using condoms and things like that, and  
25 I then was dismissed, went home, and actually on the

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1 way home I called to see my grandparents and I was in  
2 a bit of shock and then rang Louise.  
3 I can't even remember what I said to you. What  
4 did I say to you?

5 **LOUISE:** You told me that you'd got an infection and you  
6 didn't really know what it was.

7 **TREVOR:** Yes.

8 **LOUISE:** That your head was -- to use a good Northern  
9 Ireland term, you might have to put a glossary up for  
10 us -- melted and that he couldn't -- he said, "I had  
11 to stop at my granny's for a cup of tea. I can't take  
12 this in. My head's melted". I was working at the  
13 time. That's why he phoned me. I wasn't at home.

14 **TREVOR:** I didn't understand what hepatitis C was at all.

15 **MS RICHARDS:** You both said in your statements, you,  
16 Trevor, based upon being at this consultation, you,  
17 Louise, based upon Trevor talking to you about it  
18 afterwards, that there was very little information or  
19 practical advice about risks of infection or any  
20 discussion about the likely progression of the disease  
21 with you at that time, at that initial meeting.

22 **LOUISE:** Absolutely none. My source of information was to  
23 go on to dial up the internet as it was then and the  
24 only information I could access, and it was very  
25 limited, was from the British Liver Foundation.

9

1 October 1995. The test result being reported a number  
2 of months later on 26 March 1996, and then if we look  
3 at the result itself in the middle of that page:

4 "Hepatitis C virus RNA positive", and then we  
5 see:

6 "Hepatitis C virus genotype 3a identified."

7 So there's a positive test result in March 1996  
8 in your records. If we then have up on screen,  
9 please, Paul, 1372008 and we go to the next page,  
10 please, so we can see the date at the top of the page.  
11 It's not particularly clear but it's certainly  
12 March 1996. It looks like the date's been written  
13 over.

14 Then if we go to the body of the reason for  
15 attending was:

16 "Buffing metal three days ago, not wearing  
17 protective glasses and got a speck of metal in right  
18 eye."

19 So it would seem that you have attended this  
20 appointment not specifically for anything relating to  
21 any underlying test results but because you had had an  
22 injury.

23 **TREVOR:** Yes, that's correct.

24 **MS RICHARDS:** It talks about the metal speck being removed  
25 without any problem and then it says this:

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1 **MS RICHARDS:** What did you find out and what was your  
2 reaction?

3 **LOUISE:** Basically, I remember reading, it was one or two  
4 paragraphs which was doom and gloom. Hepatitis C  
5 leads to liver disease, eventually leads to scarring  
6 of the liver and cirrhosis and ultimately death and  
7 that was it.

8 We were not given any leaflets. Although, and  
9 it is in the statements, we subsequently had  
10 conversations with Dr Mayne, I would emphasise we were  
11 not specifically invited in for a meeting with  
12 Dr Mayne or any other clinicians to discuss the  
13 diagnosis, the prognosis and the implications for us  
14 and our children.

15 **MS RICHARDS:** Now, we can date we think the meeting by  
16 reference to documents in Trevor's medical records and  
17 we're going to have a look at a small number of the  
18 records on the screens in front of you.

19 Paul, can I have up, please, 1372005. Can we go  
20 to the next page, please. So if we could have  
21 highlighted the bottom of the page we can see some  
22 dates, "report date" 26 March 1996 and then on the  
23 right-hand side we've got "specimen date"  
24 23 October 1995, received 23 October 1995.

25 That seems to suggest blood taken from you in

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1 "Also held discussion re HCV positivity,  
2 explained re historical aspect", and then there's  
3 a reference subtypes, PCR, and then a reference to  
4 LFTs, liver function tests.

5 This is the first reference in your medical  
6 records to any discussion with you about hepatitis C.

7 **TREVOR:** Yes.

8 **MS RICHARDS:** That's consistent with your recollection  
9 that you were told for the first time in 1996.

10 **TREVOR:** Yes.

11 **MS RICHARDS:** Then if we have the previous page of that  
12 exhibit, please, Paul, we can see 20 May 1996 -- so  
13 two months later:

14 "Reason for attending, attended for discussion  
15 with Dr Mayne re HCV. Wife unable to attend."

16 Louise, I think you had an observation about  
17 "Wife unable to attend"?

18 **LOUISE:** I do. For the first time ever, Trevor received  
19 a letter asking him to come for a review appointment.  
20 In it, it actually, Dr Mayne states that she hadn't  
21 seen him for quite a while and we commented to each  
22 other --

23 **TREVOR:** That's not normal.

24 **LOUISE:** -- on it that this is a new thing they are doing  
25 and Trevor attended on his own.

12



1 Now, I would take you back to the previous  
2 document where it says that Trevor having attended for  
3 metal in his eye, the positivity, HCV, was discussed  
4 with him and that is not Trevor's recollection.  
5 Just to be totally clear here, Trevor didn't  
6 come home from having had the examination as a result  
7 of the metal in his eye to tell me had hepatitis C.  
8 If it was discussed with him, it did not register with  
9 him at all. This is the meeting from which Trevor was  
10 in such shock he had to go to his granny's.

11 **TREVOR:** That's correct.

12 **LOUISE:** So had I known that this was a very, very  
13 important meeting in the life of the Marsden family,  
14 I would have been there. I would never have let  
15 Trevor attend on his own.

16 **MS RICHARDS:** Thank you. Then we'll just look at the rest  
17 of the note which says:

18 "Trevor was reassured that although he had been  
19 HCV positive for probably plus 20 years his ALT,  
20 et cetera, had remained stable and he was not at  
21 present progressing to chronic liver disease. No need  
22 for interferon yet but to have ..."

23 I am not entirely sure what the next --

24 **SIR BRIAN LANGSTAFF:** "... ultrasound, et cetera ..."

25 **MS RICHARDS:** "... ultrasound, et cetera, and complete

13

1 crossed out on this page.

2 **LOUISE:** That's correct.

3 **MS RICHARDS:** But this is a reference in 1991 in Trevor's  
4 records to hepatitis C. As I understand your  
5 recollections and your evidence, this was not  
6 something that was ever discussed with you or drawn to  
7 your attention in 1991.

8 **TREVOR:** No.

9 **LOUISE:** Never.

10 **TREVOR:** Never.

11 **MS RICHARDS:** You haven't been able to find in Trevor's  
12 medical records any test results in relation to  
13 hepatitis C from 1991.

14 **LOUISE:** No, that's correct.

15 **MS RICHARDS:** So you don't know what happened as a result  
16 of this document, if anything.

17 **LOUISE:** Correct.

18 **MS RICHARDS:** We should just -- just before I go back to  
19 Dr Mayne's statement, in 1996 when you were finally  
20 told that you had hepatitis C, had you been made aware  
21 that you were being tested for hepatitis C?

22 **TREVOR:** Not to my knowledge, no.

23 **MS RICHARDS:** Now, again we have a detailed statement from  
24 Dr Mayne and, sir, obviously this will be disclosed to  
25 core participants and published on the Inquiry website

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1 range of blood taken", and then there's a further  
2 reference to a plan.

3 That is I think consistent with your  
4 recollection that when you were first told, Trevor,  
5 you were told you had had it for years.

6 **TREVOR:** Yes.

7 **MS RICHARDS:** But you didn't realise until that point that  
8 you had had this condition for years.

9 **TREVOR:** No.

10 **MS RICHARDS:** There's one are further document that we  
11 should look at and that, please, Paul, is 1372003.  
12 This is a document from 1991. We can see the date  
13 there, 18 January 1991, and if we go down towards the  
14 bottom of the page, please, there's RV, review one  
15 year, and then we have a number of things written  
16 down, some of them crossed out.

17 So we have:

18 "Next appointment needs HB antigen", written  
19 there, underlined. Underneath that are the words,  
20 "hep C" crossed out, "LFTs" underlined, "Letter for  
21 family tree inhibitor". Above the words "Next  
22 appointment" we see the words "anti-hep C" and then we  
23 see across from that, also crossed out, "serum in lab  
24 which will be tested".

25 You don't I think know why things have been

14

1 in accordance with normal procedures but I am just  
2 going to read out a small number of paragraphs both in  
3 fairness to Dr Mayne but also to give you the  
4 opportunity to comment if you wish to on them.

5 So Dr Mayne says this in her statement. She  
6 says that:

7 "The patient [that's you, Trevor] developed  
8 clinical jaundice in the 1970s", and she refers, as  
9 you've said, Louise, to Trevor being transferred to  
10 what was called the Fever Hospital at that time.

11 It says that your blood was tested for all known  
12 causes of jaundice but results were negative:

13 "... but the virology laboratory, as was their  
14 practice, kept an aliquot of the patients serum to be  
15 retested in the future when other infections might be  
16 discovered or might evolve."

17 Pausing there, were you aware that a sample of  
18 your blood had been kept in the virology laboratory  
19 from the 1970s for possible testing in the future?

20 **TREVOR:** No, I didn't know that, no.

21 **MS RICHARDS:** Dr Mayne continues as follows:

22 "The hepatitis C virus became isolated in 1991.  
23 Tests became available to detect HCV antibody around  
24 that time but tests for active HCV infection were not  
25 available until 1993. As far as I can recall,

16



1 I believe that the original 1976 sample was retested  
 2 in 1991. In 1991 a further sample was taken and  
 3 tested and a further sample was taken and tested in  
 4 1993 making three tests in all."  
 5 Were you aware of any testing for hepatitis C  
 6 going on in '91 or '93?  
 7 **TREVOR:** No.  
 8 **MS RICHARDS:** Then she says:  
 9 "The customary length of time elapsed between  
 10 testing and results becoming available. Patients were  
 11 seen as soon as possible after their results were  
 12 received for consultation and discussion."  
 13 You weren't, as I understand your recollection,  
 14 seen at any point in 1991 or 1993 or at any time until  
 15 1996 for any discussion about hepatitis C.  
 16 **LOUISE:** That's correct.  
 17 **TREVOR:** That's correct.  
 18 **MS RICHARDS:** Then she says this:  
 19 "Present day practice would require oral or  
 20 written permission to carry out viral blood tests. At  
 21 the time in question, locally, nationally and  
 22 internationally expediency seemed paramount and  
 23 specific consent was often not obtained."  
 24 Then she contrasts that with the situation  
 25 relating to HIV where she says tests were not carried

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1 up. But, no, I don't know why she did that.  
 2 **MS RICHARDS:** And then she continues as follows in  
 3 relation to 1991 tests. She says this:  
 4 "The test in 1991 demonstrated that the witness  
 5 had met the hepatitis C virus at some time. It showed  
 6 that he had antibody but not active infection at the  
 7 time of testing. He was clinically well, therefore,  
 8 he was not informed about this particular result. It  
 9 was thought it might cause undue anxiety and worry.  
 10 At that time it was unclear what the future would hold  
 11 for someone with such a result."  
 12 So again pausing there, Dr Mayne's evidence  
 13 suggests there was a test that was actually completed  
 14 in 1991. It showed you had in her words "met the  
 15 hepatitis C virus", but because you were clinically  
 16 well, there wasn't active infection, and to avoid  
 17 worrying you you weren't told.  
 18 **TREVOR:** Well, I think a lot of people that would know  
 19 Dr Mayne, any time you -- to answer your question  
 20 earlier when she said if there was anything you wanted  
 21 to ask for information, I did ask a lot of awkward  
 22 questions and so did my wife but it was a case of,  
 23 "Oh, it will be okay. It's nothing for you to worry  
 24 about", and anybody that knows Dr Mayne knows that's  
 25 what she was like and it was very hard to get

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1 out without consent.  
 2 Now, Dr Mayne then addresses what you've said in  
 3 your statements about the consultation in 1996,  
 4 Trevor, when you were told about hepatitis C and she  
 5 says this:  
 6 "Dr Orla McNulty and a member of the nursing  
 7 staff and myself met with the patient. We sat  
 8 together and chatted for almost an hour about the  
 9 jaundice. It was pointed out to the witness that he  
 10 had survived for 30 years feeling fairly well and that  
 11 his liver function tests were good. We were unable to  
 12 predict his future which may have been the aspect of  
 13 the meeting which en route home may have caused the  
 14 patient great anxiety. He may have forgotten but it  
 15 was suggested at the time if he had any further  
 16 questions or worries he could contact the centre and  
 17 make a further appointment. He also could make  
 18 contact with the centre's social worker."  
 19 Do you have any observations in relation to that  
 20 part of Dr Mayne's evidence?  
 21 **TREVOR:** I don't recall the jaundice. I don't recall  
 22 the -- because the jaundice was something that I had  
 23 when I was in the fever hospital and that was gone,  
 24 I think I was maybe 16 at the time. That was away  
 25 back. I can't remember even why she would bring that

18

1 information out.  
 2 **MS RICHARDS:** Louise, you want to say something?  
 3 **LOUISE:** Yes, this makes me very, very angry. This is one  
 4 of the things that I have great difficulty and it's  
 5 the date 1991, bearing in mind Trevor wasn't told  
 6 until 1996. So Trevor wanted a football team but his  
 7 first wife only gave him four and his second wife will  
 8 have to give him the rest. 1991 -- or, sorry, in  
 9 [redacted] 1992 we had our son, Sam, and what angers  
 10 me is, and I know having been tested I was not  
 11 positive with hepatitis C --  
 12 **TREVOR:** Yes. We asked the question, Louise.  
 13 **LOUISE:** Sam was born in [redacted] 1992. She knew in  
 14 1991 definitively from the records I could have been  
 15 positive and I could have passed that on to our son.  
 16 **TREVOR:** Sorry, can I go back. It was we had a discussion  
 17 with Dr Mayne. I was with my wife. I got very  
 18 worried about this.  
 19 **LOUISE:** That wasn't in 1991, Trevor.  
 20 **TREVOR:** Okay. But we did ask the question could it be  
 21 passed on to our children.  
 22 **MS RICHARDS:** That I think from your statement, Louise,  
 23 was probably 1997.  
 24 **TREVOR:** Yes.  
 25 **LOUISE:** That's correct.

20

1 **MS RICHARDS:** That's when you were tested.  
 2 **TREVOR:** Yes.  
 3 **LOUISE:** Correct.  
 4 **MS RICHARDS:** And your result was, as you say, negative  
 5 but that was some six years after the events that  
 6 Dr Mayne has just described.  
 7 **LOUISE:** That is correct.  
 8 **MS RICHARDS:** Then Dr Mayne's statement continues:  
 9 "By 1993 a test became available which could  
 10 detect active hepatitis C infection. It took time  
 11 before the test came into routine use. The witness's  
 12 definitive result of active infection was obtained in  
 13 March 1996 and confirmed in August 1996. It was now  
 14 felt important that he should know the findings hence  
 15 the invitation to come and meet with the staff."  
 16 **TREVOR:** Yes.  
 17 **MS RICHARDS:** So again that would appear to confirm your  
 18 recollection that you knew nothing of any of this  
 19 until 1996.  
 20 **LOUISE:** That is correct and I would emphasise it was, for  
 21 Trevor, his recollection of being told is May of '96.  
 22 **MS RICHARDS:** Just finally in relation to this issue in  
 23 Dr Mayne's evidence, she refers in her statement and  
 24 has referred in earlier statements to a weekend,  
 25 a residential weekend that took place in Enniskillen

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1 **TREVOR:** No.  
 2 **LOUISE:** Correct, so Dr Mayne is saying in her statement  
 3 that Trevor should have attended, which he did, and  
 4 taken the opportunity to educate himself and become  
 5 more informed and empowered but in 1995 Trevor didn't  
 6 know, so he didn't see the relevance of maybe being  
 7 more proactive, and I would also comment on the fact  
 8 that the event was sponsored by I think you said nine  
 9 pharmaceutical companies.  
 10 **MS RICHARDS:** That's what Dr Mayne's statement says. It's  
 11 right I should say it's a detailed statement. There  
 12 is more in the statement than I have read out but  
 13 those were the particular points I wanted to ask you  
 14 to comment on. The full statement, as a matter of  
 15 fairness to Dr Mayne, will be published on the Inquiry  
 16 website.  
 17 Louise, you recall then, as I say, I think in  
 18 1997 a consultation at which you attended --  
 19 **SIR BRIAN LANGSTAFF:** Before we leave 1996, at the moment  
 20 we have three dates coming from different sources as  
 21 to the time that you, Trevor, were told that you had  
 22 active hepatitis C. That's March, May and August from  
 23 what Dr Mayne has said.  
 24 Can we go back to the March, which I think is  
 25 008. It's the one we had before that. I think it

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1 in 1995 where there was a meeting for patients and  
 2 centre staff fully sponsored by nine international  
 3 pharmaceutical companies. She says a number of  
 4 experts, both virologists and haemophilia doctors,  
 5 came from England and Scotland to address the  
 6 conference and make themselves available to  
 7 individuals.  
 8 As I understand it, Trevor, you were in fact at  
 9 that weekend.  
 10 **LOUISE:** Yes, yes, I was there. I took the three girls  
 11 along and there was activities for the children.  
 12 Louise looked after the farm while I went down,  
 13 actually spent the weekend there. It was very  
 14 bizarre, with my mother-in-law in a caravan, very  
 15 small.  
 16 Anyway, the idea was that she would look after  
 17 the children and I obviously was looking for  
 18 information to my condition and that was kind of hard  
 19 because nobody wanted to talk about it.  
 20 **MS RICHARDS:** But in 1995 -- so the residential weekend  
 21 described by Dr Mayne is in 1995.  
 22 **TREVOR:** Yes.  
 23 **LOUISE:** And it's pre-him being told his diagnosis.  
 24 **MS RICHARDS:** You didn't actually know you yourself were  
 25 infected until 1996.

22

1 was --  
 2 **MS RICHARDS:** This is the March document, sir, and then --  
 3 **SIR BRIAN LANGSTAFF:** Yes, if we go down on that, stop  
 4 there. According to the note describing a discussion  
 5 about hepatitis C positivity, "explained re the  
 6 historical aspect", whatever that might mean, subtypes  
 7 PCR and then "potential prescriptions". Yet  
 8 "potential prescriptions" was what was on the note as  
 9 well in May, if you look at that, which is the next  
 10 page I think. That's it. Scroll down.  
 11 It looks very similar handwriting but let's  
 12 scroll down to that. Then, "No need for interferon  
 13 yet".  
 14 **MS RICHARDS:** Keep going.  
 15 **SIR BRIAN LANGSTAFF:** So for some reason there seems to be  
 16 a description of the same conversation but two  
 17 different dates ascribed to it.  
 18 **MS RICHARDS:** Sir, yes, and it may be we need to ask  
 19 Dr Mayne more questions in due course about these  
 20 facts. The "potential P" in the March '96 may be  
 21 potential prognosis.  
 22 **SIR BRIAN LANGSTAFF:** I think it's prescriptions normally.  
 23 **MS RICHARDS:** But there is no other reference other than  
 24 "no need for interferon yet" to treatment.  
 25 **SIR BRIAN LANGSTAFF:** So there remains a mystery and

24

1 Dr Mayne says nothing about those two dates?  
 2 **MS RICHARDS:** No.  
 3 **SIR BRIAN LANGSTAFF:** So far as you are concerned, you  
 4 were spoken to only once --  
 5 **TREVOR:** Yes, that's correct.  
 6 **SIR BRIAN LANGSTAFF:** -- to tell you about that and that's  
 7 the time you had to stop for a wee cup of tea at your  
 8 grandma's.  
 9 **TREVOR:** Yes, that's correct.  
 10 **MS RICHARDS:** Louise, you then recall a consultation which  
 11 you attended in 1997 and you yourself were tested in  
 12 1997. What can you recall about that?  
 13 **LOUISE:** Dr Mayne was present. She describes it very well  
 14 in her statement and, again, I am paraphrasing but she  
 15 talked about how clever the hepatitis C virus was and  
 16 she likened it to a drop of blood, two drops of blood  
 17 on a work surface, one HIV and bleach or wiping it  
 18 away would do away --  
 19 **TREVOR:** With the --  
 20 **LOUISE:** -- with any risk of infection, but the  
 21 hepatitis C was a more clever virus and that if you  
 22 wiped the work surface with bleach or wiped it away  
 23 that wouldn't necessarily kill the virus. She told me  
 24 that there was no risk of the virus being sexually  
 25 transferred from Trevor to me and she then tested me,

25

1 given, you've described in your statement, Louise, two  
 2 meetings at which you were present. You've described  
 3 a consultation with Dr Mayne in which you say you  
 4 asked questions to which she provided no answers:  
 5 "She stated what I was asking for was more  
 6 information than I needed to know and I shouldn't  
 7 worry about it", and that's where the offer to test  
 8 you for hepatitis C was discussed.  
 9 **LOUISE:** Correct.  
 10 **MS RICHARDS:** Then you've described a separate meeting  
 11 facilitated by the Haemophilia Society in paragraph 25  
 12 of your statement which Dr Mayne attended and that,  
 13 you have said that was the meeting at which she used  
 14 this comparison between hepatitis and HIV.  
 15 **LOUISE:** She did.  
 16 **TREVOR:** Yes.  
 17 **MS RICHARDS:** We will obviously come back to and talk  
 18 about the impact of the diagnosis, both physically and  
 19 more generally, but before we do that I wanted to ask  
 20 you both about the issues relating to vCJD  
 21 notification.  
 22 In 2001, Trevor received a letter, and we'll  
 23 look at that. It's 1372009. It's a letter of  
 24 12 February 2001. If we just go down the page  
 25 a little, please, Paul, we will see it says:

27

1 which seems a bit of a contradiction.  
 2 Subsequent to that, I found out from another  
 3 source -- we actually attended a conference in  
 4 Southern Ireland which they were obviously in the  
 5 build up to the whole Lindsay Inquiry and I found out  
 6 more information there than I did from the clinicians  
 7 in Northern Ireland.  
 8 One of the other things I found out was that  
 9 even though I had asked Dr Mayne, all of our girls, we  
 10 have three girls, [redacted] they should all have  
 11 their Factor IX levels tested, [redacted].  
 12 [Redacted]. But Dr Mayne was very dismissive.  
 13 **TREVOR:** Yes.  
 14 **LOUISE:** It was -- she's very conservative with the  
 15 information. I'm not saying that she lied to us but  
 16 she certainly limited what she told us.  
 17 In relation to the effect that all of this had  
 18 on our relationship as a couple and the consequence of  
 19 the first treatment that Trevor had -- do you want me  
 20 to speak --  
 21 **MS RICHARDS:** I will come on to that in a few minutes, if  
 22 I may.  
 23 **LOUISE:** That's fine.  
 24 **MS RICHARDS:** Just before we leave the question of how  
 25 Trevor was informed and what information was or wasn't

26

1 "I am writing to confirm that you were not  
 2 exposed to any of the affected batches in question."  
 3 So this is February 2001, a letter from Dr Julia  
 4 Anderson to you saying, look, you weren't exposed.  
 5 If we go to the next page please, Paul, we can  
 6 see there was a fact sheet that was enclosed with that  
 7 and if we look at paragraph 7 it says:  
 8 "There may be further notifications in the  
 9 future if other patients with vCJD have been blood  
 10 donors."  
 11 **TREVOR:** Yes, I got that letter, yes.  
 12 **MS RICHARDS:** You then got a further notification in 2004.  
 13 **TREVOR:** Yes.  
 14 **MS RICHARDS:** We'll look at that. It's the next document,  
 15 please, Paul. It's the next page in this exhibit.  
 16 We see a letter that's a doctor to doctor letter  
 17 22 September 2004, but we'll go to -- if we go on two  
 18 pages please, Paul, to a letter dated 20 September  
 19 2004, that's it, this is the letter that was sent by  
 20 Dr Frank Jones consultant haematologist to you,  
 21 Trevor, on 20 September 2004. It refers to  
 22 haemophilia directors having been asked by the  
 23 Department of Health to send a letter and information  
 24 to all patients with bleeding disorders currently  
 25 registered at their centre. It refers to public

28



1 health measures to protect people from what was  
2 described as the very small risk of developing vCJD  
3 through blood or organ donations.

4 **TREVOR:** Yes.

5 **MS RICHARDS:** Then it says this:

6 "As you will see from the enclosed, we are  
7 offering to see any of our patients (or their parents)  
8 who wish to discuss their own situation, including  
9 whether or not they received any such batches."

10 Trevor, you completed a form. If we go on two  
11 pages, please, Paul, you completed a form to say that  
12 you wanted to know -- you would like to know if you  
13 received an implicated batch. That was  
14 26 September 2004.

15 **TREVOR:** That's correct, yes.

16 **MS RICHARDS:** If we just go one page before that, please,  
17 Paul, to a letter of 5 October 2004, we can see there  
18 that Dr Jones has received your reply slip and says:

19 "I understand you wish to know in writing  
20 whether you have received an implicated batch. Please  
21 understand that this may take some time as not only  
22 haemophilia patients are involved in this look back  
23 exercise. Please be patient with us as you will  
24 understand that we have received no additional  
25 assistance to carry out this task."

29

1 inform us that Trevor was indeed a recipient of  
2 products that had been donated by donors who had been  
3 identified as having been -- had died of variant CJD.

4 **MS RICHARDS:** So there were other patients there --

5 **TREVOR:** Yes.

6 **MS RICHARDS:** -- beside Trevor.

7 **TREVOR:** That's correct.

8 **MS RICHARDS:** And you were informed in a group that you  
9 had received implicated batches.

10 **TREVOR:** Exactly, that's correct.

11 **LOUISE:** Correct.

12 **MS RICHARDS:** You said, Louise, in your statement it was  
13 similar to the meeting regarding HIV, this group  
14 meeting.

15 **TREVOR:** Yes.

16 **LOUISE:** It was, yes. It was like Groundhog Day.

17 **MS RICHARDS:** You, Louise, stood and spoke you say in your  
18 statement.

19 **TREVOR:** Yes, she did.

20 **MS RICHARDS:** What did you say?

21 **LOUISE:** I did. I, again, said that the elephant in the  
22 room was the anger, that the infected and the affected  
23 once again, using one of Trevor's terms, just when you  
24 thought it was safe to get out of the bath, you know,  
25 they had given you something else.

31

1 Those are the documents relating to vCJD in your  
2 medical records. What happened next?

3 Louise, I think you and Trevor both have  
4 a recollection of a meeting you attended.

5 **TREVOR:** Yes, we did, in Birmingham.

6 **LOUISE:** We were invited to go to Birmingham to a meeting  
7 on the back of this. It was facilitated in terms of  
8 the expenses by the Haemophilia Society and we  
9 actually remarked on the fact that it was being  
10 funded, that we were having all of our expenses paid.  
11 It was just in in the morning and out in the evening.

12 So we went. Trevor's a very gregarious person.  
13 By the time I had caught up with Trevor he practically  
14 knew everyone who was at the table. We were sitting  
15 in very small -- at very small round tables and there  
16 were two clinicians present at the table.

17 **TREVOR:** That's when I got worried.

18 **LOUISE:** And these very well attired gentlemen came in and  
19 sat down at what I will describe as a long top table  
20 and they informed us that they had been tasked, in  
21 other words they were a quango, they had been tasked  
22 by the Government to look into this issue of people  
23 receiving blood products from donors or other sources  
24 in relation to variant CJD and that the reason why we,  
25 the attendees, had been asked to the meeting was to

30

1 **TREVOR:** Yes.

2 **LOUISE:** And --

3 **TREVOR:** I felt there was a red dot on me, that they were  
4 out to get me.

5 **LOUISE:** Yes, it was --

6 **TREVOR:** It was terrible.

7 **LOUISE:** It was bizarre. That's the best way I can  
8 describe it and subsequent to that meeting, we have  
9 heard absolutely --

10 **TREVOR:** Nobody has come back.

11 **LOUISE:** -- nothing. Nobody offered us one to one  
12 counselling. It was just, "We've given you this  
13 information and we're being employed by the  
14 Government", no doubt, pardon my cynicism, getting  
15 lots and lots of money, I don't know what those people  
16 and they were all gentlemen at the top table, were  
17 doing or are doing but we were given absolutely no  
18 practical help or assistance of any kind.

19 **TREVOR:** No.

20 **MS RICHARDS:** You have said in your statements that there  
21 has been no follow-up since then.

22 **TREVOR:** Absolutely not.

23 **LOUISE:** Correct.

24 **MS RICHARDS:** And you have received no further information  
25 whatsoever in relation to variant CJD.

32

1 **LOUISE:** That is correct.  
 2 **TREVOR:** We did research it. I mean, you know, at the  
 3 time but it's ... no.  
 4 **MS RICHARDS:** Trevor, you have said in your statement that  
 5 you live in fear that variant CJD may surface.  
 6 **TREVOR:** Yes, that's correct.  
 7 **MS RICHARDS:** One of your daughters, Nicola, in her  
 8 statement describes this information, the potential or  
 9 the exposure to the risk of vCJD as almost the last  
 10 straw. She says it's something constantly at the back  
 11 of her mind as well.  
 12 **TREVOR:** Exactly, yes.  
 13 **MS RICHARDS:** You have discovered recently, I understand,  
 14 when your solicitors looked at your medical records,  
 15 Trevor, for the purpose of assisting you in preparing  
 16 your statement for the Inquiry that there are positive  
 17 test results in 1996 for CMV and parvo virus.  
 18 **TREVOR:** That's correct.  
 19 **MS RICHARDS:** Is that right?  
 20 **TREVOR:** Yes.  
 21 **MS RICHARDS:** You were not told in 1996, as I understand  
 22 your statement, either that those tests were being  
 23 carried out or what the results were.  
 24 **TREVOR:** That's correct.  
 25 **MS RICHARDS:** You saw it for the first time when your

33

1 raced motorbikes and he wanted to live his life just  
 2 like any other person. I don't know whether the  
 3 haemophilia gene comes with the lunatic gene, but that  
 4 was Trevor. When he wanted to race, Dr Mayne fully  
 5 supported him. She helped him get his racing licence  
 6 and he did indeed for a short time race motorbikes.  
 7 Jumping a bit and taking you back to '85,  
 8 sliding door moment in the Marsden household. When  
 9 that happened, the governing body that oversaw  
 10 motorcycle racing, in getting your licence you had to  
 11 get a medical and the doctor at the time affiliated  
 12 with them, Dr Sam Tanner, decided that Trevor was  
 13 a risk. He was a risk to himself and he was a risk to  
 14 other motorcyclists, even though it was safer, they  
 15 were all going the one way on a track or the roads.  
 16 We took the conscious decision for Trevor to  
 17 abandon that because in trying to pursue what he  
 18 wanted to do he had to out himself as a haemophiliac.  
 19 Although he was HIV negative, he did not tell anyone  
 20 he was a haemophiliac post 1985. We were  
 21 frightened -- and I don't use that term lightly.  
 22 **TREVOR:** Yes.  
 23 **LOUISE:** -- to discuss it with anyone.  
 24 **TREVOR:** You don't tell people.  
 25 **LOUISE:** We told our children not to disclose that, which

35

1 solicitors drew it to your attention.  
 2 **TREVOR:** That's correct, here, yes.  
 3 **MS RICHARDS:** Going back then to the hepatitis C, you  
 4 embarked upon a course of treatment with interferon.  
 5 **TREVOR:** That's correct, yes.  
 6 **MS RICHARDS:** Can I ask you to describe, Trevor or Louise,  
 7 either of you, whoever wishes to answer, what the  
 8 impact was physically and mentally of both the  
 9 hepatitis C and the interferon treatment.  
 10 **LOUISE:** Me?  
 11 **TREVOR:** Well, can I say it was ... you answer.  
 12 **LOUISE:** It was absolutely carnage. After Trevor was  
 13 told, and I'm going to put a bit of background to  
 14 this, Trevor's relationship with Dr Mayne was one of  
 15 absolute trust. I'm not saying there were three in  
 16 our marriage but it was intrinsic. His belief in her  
 17 judgment that no matter what happened he would use the  
 18 phrase, "Just get me to the hospital. Dr Mayne will  
 19 sort me out". He had absolute faith in Dr Mayne.  
 20 Being fair to Dr Mayne, if she was on your side,  
 21 she was on your side.  
 22 **TREVOR:** Yes, she fought very hard.  
 23 **LOUISE:** I married Action Man. Trevor rode horses. He  
 24 worked on a farm, one of the most dangerous  
 25 occupations you can have. He rode motorbikes and he

34

1 is very, very hard. All of a sudden it's a light  
 2 switch. You've had the norm where it wasn't an issue.  
 3 Daddy was haemophiliac blah-di-blah and then all of  
 4 a sudden, secret service, don't mention it to anybody.  
 5 **TREVOR:** Safest people to talk to were the cows.  
 6 **LOUISE:** So Trevor then was faced with being diagnosed  
 7 with hepatitis C. He struggled. He thought that  
 8 Dr Mayne would ring him up and tell him this has all  
 9 been a mistake, Trevor. We've mixed your results up  
 10 with someone else. Emotionally it was  
 11 a roller-coaster. It was a white knuckle ride and we  
 12 were up and down, and I use that genuinely "we",  
 13 because although Trevor is infected and was  
 14 experiencing it, so did everyone in the house, the  
 15 children, myself.  
 16 What didn't help was Trevor did not want to  
 17 share this with anyone else or the rest of his family.  
 18 So, again, as a family unit we're trying to keep a lid  
 19 on it, the children are seeing things happening, I'm  
 20 trying to explain that to them but not give them too  
 21 much information so it wouldn't leak out. Secret  
 22 service.  
 23 So upon Trevor's diagnosis as a couple we  
 24 struggled. I wanted to be pragmatic and the realist.  
 25 This is what the diagnosis is, we need to move on.

36

1 Trevor couldn't come to terms with it. We argued. We  
2 fought. We didn't throw things but it was very, very  
3 volatile and I do think that there's a direct  
4 correlation between Trevor -- I've sat through  
5 a number of witnesses giving their statements and I am  
6 convinced that the reason the information was  
7 disclosed in 1996 was because the interferon and the  
8 ribavirin became available in '97 and they needed  
9 people to clinically trial test it and who better than  
10 "the closed group" of haemophiliacs whom they'd all  
11 the medical records for, who were like lambs to the  
12 slaughter. Compliant was the word Susan used  
13 yesterday. I couldn't get a more apt word.

14 So when Trevor went on to the first course of  
15 treatment and he had a start stop, he started it  
16 initially and the side effects were so traumatic he  
17 stopped. He then had to go back and they -- again,  
18 I don't use this word lightly -- threatened him that  
19 if he stopped the treatment again he wouldn't get  
20 another chance to have the treatment.

21 **TREVOR:** They said it was so expensive that --

22 **LOUISE:** So the day Trevor rocked up to the hospital and  
23 got his little EpiPen on his own, came home, "They've  
24 shown me how to do this, it's just like injecting  
25 yourself with insulin, blah-di-blah, and I take it and

37

1 me and the advice I was given by the doctor I spoke to  
2 was, "It's flu-like symptoms, give him two  
3 paracetamol".

4 The next day, Trevor would recover from the  
5 injection and then the following day he would have to  
6 give himself another injection. So in his head as he  
7 was coming round on the second day, he was already  
8 having to think about day 3, another injection, every  
9 other day another injection. He did not want to have  
10 the treatment. He wanted to, again, give it up.

11 I got very angry and I told Trevor, "We have four  
12 children. You cannot leave me. You have as much of  
13 a responsibility to our four children as I have and  
14 you have to take this treatment".

15 People, including Trevor's family, saw a couple  
16 at war, Eastenders, and because Trevor wouldn't  
17 discuss it with anyone, it was, "You'd be better off  
18 without her". Trevor in his head thought that if he  
19 could reset the clock and go back to being single, it  
20 would all be hunky-dory. He had it in his head that  
21 if he left me and the children it would all go back,  
22 everything would reset itself, everything would be  
23 fine.

24 He [redacted], he had suicidal ideology, he  
25 [redacted]. He tried to commit suicide because of

39

1 have to do it every other day", his took the first  
2 injection, he started to feel unwell. Trevor's cure  
3 for everything is a warm bath. He got into the bath.  
4 He couldn't get out of the bath.

5 To put it in perspective, we have four children  
6 at this stage. Sam is 5, Rachel is 10, Lucy is 13,  
7 and Nicola is 15.

8 He's not the heaviest person in the world but  
9 I couldn't get him out of the bath. He didn't want  
10 the two older girls coming into the bathroom to help  
11 him. He had the worst side effects. If you look at  
12 what comes with the treatment and it says "in a very  
13 few cases", Trevor had all of those.

14 **TREVOR:** They call it the rigours.

15 **LOUISE:** He had rigours. To me it was like an epileptic  
16 fit. I got him into the bed. I got the children to  
17 get their hot water bottles. We packed him with hot  
18 water bottles round him, extra duvet. He just was  
19 like this shaking.

20 I rang ward 22. That was his ward at the  
21 hospital, I told them I don't know what to do. My  
22 children, the two younger ones were crying and  
23 hysterical. "Is my Daddy dying? What's happening to  
24 my Daddy". They had never seen their father like  
25 this. I was trying to get the two older girls to help

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1 something else. Thank goodness every cloud has  
2 a silver lining. We no longer had any guns in the  
3 house because I know that would have been Trevor's  
4 first choice. As it was, the land, the farm, is  
5 truncated by the railway and it sounds like something  
6 from a bad movie but that's where Trevor went to.  
7 I was working at the time. First form of  
8 diversification financially for any farmer: send your  
9 wife out to work. So I was working. I came home.  
10 I knew something was wrong and I knew I had to find  
11 Trevor, and that's where I found Trevor, on the  
12 railway line.

13 Thank goodness the train wasn't running on time  
14 because otherwise Trevor wouldn't be here. But the  
15 children had a really hard time. I had a really hard  
16 time. We didn't discuss it with his parents. When  
17 Trevor was really bad, I took time off work, said  
18 I was sick. They put me through disciplinary.  
19 I worked for [redacted] at the time and if you weren't  
20 working you were costing them money.

21 The girls, 15 and 13, Lucy and Nicola, they took  
22 time off school so it impacted upon their education  
23 and I wrote them notes to say they were ill. That was  
24 an issue in terms of their attendance levels. But we  
25 were trying to manage and care for Trevor in the way

40



1 that Trevor wanted because Trevor didn't want anyone  
2 to know. He felt because he was a farmer that somehow  
3 his Dad who was a workaholic and who had done very,  
4 very well in going from one farm to five farms, he was  
5 letting his Mum and his Dad down. His Dad was stoic.  
6 He took the view that, you know, if your leg or your  
7 arm wasn't hanging off you, you were out at 5.30 in  
8 the morning to do a day's work. I only ever remember  
9 Trevor's father coming to the hospital on one occasion  
10 when Trevor had had a road traffic accident which was  
11 very nearly fatal.

12 We were putting a bendy straw into the corner of  
13 Trevor's mouth for him to drink water because he could  
14 not raise himself up off the bed. He was having to  
15 use a bottle because physically I couldn't always get  
16 him to the bathroom and when the girls looked after  
17 him, that was an issue. What man -- I mean, I said  
18 earlier I married Action Man and as our son Sam put  
19 it, Trevor went from hero to zero in a very, very  
20 short time. It was harder for Trevor to cope with his  
21 morbidity than his mortality and that's why I believe  
22 he was suicidal. For him it was better to shuffle off  
23 this mortal coil than to live his life the way he was.

24 He psychologically couldn't cope with it and  
25 physically, with having the interferon and the

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1 would never countenance that. That was not on his to  
2 do list. He just could not have coped with that.

3 So financially we were struggling with trying to  
4 keep a farm and if anybody thinks that land is an  
5 asset, it is a burden. It is a responsibility. It  
6 doesn't keep you, you have to keep it. We had the  
7 financial burden of four children who were --

8 **TREVOR:** All to university.

9 **LOUISE:** -- yes, coming to the stage where they wanted to  
10 go on to third level education. I worked in the  
11 insurance sector. Cash flow was king. As  
12 a self-employed person if you don't work, money  
13 doesn't come in. My salary was keeping the farm and  
14 it wasn't enough to keep the farm.

15 We had financial difficulties. That impacted  
16 negatively and if anyone knows anything about the  
17 financial services sector, once you have bad credit or  
18 you have judgments against you, you can't work in the  
19 financial sector because that's the first thing they  
20 do is they check you out.

21 I could no longer work full-time because  
22 I needed to be a carer. So I then had to get jobs  
23 which were less money but less time to have the  
24 ability to help Trevor and all of the struggling with  
25 everything, it was carnage.

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1 ribavirin, his body was to him disintegrating, his  
2 hair was falling out, all of the physical symptoms  
3 that he was experiencing he couldn't get his head  
4 round.

5 I went to the Royal and I asked [redacted] the  
6 haematology nurse for help and I will never forget it.  
7 She actually put her hand up and she said, "We can  
8 treat Trevor medically and that's all". I know it is  
9 referenced that we were offered help. I do not recall  
10 any of those, anybody having that conversation with  
11 me. The only thing I remember is between the first  
12 and the second course of treatment we were introduced  
13 to a social worker, actually she lived locally and  
14 I knew her, and I -- and you'll have to excuse my  
15 sarcasm -- said been there, done that, got the  
16 T-shirt, the baseball cap and the stick of rock and  
17 the Marsdens are still together as a family in spite  
18 of you. It was too little too late.

19 At that time, we had and I don't know how we did  
20 it, I look back on it and to me the mid to the  
21 beginning of the noughties is a period in my life that  
22 was totally surreal. I don't know how we kept all the  
23 plates spinning and added to that there was then the  
24 financial burden. We could have been very well off if  
25 at that stage Trevor would have sold up the farm. He

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1 **TREVOR:** One of the things that I seen, obviously, my  
2 children were suffering, my wife, obviously -- I took  
3 it upon myself to sell some of the land off, which if  
4 anybody knows anything about farmers and things it's  
5 one thing you don't do is sell land. My Dad was --  
6 well, we didn't talk about it for a long -- I'm good  
7 with my Dad now. I didn't share a lot with my Dad.  
8 Probably in hindsight I should have, but  
9 that ... I don't know. It was ...

10 **LOUISE:** Just before we leave it, I would like to also  
11 make two comments. One is about the household regime.  
12 So you live your normal everyday life, all the little  
13 things, all your toothbrushes sit in one glass. If  
14 you're drinking something and your child asks you,  
15 "Daddy, can I have a drink", you do that.

16 Again, I can only liken it to flicking a switch.  
17 All of a sudden Trevor's toothbrush sat in a separate  
18 glass. Trevor wet shaves, we used soap in the house  
19 at that stage and he quite often used the soap for  
20 lather. We had to change to liquid soap because if he  
21 got blood on the soap then what if the kids then  
22 washed their hands and they got the blood. So then  
23 you think about towels, so Trevor had to use separate  
24 towels and, "Don't take that drink out of your Daddy's  
25 glass".

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1 Our children had to adjust to this. Trevor had  
2 to adjust. It was like all of a sudden he was a leper  
3 and that's very, very hard to do and very, very hard  
4 to explain to your five year old, "Yesterday you could  
5 drink out of Daddy's glass but today you can't", you  
6 know, very, very hard.

7 As a person, and this is about me personally,  
8 I obviously was tested. I knew I did not have  
9 hepatitis C but you read it can be transferred by  
10 bodily fluids.

11 Well, without painting too graphic a picture it  
12 was very, very hard to be intimate with Trevor. In my  
13 head, I was thinking he's got this. He obviously had  
14 the treatment but didn't clear the virus. So every  
15 time we have intercourse, every time I'm intimate with  
16 Trevor, I'm putting myself at risk and that had --  
17 that was another impact on our relationship as  
18 a couple and being very honest with Trevor, and  
19 I don't think I've articulated this to him ever, it  
20 would have been much easier to walk away. I could  
21 have made a financial claim on the farm, taken the  
22 four children and it wouldn't have been ideal but it  
23 would have been a way out for me.

24 I had Hobson's choice. I knew Trevor would not  
25 have survived. He [redacted] and had suicidal

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1 **MS RICHARDS:** What, if any, side effects did you  
2 experience in that second course of treatment in 2006?

3 **TREVOR:** It wasn't much better.

4 **LOUISE:** They were similar. It was pegylated interferon  
5 with the ribavirin, and with the pegylated interferon  
6 Trevor's cell count dropped dramatically. So they  
7 then had had to give him Neupogen. He was told that  
8 because his immune system was weakened as a result of  
9 the treatment that he had to be very, very careful  
10 about any kind of infection.

11 It was a roller-coaster. What helped  
12 significantly was our four children were older, much  
13 more mature and, truthfully, Trevor wouldn't have got  
14 through the second treatment except for the children.  
15 At one time and in our house everything's discussed  
16 over a cup of tea, I remember Rachel -- Trevor saying  
17 he couldn't go on with the injections and Rachel, who  
18 is our number three daughter, threw her arms round  
19 Trevor and said, "You have to because you have to walk  
20 me up the aisle", and that was the sliding door moment  
21 for Trevor in relation to making him very determined  
22 that he would finish it.

23 **MS RICHARDS:** That second course of treatment that started  
24 in 2006 did succeed in clearing the virus.

25 **TREVOR:** It did, yes.

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1 ideology and I had to, even though at the time it  
2 wasn't how I felt, I knew for us to survive as  
3 a family I had to stay with Trevor because even if  
4 I left with the children, if something happened to  
5 Trevor (1) I couldn't have lived with myself and (2)  
6 our four children who absolutely adore their Daddy  
7 would never have coped with it.

8 The only person that kept me sane was my friend  
9 from school, Laura Neil, and she gave me guidance and  
10 helped me when we were isolated. We'd gone to the  
11 hospital. Talk to the hand. We couldn't go to  
12 Trevor's family because that was Trevor's choice and  
13 I did think about that, but then I thought to myself  
14 and everyone is different and I'm not judging them  
15 because I know what it's like to be judged. They  
16 couldn't have coped. They would have shot the  
17 messenger and that just would have made things much  
18 worse.

19 **MS RICHARDS:** You have referred to the fact that the first  
20 course of treatment with the horrific side effects you  
21 have described did not succeed in clearing the virus.

22 **TREVOR:** No.

23 **MS RICHARDS:** It was 2006 before you embarked upon  
24 a further course of treatment.

25 **TREVOR:** That's correct, yes.

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1 **MS RICHARDS:** But, Trevor, you say in your statement that  
2 you don't feel particularly better or differently. It  
3 feels as though you still have it; is that right?

4 **TREVOR:** I may be paranoid but when the hospital were  
5 telling me, you know, that I could get these  
6 infections so easily and my levels were bad and come  
7 on up to the hospital and I'm going what? You know  
8 why would I go there. Everybody's got an infection  
9 there. I would be better sleeping with the cows. It  
10 was not -- there was a lot of -- I don't trust a lot  
11 of people and I don't -- there's things going on, this  
12 sounds really weird, I know my body so well with  
13 everything I went through I can feel things going on  
14 that I know when I'm not well, for instance. I know  
15 when there's something really badly wrong and I try  
16 and stay out of hospitals, try not to get kicked with  
17 a cow, you know, but these things happen and I can't  
18 explain it but I'm really in touch with myself and  
19 I actually feel quite good at the minute but you don't  
20 know what's going to happen.

21 It's frightening when every time I come here  
22 I've got another infection. I must stop coming.

23 **MS RICHARDS:** Trevor, you have had difficulties with your  
24 memory --

25 **TREVOR:** Yes.

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1 **MS RICHARDS:** -- that led to it being suggested that you  
 2 might have early onset Alzheimer's.  
 3 **TREVOR:** That's correct, yes.  
 4 **MS RICHARDS:** That's, as I understand it, but please,  
 5 Louise, Trevor, correct me if I'm wrong, it's now your  
 6 understanding that that is not the correct diagnosis.  
 7 **TREVOR:** That's correct, yes.  
 8 **MS RICHARDS:** You understand it to be more likely that the  
 9 memory problems that you experience are part of the  
 10 brain fog that we've heard from others described  
 11 associated with hepatitis C and treatment for  
 12 hepatitis C.  
 13 **TREVOR:** That's correct. When I came here, it was like  
 14 a jigsaw puzzle falling into place. When everybody  
 15 was giving evidence here and they were having the same  
 16 effect it really helped me try and understand that  
 17 because I know probably men aren't that good at  
 18 remembering things anyway, but any time I had to then  
 19 phone Louise to see why I was there, I would be  
 20 driving up a road and didn't know where I was going.  
 21 It was really bad at one stage, really bad. That's  
 22 why they thought it was obviously Alzheimer's.  
 23 **MS RICHARDS:** In terms of follow-up care in relation to  
 24 your liver --  
 25 **TREVOR:** Yes.

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1 visible abnormality.  
 2 **TREVOR:** That's correct.  
 3 **MS RICHARDS:** Have you been told if there's going to be  
 4 any ongoing follow-up care or assessment of your  
 5 liver?  
 6 **TREVOR:** Not as yet, no.  
 7 **LOUISE:** He did ask about getting an MRI and he was told  
 8 there was a very long waiting list.  
 9 **MS RICHARDS:** Can I just ask about issues relating to  
 10 stigma. You have talked about how you have kept  
 11 things private within the Marsden household but you  
 12 have also described in your statements how you live in  
 13 a small community and people did find out about the  
 14 infection with hepatitis C.  
 15 What was the effect of that?  
 16 **LOUISE:** Well, Trevor found it very difficult. As I've  
 17 said, he's a very gregarious person and I suppose for  
 18 Trevor who has never lived anywhere else than where he  
 19 lives in his entire life felt that people judged him.  
 20 You know, people had spoken to him then didn't speak  
 21 to him. Socially he was a bit of a pariah. I suppose  
 22 that's the politest way to put it.  
 23 Now, in saying that, in the wake of the  
 24 tribunal, there are people who have spoken to Trevor  
 25 and expressed empathy that were amongst those that at

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1 **MS RICHARDS:** -- having cleared the virus you have been  
 2 told since the second course of treatment, what, if  
 3 any, follow-up care or treatment have you received in  
 4 terms of monitoring the state of your liver and any  
 5 damage?  
 6 **TREVOR:** When I came here I got information that you could  
 7 get a liver scan. What was the name of the scan?  
 8 **LOUISE:** It's an ultra --  
 9 **TREVOR:** Ultrascan, yes. So I went for that.  
 10 **MS RICHARDS:** When you say when you came here, as I  
 11 understand it, it was when you came to the Inquiry  
 12 hearings this year.  
 13 **TREVOR:** That's correct.  
 14 **MS RICHARDS:** End of April early May this year and you  
 15 heard evidence from others who talked about follow-up  
 16 care and fibroscans and ultrasounds, you had not had  
 17 any of that before?  
 18 **TREVOR:** No.  
 19 **MS RICHARDS:** And you then went to the hospital.  
 20 **TREVOR:** Yes.  
 21 **MS RICHARDS:** And asked and you were given an ultrasound.  
 22 **TREVOR:** That's correct.  
 23 **MS RICHARDS:** You have not had a fibroscan.  
 24 **TREVOR:** No.  
 25 **MS RICHARDS:** But an ultrasound and told that there was no

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1 the time ignored him.  
 2 **TREVOR:** Yes.  
 3 **MS RICHARDS:** What you said in your statement, that the  
 4 experience you had had hitherto was:  
 5 "Many locals treated me differently. In my  
 6 local shop people would stare at me as though I was on  
 7 stand in court having committed a heinous crime."  
 8 **TREVOR:** Yes.  
 9 **MS RICHARDS:** "It's remained that way and is just the way  
 10 people are towards such things where I live. I've  
 11 tried not to let it affect me. I don't row with  
 12 people about it. Once I went into a shop and the girl  
 13 serving me asked why don't you do your local shop.  
 14 This is how I've got used to being treated."  
 15 **TREVOR:** Yes, well, I did answer. I told her that in the  
 16 local area that they were so interbred there it was  
 17 only the fresh air kept them alive. She showed me the  
 18 door.  
 19 Okay, it maybe wasn't the best answer but you  
 20 need to have a sense of humour and I think that is one  
 21 of the things that helped carry me through. That's  
 22 how I get round the stigma.  
 23 **MS RICHARDS:** You have touched on the impact on your  
 24 children and we have statements from each of your four  
 25 children which explain very vividly their perspective

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1 and the impact upon them but is there anything else  
 2 you would like to say about how you view what effect  
 3 this has had upon your kids?  
 4 **LOUISE:** Our children have been tried, tested and they  
 5 have not been found wanting. We are very, very lucky.  
 6 They should never have had to experience what they did  
 7 and see their Dad and me as well go through and, you  
 8 know, see me angry and shouting at Trevor and Trevor  
 9 shouting at me. All of Trevor's health problems that  
 10 he experiences today all come from him having been  
 11 infected with contaminated blood and blood products  
 12 and I am just thankful that the Marsdens have survived  
 13 as a family unit.

14 **MS RICHARDS:** Your own health, Louise, has suffered. You  
 15 speak of anxiety and insomnia in your statement.

16 **LOUISE:** Well, I find it very -- I am -- I just find it  
 17 very, very difficult. Except for my friend, Laura,  
 18 who without judging me has given me unconditional love  
 19 and support, I probably would be in a very bad way.  
 20 I feel that I have to stay strong and healthy to care  
 21 for Trevor. I know that sounds a bit bizarre but,  
 22 yes, there are nights when I don't sleep. There's  
 23 information I don't give to Trevor because I know how  
 24 it will impact upon him. An example would be  
 25 Dr Mayne's statement. I got it last week. I perused

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1 Damocles is the variant CJD. We've done the HIV,  
 2 we've done the hep C, but who knows.  
 3 **TREVOR:** Well, can I just say that I know what happened in  
 4 the past was wrong. What I did or tried to do was  
 5 wrong. I've got a second chance. A lot of people  
 6 don't get a second chance. But, just for the record,  
 7 I'm not going to buy that land.

8 What I have in front of me is my wife and I love  
 9 her very much. That's all I need.

10 **LOUISE:** And our children, and best things in life aren't  
 11 things.

12 **TREVOR:** Yes.

13 **MS RICHARDS:** Louise, you have, I think, taken on the  
 14 management of the finances of the household. You have  
 15 described, both of you, in your statement that the  
 16 financial situation that you find yourselves in is not  
 17 a good one. You have -- work would need to be done to  
 18 your home, which you are not in a position to fund.  
 19 You have from time to time had dealings with the  
 20 previous trusts and schemes.

21 **LOUISE:** Yes, Caxton.

22 **TREVOR:** Yes, Caxton.

23 **MS RICHARDS:** What was your experience, Louise, of making  
 24 applications to the Caxton?

25 **LOUISE:** I actually found the Caxton Fund was reasonably

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1 it, decided --

2 **TREVOR:** Yesterday morning.

3 **LOUISE:** -- no, I'll wait until, it was yesterday  
 4 afternoon when I went through the statement with  
 5 Trevor, because better one sleepless night than maybe  
 6 seven or eight sleepless nights for Trevor.

7 So, yes, I have tried to manage things for  
 8 Trevor. He's much more anxious now than he ever was.  
 9 You asked him and he didn't really fully answer about  
 10 the physical problems he has at the minute. He finds  
 11 he will tire easily. Sometimes foods that he eats, if  
 12 he has something that had a high level of fat in it,  
 13 he might have to go and lie down within 15/20 minutes  
 14 of eating it because he will say he feels like  
 15 somebody has kicked him in the liver.

16 **TREVOR:** My liver, if I took cream I would be in a bad  
 17 way. I do know -- well, it does affect me now, well  
 18 I'm nearly 60. If you don't catch on now, there's  
 19 something wrong.

20 **LOUISE:** So we have adjusted our life style and I feel  
 21 that I manage, help Trevor manage the symptoms and do  
 22 what we can. Obviously psychologically it's very hard  
 23 because no-one truly knows, no matter how long they've  
 24 been or how well they know someone else, what goes  
 25 through your head and for us I suppose the Sword of

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1 easy to deal with. They were helpful, very quick in  
 2 their administration. My issue would be when it  
 3 transferred, when it was devolved and transferred over  
 4 to Northern Ireland, and that is a much more difficult  
 5 situation. Everything is public money and  
 6 I understand that but I'll give you an example.

7 Some of the windows in the house, it's double  
 8 glazing, the vacuum in them is damaged. Some of them  
 9 are cracked and I rang up and I spoke to the young man  
 10 who administers the fund or does the paperwork in  
 11 Northern Ireland and I asked him about getting the  
 12 double glazing units replaced and he said, "Well, we  
 13 wouldn't fully fund that", so let's use the example of  
 14 all the units costing £2,000. He said, "They might  
 15 look at it favourably and give you £1,000 of that  
 16 £2,000 but then you would have to find the other  
 17 £1,000".

18 My argument to him is, "Well, if I had the other  
 19 £1,000 I would only be wanting £1,000, so if I apply  
 20 for it and you grant aid £1,000 will you let me  
 21 replace whatever units that will pay for or do I have  
 22 to replace all of them, which means then I have to  
 23 either borrow the money or secure it from some other  
 24 means", and he couldn't answer that.

25 So Caxton were very helpful and we did receive

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1 help from them but I can't say the same about how it's  
2 being administered at the moment.

3 **MS RICHARDS:** Louise and Trevor, those are the questions  
4 I have for you but before I ask if you have anything  
5 to add I am just going to ask Mr Snowden if there's  
6 anything further he wants me to ask. *(Pause)*  
7 There's just one point which Mr Snowden asks me  
8 to raise and it just takes us back to the records from  
9 1996 that we were looking at. Paul, could we have up,  
10 please, 1372008 and could we go to -- thank you, you  
11 are ahead of me, that's the very document --  
12 March 1996. We looked at this earlier. If we just  
13 look down the bottom of the page, the very bottom,  
14 there was something we didn't draw attention to. It  
15 says "GP letter" and there's a tick to suggest that  
16 a letter was going to be sent to your GP, to Trevor's  
17 GP, following this consultation.

18 **TREVOR:** Yes.

19 **LOUISE:** Yes.

20 **MS RICHARDS:** Is there any such document, as far as you  
21 have seen, in Trevor's records?

22 **LOUISE:** No, I went through all of Trevor's GP records and  
23 when I read on one occasion where his doctor,  
24 Dr Ezler, mentioned he had hepatitis C, I then looked  
25 retrospective or backwards from that looking for

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1 the difficulties flow from having received  
2 contaminated blood. For us, the big thing, the Sword  
3 of Damocles is the fact he knows he got products from  
4 someone who died from variant CJD. If you Google  
5 that, the prognosis isn't good if you happen to be  
6 unfortunate enough for it to manifest itself in you.

7 The second thing I would like to touch on is the  
8 protocol for treatment and I have to emphasise I am  
9 simply speaking in relation to Northern Ireland.  
10 Trevor has never been treated at any other Haemophilia  
11 Centre in the United Kingdom. December 1987 Trevor  
12 had a road traffic accident -- not his fault. He went  
13 into a post and rail fence, a rail came in through the  
14 door of the car and went into his head.

15 Fortunately, we live in a very small area and  
16 one of his cousins got to Trevor before the ambulance  
17 did, collected me and we went to the Royal Victoria  
18 Hospital in Belfast. Because of a trip we had made,  
19 I had Factor IX in the fridge. I had started to  
20 reconstitute that Factor IX in the car on the way up  
21 to the hospital.

22 When we got into the ambulance room, I gave the  
23 syringes to the nurses. I started to explain to them  
24 how to do it and I turned round and there at that  
25 stage was the doctor standing on the opposite side of

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1 a letter from the hospital to our GP informing him and  
2 I cannot see -- I know that is ticked but I do not see  
3 any letter either in the hospital records or in his GP  
4 file informing our GP that Trevor had hepatitis C, so  
5 I do not know how that was communicated or when.

6 **MS RICHARDS:** Two inferences might be either that the  
7 letter was not sent, contrary to the tick, or that the  
8 records are incomplete.

9 **LOUISE:** Correct.

10 **TREVOR:** Yes, that is right.

11 **MS RICHARDS:** Those are all the questions I have for you.  
12 Trevor, Louise, is there anything further you  
13 would like to say?

14 **LOUISE:** Yes, I would, surprisingly enough.  
15 You'll just have to bear with me and dispel  
16 belief. You asked me about how do I cope with it and  
17 for me this is my big dream. I want to put all the  
18 clinicians that ever treated Trevor into the Delorean  
19 car and I want to take them back to the future and  
20 come hear me, just like in the film Erin Brockovich,  
21 I would like them all to roll up their sleeves and  
22 say, "You're having what he's having", and see if  
23 they'd be happy with that. But that's just a pipe  
24 dream.  
25 Trevor's health, what he experiences now, all of

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1 a trolley to me with Trevor in between. I handed him  
2 a syringe and told him to put it into Trevor and we  
3 then bizarrely played push me pull you with the  
4 syringe over the top of Trevor's body.

5 **TREVOR:** Did I say I was dying at this stage, by the way.

6 **LOUISE:** Eventually, having refused to do it, I screamed  
7 at him, "For God's sake, put it in him or I will".  
8 A senior nurse who had a compression bandage on  
9 Trevor's head very quietly said, "I think you should  
10 put it into him".

11 When I spoke to the haematology doctor who  
12 turned up three and a half hours later, he said to me,  
13 and it wasn't good for me, "If you hadn't have had the  
14 Factor IX they wouldn't have infused him until either  
15 a doctor who knew him arrived", and he had arrived  
16 three and a half hours after Trevor did, "or they had  
17 found Trevor's medical records". That took them a day  
18 and a half. That did not instill me with confidence.

19 **TREVOR:** You wonder why I'm sleeping with the cows!

20 **LOUISE:** September 2018 and Trevor is travelling from  
21 Holland where he's been with friends. He gets to  
22 London for his connecting flight and he has a bleed in  
23 his left foot. He rings. He's advised to make his  
24 way into London. He rings me and I said, "Trevor,  
25 just get on the flight to Belfast". He's in such pain

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and discomfort he can't walk but he manages through the help of ground staff to get on to the plane. The Marsdens kick in. I again because of a trip Trevor had made had Factor IX in the fridge. I reconstituted it, I despatched it to Belfast City Airport. Our daughter Rachel who works as a firefighter there took it air side and met Trevor on the plane. He got into an ambulance which was waiting on the tarmac and he was taken to the Royal Victoria Hospital.

**TREVOR:** I said not to tell the kids.

**LOUISE:** Trevor knew what had happened to him. Rachel had his letter that was how she got the medication air side, had the letter and she asked the paramedics to put it into him. Rachel has never had the training to do that. They refused. Trevor got to the Royal Victoria Hospital and they refused. Eventually, a haematology doctor came and she infused Trevor with the Factor IX. His consultant Dr Gary Benson has told us repeatedly the protocol for treatment has to be that Trevor gets his Factor IX as soon as possible to bring his levels up to normal.

There has to be a protocol for treatment of haemophiliacs in Northern Ireland. I don't know what exists in mainland GB but there has to be a protocol so there is absolutely no delay in Trevor getting his

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and suffering as a result. I would like to throw that question out in particular to all the clinicians. Did they adhere to that? I know hindsight always has 20/20 vision but what they did, was it well done?

Lastly, I want to thank the tribunal. For us it has been -- certainly for Trevor -- it has been very cathartic. It has given Trevor something that he has waited for for years which is validity and the opportunity to speak openly about things that he just bottled up. He doesn't need when he talks to anyone else here to give them the whole back story or to couch it in a particular way or be conservative with the information. It is just unfortunate that it has taken this long.

We wouldn't be here as a family unit without our four children: Nicola, Lucy, Rachel and Sam.

Lastly, my friend Laura Neil who counselled me and who helped keep the plates spinning in the air. And it would be very remiss of me not to mention Sammy Wilson. Whatever your politics are, like him or loathe him, he has been a great friend to Trevor. He has supported him and he has been a friend to the tribunal. We all would not be sitting here without Sammy's friendship with Trevor Marsden and I can't thank Sammy enough.

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Factor IX.

[Redacted]

You asked Trevor about what has been his treatment since even the tribunal. He had one joint clinic with the hepatologist. They were promised it would all be joint clinics. He had one meeting with a hepatologist. He never saw a liver specialist again.

So all Trevor's treatment for hepatitis C has been by the Haemophilia Centre.

For me, and I am not as well educated or up in things as I would like to be or as all of these learned people to my left. My limited understanding of the law in the United Kingdom is it is based on the rights of the individual. Where were Trevor's rights? He didn't sign over his rights to Dr Mayne. At the age of 18 he had autonomy under the eyes of the law for himself. Somewhere along the lines, person or persons unknown clearly lost their moral compass.

I thought that there were principles that doctors signed up to. Whether you term it as the Hippocratic oath or good practice, let's not get into semantics. But of the four principles, one of them is humanity. Where was the humanity in how Trevor was treated and their values not to cause further damage

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And lastly, I just want to mention something that Trevor said to me. He had been out -- he'd had a meal with Sammy some weeks ago and Trevor came in --

**TREVOR:** Doesn't take me out a lot.

**LOUISE:** -- and he said, "A strange thing happened tonight." He said, "I had a drink and Sammy asked could he taste what I was drinking."

**TREVOR:** It was only cider.

**LOUISE:** And he said, "Even though he knows I have all of these things, he drank from my glass."

**TREVOR:** I was shocked.

**LOUISE:** And that meant an awful lot. Thank you for your patience.

**TREVOR:** Sir Brian also, thank you very much.

**SIR BRIAN LANGSTAFF:** In a moment we'll take a break until 12.15 but first let me thank you for such a clear, detailed and compellingly frank account. You've in many ways laid yourselves and lives bare for all to see and I hope that those who were listening to it here and elsewhere know what courage that must take. I certainly do. Thank you.

**LOUISE:** Thank you.

**SIR BRIAN LANGSTAFF:** 12.15.  
(11.48 am)

(A short break)

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1 (12.21 pm)

2 **SIR BRIAN LANGSTAFF:** How does our next witness wish to be  
3 known?

4 **MS FRASER BUTLIN:** His name is Mark.

5 **SIR BRIAN LANGSTAFF:** Mark, please.

6 **MARK STEWART, sworn**

7 **Questioned by MS FRASER BUTLIN**

8 **Q.** Mark, you have mild von Willebrand's disease as did  
9 your late brother and late father?

10 **A.** That's right, yes.

11 **Q.** Your late brother died from hepatitis C following  
12 infection from Factor VIII and his widow will be  
13 giving evidence later today but you have asked for  
14 a photograph of him just to be put up at this stage.  
15 It's number 39.

16 Before I ask you about your own treatment and  
17 infection I want to briefly touch upon your father and  
18 we also have a photograph of him at 038.

19 He was Angus senior?

20 **A.** Yes.

21 **Q.** Your Dad was diagnosed with von Willebrand's after you  
22 and your late brother were diagnosed.

23 **A.** Yes.

24 **Q.** It hadn't affected him as a child and young person,  
25 though later on he needed some prophylaxis to control

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1 first exposure to Factor VIII which at that time was  
2 unheated. This is very well documented and we know  
3 now that he is anti-HCV positive. His AST is  
4 consistently abnormal. We are now in the process of  
5 treating some of our patients who have chronic non-A  
6 non-B hepatitis with interferon. I mentioned this  
7 study to him but he said we can leave him out.  
8 However, I feel I have explained to him about non-A  
9 non-B hepatitis and the possibilities of that kind of  
10 treatment in the future."

11 It's a letter from Dr Lee to your Dad's GP in  
12 '91. What is your view of that part of the letter?

13 **A.** It ain't -- he didn't say that. He wouldn't say that.  
14 If you are just being told you got hepatitis C but  
15 we've got a agreement you're not going to say, "Oh,  
16 you can leave me out". He wouldn't have said that,  
17 you know what I mean. And that's -- the other letter  
18 what I said ain't addressed to him, at the top of it  
19 it says, and that was in I think July 1990, it says on  
20 it review on 8 March. See that letter weren't sent.

21 This was the first he's saying he's been told, which  
22 he wasn't, and he wouldn't have said no to treatment.

23 **Q.** You and your mother, your understanding is that your  
24 Dad was never told that he had hepatitis C.

25 **A.** Yes.

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1 nose bleeds.

2 **A.** That's right, yes.

3 **Q.** We will come to when he was infected a little later  
4 but in terms of being told about having hepatitis C,  
5 your understanding is that your Dad was never told he  
6 had hepatitis C?

7 **A.** Never told.

8 **Q.** You've looked through your Dad's records and for  
9 various reasons we won't put them up on the screen but  
10 there's a letter in 1990 telling your father that he  
11 has hepatitis C.

12 **A.** Yes.

13 **Q.** But there's no address on it?

14 **A.** That's right.

15 **Q.** Your understanding is that your father never received  
16 it?

17 **A.** That's right.

18 **Q.** Then if we have document 10000030, Paul, this is  
19 a letter from your father's records but exhibited to  
20 your own statement and we can see at the bottom of the  
21 second page, sorry, you were just there a moment ago,  
22 Paul, there it is.

23 Within the letter to his GP, it says:

24 "He has chronic hepatitis. We know that he had  
25 non-A non-B hepatitis in March 1980 when he had his

66

1 **Q.** And then sadly in July 2002 your Dad was told he had  
2 an enlarged liver and hepatocellular carcinoma.

3 **A.** Yes.

4 **Q.** And he died in September 2002?

5 **A.** Yes.

6 **Q.** Mark, when you were a child, how often did you require  
7 treatment?

8 **A.** Once a month, something like that, not even that.  
9 Once every couple of months. I'd have little spells,  
10 you know, and then it would dry up for six months,  
11 then have a couple more bleeds, just little nose  
12 bleeds, that's all they were.

13 **Q.** It really was just the nose bleeds that was a problem  
14 for you?

15 **A.** Yes.

16 **Q.** When you were in hospital in November 2006, you had  
17 a look through your medical records --

18 **A.** Yes.

19 **Q.** -- and found some old blood test results.

20 **A.** Yes.

21 **Q.** At that point in time in 2006 had you been told  
22 anything about hepatitis C?

23 **A.** Nothing.

24 **Q.** Could we have document 1000002 this was one of the  
25 documents you found when you looked through your

68

1 medical records. It's a blood result from 2 June 1992  
 2 and we can see towards the bottom:  
 3 "Hepatitis C antibodies by EIA positive,  
 4 hepatitis C antibodies by RIBA indeterminate result."  
 5 Then if we have 003, please, another result from  
 6 25 November 1994. Again, at the bottom there is  
 7 a positive result by EIA and a reactive result by  
 8 RIBA. If we just pause and note your hospital number  
 9 at the top of that page, 217031, and if we then go to  
 10 005 please, Paul, we have a further blood test result  
 11 from November 2002 that says HCV RNA not detected but  
 12 then on closer inspection you notice that the hospital  
 13 number on that test result is different.

14 A. That's right, yes.

15 Q. When you saw those results in your medical records  
 16 what went through your mind?

17 A. That something wasn't right. Because I know my Dad  
 18 died of liver cancer and on his death certificate it  
 19 says hepatitis C but that's it. We weren't told the  
 20 connection with hepatitis C, the cause of liver cancer  
 21 or anything because at the time of my Dad's death,  
 22 sort of thing, it was put, you know, it was his  
 23 lifestyle. That's the way the doctor said it, sort of  
 24 thing, to my Mum. And we just assumed it was, you  
 25 know, one of them things haemophilias got. But there

69

1 we cannot exclude any labelling or sampling errors.  
 2 I'm extremely sorry for this mistake. If a patient is  
 3 found to be HCV antibody positive and RNA negative, as  
 4 was seen in this case in 2002, please send a follow up  
 5 blood sample to confirm these results. It is  
 6 recommended that patients with these discordant  
 7 results should be tested yearly for HCV RNA to monitor  
 8 any change."

9 You are concerned about why samples weren't  
 10 checked earlier and why you weren't automatically  
 11 recalled for further testing.

12 A. Yes.

13 Q. Because of that discovery that you had hepatitis C,  
 14 you then wanted to know when you'd been infected and  
 15 that's what we're going to look at now.

16 A. Yes.

17 Q. You worked your way back through your records?

18 A. I did, yes.

19 Q. Throughout your childhood, you were treated with  
 20 cryoprecipitate except for one occasion?

21 A. One occasion.

22 Q. Throughout that time of receiving cryoprecipitate,  
 23 what was your understanding of how successful it was?

24 A. Very successful, yes.

25 Q. Did you have any problems with receiving

71

1 was never any discussion or anything.

2 Q. You said in your statement that when you saw the  
 3 results you were very worried and very confused about  
 4 what was going on?

5 A. Yes.

6 Q. You spoke to the doctors?

7 A. Mm-hm.

8 Q. And they retested you?

9 A. Yes.

10 Q. In January 2007 those tests came back positive?

11 A. Yes.

12 Q. If we can have document 007, please, Paul, the tests  
 13 came back in January 2007, we have this letter from  
 14 14 February 2007. It records this:

"This patient was found to be hepatitis C HCV  
 16 IgG antibody positive in November 2002. However, HCV  
 17 RNA was not detected in serum tested around the same  
 18 time. We did not receive any follow-up sample until  
 19 recently."

20 They'd then done a retrospective analysis of the  
 21 1999 and 2000 samples and they were positive and in  
 22 the next paragraph the letter says:

23 "The initial RNA test in 2002 was performed by  
 24 an earlier version of the PCR assay which possibly  
 25 gave a false negative result. However, at this stage

70

1 cryoprecipitate?

2 A. Nothing, no.

3 Q. Can we have document 1000012. This is a document from  
 4 the minutes of the UK Haemophilia Centre directors on  
 5 30 September 1980 and if we go on to internal page 9  
 6 of the document we see a heading of "Hepatitis" and it  
 7 says this:

8 "Dr Craske presented a short written report  
 9 outlining the findings of the working party during the  
 10 last year and described future plans of work to be  
 11 undertaken by the working party. Various projects  
 12 were progressing in Oxford, London and Sheffield.  
 13 Liver biopsy studies were being undertaken at the  
 14 Royal Free Hospital and at Sheffield", the preliminary  
 15 results would be presented that afternoon.

16 At the bottom of the page:

17 "The working party plan to continue with the  
 18 national surveillance for hepatitis C and symptomless  
 19 cases of hepatitis were being studied in detail at the  
 20 Royal Free and at Oxford. Large pool concentrates  
 21 appeared to give a higher risk of hepatitis than small  
 22 pooled concentrates and Dr Craske felt that increased  
 23 use of small pooled concentrates would help to reduce  
 24 the incidence of hepatitis in the haemophilic  
 25 population. First time exposure to large pooled

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1 Factor VIII concentrate resulted in many cases of  
2 hepatitis, especially in von Willebrand's disease  
3 patients. Professor Bloom wondered whether  
4 cryoprecipitate would be a better product to use for  
5 mild haemophiliacs and von Willebrand's disease but  
6 pointed out there was a problem over the amount of  
7 Factor VIII in these materials. Dr Craske agreed and  
8 he said that the NHS product was certainly better than  
9 the commercial products because of the screening of  
10 the blood donors and the regular donor panels which  
11 were used in the UK."

12 You have highlighted that because of the date,  
13 30 September 1980.

14 A. Mm-hm.

15 Q. At that point in September 1980 you'd only been given  
16 cryoprecipitate?

17 A. Yes.

18 Q. Could we have 1000008, please. This is a note from  
19 your medical records dated 12 May 1981 and your  
20 consultant is noted as Dr Kernoff. It says that you  
21 have epistasis and that you are to commence  
22 concentrate on the left-hand side of the screen.

23 Then if we go to 019, please, 1000019, we have  
24 another entry relating to the same date, 12 May 1981,  
25 which indicates in the middle of the page:

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1 A. I'm sorry, I've lost the ...

2 Q. Don't worry. You are particularly concerned that you  
3 were given Factor VIII on that occasion, on that date,  
4 in light of the Haemophilia Centre minutes.

5 A. Yes.

6 Q. Can you tell us what those concerns are?

7 A. That I should be having cryoprecipitate. The  
8 concentrate, you know, carried the risk of  
9 hepatitis C. They knew that and they still give it to  
10 me.

11 Q. Because you had mild von Willebrand's?

12 A. Mild von Willebrand's.

13 Q. And until then you had had cryo?

14 A. Cryo, I used to go to the hospital for cryo. I wasn't  
15 home treatment. I was just a mild -- you know,  
16 von Willebrand's mild. Never had concentrate.

17 Q. You're also concerned that you've been used for the  
18 purposes of research?

19 A. Yes.

20 Q. We're going to go through some of the detail of that.  
21 Could we have document 1000014, please, Paul, 14.

22 Now, in the top right corner it says:

23 "First exp debt", first exposure date, of  
24 5 December 1981. We know that isn't right.

25 A. Wrong.

75

1 "Spontaneous epistaxis, cold in the head,  
2 unresponsive to 1,020 units of concentrate, slow  
3 response to cryoprecipitate", and that you were for  
4 admission.

5 At the bottom of the page we can see that  
6 a further note later on in May is made by Dr Tuddenham  
7 which we will come back to later.

8 Then if we can have 010, please. We have a note  
9 again in the middle of the page, 12 May, which shows  
10 that you were given treatment with BPL510 and the next  
11 note:

12 "Further treatment as above."

13 At the very bottom of the page on the following  
14 day it notes:

15 "LFTs weekly for six weeks."

16 So that was the only time you were given  
17 Factor VIII and on that occasion were you or your  
18 parents warned of any risks involved in you having it?

19 A. No.

20 Q. Were you or your parents told that your liver function  
21 would be tested afterwards?

22 A. No.

23 Q. You have some very specific concerns about why and  
24 when you were given that Factor VIII. What can you  
25 tell us about that?

74

1 Q. It should be May 1981 but what we can see --

2 **SIR BRIAN LANGSTAFF:** I think the dates are the same.  
3 Instead of being 12/05, it is 05/12, just  
4 transposition.

5 **MS FRASER BUTLIN:** Thank you, sir, absolutely.

6 If we look down on the right-hand side there's  
7 a table which indicates serum date and if we look at  
8 14 August 1981 your AST was tested at 154.

9 If you, therefore, look at the number of days  
10 between 12 May through to 14 August, it's an  
11 incubation period of 94 days.

12 A. It is, yes.

13 Q. If we could have 013, please, it's a letter to your GP  
14 which discusses the elevation of the AST and it, in  
15 the last paragraph, refers to your AST being elevated  
16 in August 1982, six weeks after receiving intermediate  
17 Factor VIII. Again, you think that's typographical  
18 error and it should be August 1981?

19 A. Only had it once, yes.

20 Q. The reason I have taken you through those points is  
21 because you have had concerns about the treatment in  
22 1981 and you located some academic research papers  
23 written by Professor Kernoff, Dr Thomas and  
24 Professor Lee.

25 Could we have document 1000024, please.

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We're just going to go through the paper before we get to a particular table. The study is called: "A study of the high risk of non-A non-B hepatitis after a first exposure to volunteer or commercial clotting factor concentrates, effects of prophylactic immune serum globulin."

In the summary it says:

"After a first exposure to Factor VIII concentrates 9 out of 9 British patients treated with USA derived commercial products and 10 out of 12 treated with British volunteer NHS products developed acute [non-A non-B] NANB hepatitis."

If we turn the page under "Patients and methods", it describes how the study was set up:

"During the five year period April 1978 to March 1983, 58 patients with congenital deficiencies of coagulation factors VIII or IX received 60 first exposures to Factor VIII concentrate, Factor IX concentrate or cryoprecipitate at the Royal Free Hospital Haemophilia Centre. Events following 31 of these first exposures, which included five episodes in which ISG was used in addition to concentrates, were prospectively studied by serial clinical assessment and blood sampling before and after exposure. Only a minority of the patients were virgin. Although most

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typographical error between August '82 and '81?

A. Yes, the letter sent to the doctor, yes.

Q. You identify as that patient because the incubation period is the same?

A. Yes.

Q. And because you were symptomless, the zero in the final column?

A. Yes.

Q. So there are a few details that don't match, the AST and the dosage is a bit unclear but otherwise you identify as patient 11?

A. Yes. I had two doses and cryoprecipitate up until that date, yes.

Q. You also believe that your brother was patient 19?

A. For sure, yes.

Q. And your father was patient 18?

A. Definitely, yes.

Q. If we can just look a little bit in more detail about your father, if we look across line 18 we can see that patient 18 was aged 42 having been given NHS Factor VIII and, at the end of the line, an incubation period of 48 days resulting in symptomatic jaundice.

A. Yes.

Q. So if we can then have document 1000027 this is a document called form C2, a hepatitis survey form,

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needed infrequent treatment, a majority had received blood, plasma or cryoprecipitate therapy before their first exposure infusions."

If we carry on down that page:

"Blood samples were taken, and patients clinically assessed, immediately before their first exposure infusions at one to two-weekly intervals for the next three months and at one to two-monthly intervals for a further six months. Biochemical liver function tests were carried out on all blood samples and were normal in all patients before first exposure infusions. A sera were stored frozen and selected samples from all patients retrospectively analysed for serological evidence of acute or previous viral infection."

It's noted in the next paragraph that the occurrence of acute post infusion hepatitis was the primary end point of the study.

We then carry on through the paper to table 1 which gives the results of the study and it's your firm belief that you are patient number 11 on that table.

A. I am, yes.

Q. If we look at patient 11 we can see that the age then was 13 but you think that's out because of that

78

and if we look at the table we can see in the middle there is Elstree Factor VIII concentrate with a date and at the very bottom in handwriting non-A non-B hepatitis attributed to batch number HL2644. We can see there that your father was given his first batch of concentrate on 11 January 1980.

If we go to 1000026, in the middle of the page we see a note -- sorry, just above that, Paul -- approximate date of onset of hepatitis 17 March 1980. That would give an incubation period of 66 days but in your Dad's records there's a document that shows that there was a marked rise in his AST on 28 February 1980 which would give the 48-day incubation period.

A. Yes.

Q. That's why you say you think your Dad was that patient?

A. Yes.

Q. It's your understanding, therefore, that your Dad was infected by the first batch of Factor VIII that he'd received?

A. Yes.

Q. By NHS concentrate?

A. Yes.

Q. As far as you and your Mum are aware, did your father ever consent to being part of a research study?

80

1 A. No.  
 2 Q. Did you ever consent to participate in the study or  
 3 your parents consent on your behalf?  
 4 A. No.  
 5 Q. You have further concerns that you were used for  
 6 research without your knowledge in 1998 as well.  
 7 A. Yes.  
 8 Q. Can we have document 1000015, please. This records  
 9 you being seen by a registrar while you were visiting  
 10 your father. What's your view of that?  
 11 A. That never happened.  
 12 Q. Can you tell us why you say that?  
 13 A. For a couple of reasons. I've always lived a couple  
 14 of doors away from my Mum and Dad and the Haemophilia  
 15 Centre was a day centre. Why would I be visiting him  
 16 at a day centre? I was 20-odd years old. I'd be at  
 17 work. I'd wait until he comes home or something.  
 18 That's one.  
 19 And, two, he's saying he spoke to me about it.  
 20 I can't remember that. I wasn't even a kid. I was  
 21 an adult. I would remember it and it didn't take  
 22 place.  
 23 Q. This letter suggests that there was a discussion about  
 24 hepatitis C testing in 1992?  
 25 A. Yes.

81

1 Q. Of course.  
 2 A. On that letter it says --  
 3 Q. Just a moment. It is 015, Paul.  
 4 A. It also says there my first exposure, because this  
 5 letter was written in 2007 two weeks after I finally  
 6 found out I was hep C by a certain doctor but it was  
 7 written two weeks after and in it it's got first time  
 8 exposure, the 5th of the 12th, 1981, like the other  
 9 letter what you just said, Brian, she's the only one  
 10 who uses them dates because it's the 12th of the fifth  
 11 '81, but she uses this date in another document which  
 12 I hope I'll show you, the same sort of thing, because  
 13 I don't know why she writ this letter because if them  
 14 samples were tested properly, you know, they wouldn't  
 15 have come out negative, plus there was no PCR in my  
 16 records.  
 17 Q. So two things arise from the letter. One is you say  
 18 you didn't consent to being part of any study?  
 19 A. No.  
 20 Q. And, secondly, you were not aware that you had  
 21 hepatitis C --  
 22 A. No.  
 23 Q. -- until 2006.  
 24 A. Yes.  
 25 Q. On that you say in your statement that throughout this

83

1 Q. Were you aware in 1992 that you were being tested for  
 2 hepatitis C?  
 3 A. No, I wasn't, no. Can I just say if I was aware my  
 4 thing on that is, you know, a couple of weeks after  
 5 I allegedly agreed to it I would have asked him about  
 6 the results but there's nothing. I didn't ask him,  
 7 and then two and a half years later he's tested me  
 8 again sort of thing.  
 9 Q. Because we can see at the bottom of the letter that as  
 10 part of a study of natural clearer you had stored  
 11 samples one from 2 June 1992, the other from  
 12 25 November 1994, and they were tested in  
 13 October 1998.  
 14 Again, were you aware of anything to do with  
 15 hepatitis C in those dates?  
 16 A. Nothing.  
 17 Q. As far as you're concerned, you didn't know about  
 18 hepatitis C until November 2006?  
 19 A. Yes.  
 20 Q. Did you consent to participate in this study?  
 21 A. No, I never.  
 22 Q. You say in your statement there was no consent for the  
 23 Factor VIII treatment.  
 24 A. No. Sorry, can I just come back to that letter,  
 25 sorry.

82

1 time you thought you were giving regular blood samples  
 2 purely to do with monitoring of your von Willebrand's.  
 3 A. Yes.  
 4 Q. And you say:  
 5 "I feel that my parents and I were completely  
 6 misled about what was going on and, put simply, we  
 7 were deliberately lied to in order to facilitate my  
 8 unwitting participation in illegal clinical research."  
 9 A. That's right, yes.  
 10 Q. Professor Tuddenham has responded to your statement.  
 11 It is very detailed. I am only going to highlight  
 12 particular points we are addressing today but the full  
 13 witness statement will as usual be published on the  
 14 Inquiry website in due course.  
 15 In relation to your criticism that you were  
 16 deliberately given blood products that clinicians knew  
 17 were more dangerous than others and that you -- there  
 18 was no consent for your Factor VIII treatment he says  
 19 this:  
 20 "For that reason, as far as I am aware, it was  
 21 not the case that any clinician at the Royal Free  
 22 Hospital deliberately gave a patient blood products  
 23 which they knew to be more dangerous than other  
 24 products. Whilst I can only comment from what I knew  
 25 at the time, from my perspective clinicians were aware

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1 that there was a small risk of passing on  
2 a blood-borne virus with any of the blood products  
3 discussed above."

4 He has discussed cryoprecipitate and Factor VIII  
5 earlier in his statement:

6 "In those circumstances, it was necessary to  
7 balance the risks against the benefits of prescribing  
8 a particular blood product. In many situations the  
9 decision to use BPL or Factor VIII over  
10 cryoprecipitate was based on the clinical  
11 circumstances and also the clinician's knowledge that  
12 BPL or Factor VIII was a more effective product. It  
13 is also worth noting that in the 1970s/1980s whilst  
14 the existence of the virus we identified as non-A  
15 non-B hepatitis was known of, at the time patients  
16 infected with this virus appeared to recover quickly  
17 from this infection."

18 Is there anything you would like to say in  
19 response to that?

20 A. I'd better not.

21 **SIR BRIAN LANGSTAFF:** May I just ask was there any  
22 suggestion in what Dr Tuddenham had to say or, for  
23 that matter, in the medical records that given that  
24 Mark was 13 at the time, the one and only time that he  
25 was given factor concentrate, that his parents were

85

1 time."

2 You were unhappy with the response you received  
3 because you felt it didn't really answer the questions  
4 you were asking?

5 A. Yes.

6 Q. But you were particularly upset by that comment in the  
7 second letter?

8 A. Yes.

9 Q. Can you tell us why?

10 A. Because he was my treating doctor. He was my  
11 consultant from the hospital.

12 Q. That particular point in the letter leads you to say  
13 that doctors have repeatedly and deliberately fobbed  
14 you off --

15 A. Yes.

16 Q. -- when you've asked questions about what happened?

17 A. Yes.

18 Q. Again, Professor Tuddenham has provided a response to  
19 that and says you have taken his response out of  
20 context and he meant to refer only to the period  
21 between 1992 and 1994 when he was not working in the  
22 Royal Free.

23 But your feeling was throughout that complaint  
24 process, which was lengthy and we have all the  
25 documents from it, that you never really got any

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1 asked to consent?

2 **MS FRASER BUTLIN:** No, sir.

3 **SIR BRIAN LANGSTAFF:** No suggestion that his parents were  
4 asked to consent to his participation in a trial?

5 **MS FRASER BUTLIN:** There's nothing in the medical records  
6 that I have been able to identify on either of those  
7 points or even that there was any discussion about the  
8 transition to Factor VIII.

9 **SIR BRIAN LANGSTAFF:** So if he was in a trial there is no  
10 consent apparent for it?

11 **MS FRASER BUTLIN:** Nothing in the medical records.

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

13 **MS FRASER BUTLIN:** So in January 2007 you had been told  
14 you had hepatitis C for the first time.

15 A. Yes.

16 Q. In March 2008, you wrote a complaint to the Royal Free  
17 Hospital about your treatment and Professor Tuddenham  
18 responded in two letters.

19 A. Yes.

20 Q. Can we look at document 1000020, Paul.

21 This is the second letter that was sent. At the  
22 end of the letter it says:

23 "Necessarily, my opinions are based on written  
24 records and discussions with colleagues but I have  
25 done my best to understand what went on here before my

86

1 answers --

2 A. No answers.

3 Q. -- to what had happened?

4 A. No.

5 Q. And you had never had a straight answer about why you  
6 were given Factor VIII?

7 A. Yes.

8 Q. Or whether you were definitively part of a trial?

9 A. Yes, nothing. Even though it says I was used in  
10 a trial, in a study. Even though she says as part of  
11 a study she still says I'm not in a study.

12 Q. You are referring to the letter we looked at a moment  
13 ago?

14 A. Yes.

15 Q. Until you were diagnosed with hepatitis C you were fit  
16 and healthy?

17 A. I was, yes.

18 Q. Working full time?

19 A. Yes.

20 Q. And in a happy relationship with your partner?

21 A. Yes.

22 Q. With three children?

23 A. *(The witness nodded)*

24 Q. Can you describe how you felt when your hepatitis C  
25 diagnosis was confirmed.

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1 A. Smashed. I was devastated. I was just gobsmacked.  
 2 Q. You describe in your statement that you remember  
 3 feeling really angry.  
 4 A. Yes.  
 5 Q. And asking how it could have happened and who was  
 6 responsible.  
 7 A. Yes.  
 8 Q. After that appointment you started to do some research  
 9 into hepatitis C and became very overwhelmed.  
 10 A. Yes.  
 11 Q. You started treatment for the hepatitis C in  
 12 February 2007.  
 13 A. Yes.  
 14 Q. And progressively developed very severe depression.  
 15 Can you tell us about the impact of that on you and  
 16 your family.  
 17 A. Devastating. Like something I've never encountered in  
 18 my life. It was just -- it was horrendous. It was  
 19 nightmare.  
 20 Q. What happened in your family life?  
 21 A. Meaning Francesca and the kids. Well, the treatment  
 22 got so bad, sort of thing ... I turned into someone  
 23 else, like. I ended up moving out. It was easier if  
 24 I just went and lived with my Mum.  
 25 Q. Because you were worried about the effect you were

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1 ascertains that any evidence in the form of medical  
 2 records was destroyed in a cover up. Rather than  
 3 challenging this belief directly as Mr Stewart retains  
 4 a fixed belief about his past treatment, we shifted  
 5 focus to reflect on Mr Stewart's losses and change in  
 6 health as a result of contracting hepatitis C which  
 7 had evidently been very distressing and destructive  
 8 for his family system."  
 9 If we go over the page:  
 10 "Towards the later stages of the work,  
 11 Mr Stewart and I focused on the metaphor of crossroads  
 12 how now he has a choice about whether to keep fighting  
 13 for the contaminated blood cause or to try and think  
 14 about the things in life that are important to him and  
 15 rebuild a life worth living."  
 16 Can you tell us how you feel about that letter.  
 17 A. I haven't had counselling since that letter because  
 18 that's years of counselling and they've ended up at  
 19 that point, sort of thing. Yes, it was devastating,  
 20 you know. I was telling people. They tell you open  
 21 up and everything. You open up and then you find out  
 22 they don't believe you.  
 23 Q. You say in your statement:  
 24 "I was and regularly continue to be extremely  
 25 depressed. However I am not and have never been

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1 having on your partner.  
 2 A. Yes.  
 3 Q. On the children, so you separated --  
 4 A. *(The witness nodded)*  
 5 Q. -- and moved away to live with your Mum?  
 6 A. Mmm. It was only round the corner, though. It  
 7 weren't miles away.  
 8 Q. You have never really recovered from that?  
 9 A. No.  
 10 Q. But over time you have sought treatment for your  
 11 depression.  
 12 A. Yes.  
 13 Q. And tried to work through it.  
 14 A. Yes.  
 15 Q. But even seeking the treatment's been difficult.  
 16 A. Yes.  
 17 Q. Can we look at document 1000034, please.  
 18 This is a letter from a psychologist who was  
 19 treating you to your GP in 2015 and if we go down to  
 20 the third paragraph it says this:  
 21 "Mr Stewart has a diagnosis of depression and  
 22 delusional disorder and this is in the context of  
 23 fixed beliefs that he was deliberately infected with  
 24 hepatitis C by doctors at the Royal Free Hospital.  
 25 The evidence for this belief is unclear and Mr Stewart

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1 delusional."  
 2 A. Never, yes.  
 3 Q. You say:  
 4 "I continue to mentally struggle on a daily  
 5 basis and haven't been able to move beyond my feelings  
 6 of anger, betrayal and utter despair that I've felt  
 7 since I found out and continue to feel today."  
 8 A. Yes.  
 9 Q. Do you want to add anything to that?  
 10 A. No.  
 11 Q. In terms of treatment for the hepatitis C, you started  
 12 treatment with interferon and ribavirin in  
 13 February 2007?  
 14 A. Mm-hm.  
 15 Q. That was going to be for 24 weeks?  
 16 A. Yes.  
 17 Q. Then after about six to eight weeks of treatment what  
 18 were you told?  
 19 A. I was told sort of my levels -- something about my  
 20 levels hadn't sorted itself out, sort of thing, and  
 21 I should go on 48 weeks of treatment and also the  
 22 doctor said because of my brother had like relapsed  
 23 a couple of months before, sort of thing, I should go  
 24 for 48 weeks' treatment, you know, and -- but I was  
 25 told by -- can I name him?

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1 Q. The name is redacted at this stage.  
 2 A. Well, I was told by my liver specialist that I needed  
 3 it.  
 4 Q. Apologies, I thought you were going to refer to  
 5 someone else. You can certainly refer to  
 6 Professor Dusheiko.  
 7 A. You know, one of the top liver specialists and he's  
 8 telling me I should have 48 weeks of treatment.  
 9 Q. When you got to week 24 what were you then told?  
 10 A. Then I was told you can't have the 48 weeks' treatment  
 11 because they're not going to fund it.  
 12 Q. So what did you do about that?  
 13 A. Well, I funded it but obviously I got everyone  
 14 involved sort of thing, you know. I fought the PCT,  
 15 got the MEP, I was writing to lords and MEPs and  
 16 everyone I, could sort of thing. The PCT weren't  
 17 going to fund it but ...  
 18 Q. So in the end you funded it yourself.  
 19 A. Yes.  
 20 Q. Which was something in the order of £7,000?  
 21 A. Yes.  
 22 Q. Because the advice you had received from  
 23 Professor Dusheiko was that your best chance was to  
 24 have 48 weeks of treatment?  
 25 A. Yes, and if you're liver doctor's telling you that

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1 Q. It had further impact on your mental --  
 2 A. Similar time at Christmas and all within a few weeks  
 3 of each other, so I was blind over Christmas.  
 4 Q. It had a further impact on your mental health?  
 5 A. Yes.  
 6 Q. But unfortunately that treatment didn't work and so  
 7 you went on a trial of interferon, ribavirin and  
 8 another drug for about 24 weeks?  
 9 A. Yes.  
 10 Q. And that was also unsuccessful?  
 11 A. Yes.  
 12 Q. 2013 you went onto a further trial?  
 13 A. Yes.  
 14 Q. And that was unsuccessful?  
 15 A. Yes.  
 16 Q. 2014, you went on a trial of sofosbuvir and ribavirin  
 17 for six months?  
 18 A. Yes.  
 19 Q. At the end of that trial your levels  
 20 were undetectable?  
 21 A. That's right.  
 22 Q. You have not had any further testing since then?  
 23 A. No.  
 24 Q. Can you tell us why not?  
 25 A. Because I can't trust anyone. I can't go back to

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1 you're going to, you know -- obviously, I got the  
 2 feeling of -- watching Angus at the same time as all  
 3 this is happening sort of thing, you know, I don't  
 4 want to go down that road. I was struggling anyway  
 5 so, yes, I was going to do whatever the doctor said  
 6 I was going to do.  
 7 Q. So you personally funded the second 24 weeks.  
 8 A. Yes.  
 9 Q. But at the same time you complained to the Healthcare  
 10 Commission?  
 11 A. Yes.  
 12 Q. And after some months you were sent a cheque for  
 13 £2,800 --  
 14 A. That's right, yes.  
 15 Q. -- as a gesture of goodwill.  
 16 A. Yes.  
 17 Q. What was your reaction to that?  
 18 A. Gobsnacked, you know, but ... I was on treatment and  
 19 everything. I was being beat up from all corners, you  
 20 know.  
 21 Q. You said in your statement you found it insulting?  
 22 A. It was insulting, yes.  
 23 Q. You found that treatment brutal you described in your  
 24 statement, including suffering two detached retina.  
 25 A. Yes.

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1 them, you know. I can't, I don't ... that's the best  
 2 treatment I was going to get, you know. There was  
 3 a couple of years, between say 2009 and 2013, when  
 4 there was, you know, they were on the horizon, these  
 5 new drugs, and I had a few years of thinking I ain't  
 6 not getting them, I'm on that slippery slope, so I got  
 7 the treatment and I never went back.  
 8 Q. You said in your statement that you can't face the  
 9 fear of finding out that it's returned?  
 10 A. Yes.  
 11 Q. So you would rather just not know?  
 12 A. *(The witness nodded)*  
 13 Q. You were unable to work during your first treatment.  
 14 You returned to work for a month but then stopped  
 15 completely because of your mental health difficulties?  
 16 A. Yes.  
 17 Q. But in 2016 you have managed to return to part-time  
 18 work?  
 19 A. Yes.  
 20 Q. How do you manage that?  
 21 A. Just if I feel fit enough to go to work, you know,  
 22 I give it a shot, I'll do my best sort of thing, you  
 23 know.  
 24 Q. You found a part-time role that is more flexible and  
 25 that you can do when you're able.

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1 A. Yes.  
 2 Q. But it's quite a different role to what you were doing  
 3 before?  
 4 A. Yes, yes.  
 5 Q. And you have obviously got some contact with  
 6 Francesca?  
 7 A. Yes.  
 8 Q. And you have been trying to resolve some of that. Do  
 9 you want to tell us anything about how things are now  
 10 in terms of both your own mental health difficulties  
 11 and how the family is?  
 12 A. The family's all right, you know. They've grown up  
 13 a bit. They've got bigger. But, you know, it is  
 14 a big gap I need to fill but, you know, we're doing  
 15 all right.  
 16 Q. In your statement you say this:  
 17 "My life has been devastated as a consequence of  
 18 discovering that I had been given contaminated  
 19 Factor VIII and everything that's flowed thereafter.  
 20 I'm angry about the way in which my own life has been  
 21 ruined but even more so about the effects it has had  
 22 and continues to have on my family. Despite the  
 23 battles I faced for recognition of what I've been  
 24 saying for many years and the impact of being labelled  
 25 delusional, I remain committed to securing justice for

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1 we were there because [redacted] who is also put on  
 2 the at risk register because [redacted].  
 3 Q. You were told you had not received an implicated  
 4 batch.  
 5 A. Yes.  
 6 Q. But because of having received products in the time  
 7 you would be on that list.  
 8 A. Yes.  
 9 Q. Your daughter was also told -- said to be at risk and  
 10 the doctors wanted to tell her that.  
 11 A. Yes.  
 12 Q. What did you and Francesca decide to do about that?  
 13 A. We were not going to tell her you know. She'd just  
 14 started her periods and that, it was like, she'd just  
 15 started secondly school, we were not going to tell her  
 16 something like that.  
 17 Q. Could we have document 1000031 please. This is  
 18 a letter from 12 November 2004 from Dr Lee and it  
 19 suggests that she had seen your daughter with you on  
 20 12 November to discuss the issues around vCJD:  
 21 "I have discussed with her parents together with  
 22 [your daughter] the issues that were documented in the  
 23 patient information sheet and answered their  
 24 questions."  
 25 Did that happen?

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1 my father and brother. They were murdered. There's  
 2 no other word or label I can think of to describe what  
 3 happened to them. I live in fear of suffering the  
 4 same fate and often feel it's only a matter of time  
 5 before something similar happens to me."  
 6 A. Yes.  
 7 Q. Do you want to add anything to that of how you  
 8 currently feel?  
 9 A. That's how I feel, you know. I can't think of another  
 10 word for it. They were given a death sentence and  
 11 executed, you know. They were murdered, and they  
 12 can't speak now so I have to speak up for them.  
 13 Q. There's one final area I would like to explore with  
 14 you and that is the issue of vCJD. You were notified  
 15 in September 2004 that you were in the group of at  
 16 risk patients?  
 17 A. Yes.  
 18 Q. What did you do then?  
 19 A. Well, I had to make an appointment to go and see them.  
 20 They sent me a letter and I went along, me and  
 21 Francesca went to see them.  
 22 Q. What were you told?  
 23 A. We were told that we were going to be put on  
 24 a register for, you know, for vCJD. There ain't  
 25 a cure, there ain't a test. At the same time as that

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1 A. No, it didn't, no.  
 2 Q. If we look at 1000032, we can see that this is  
 3 a letter from Professor Tuddenham to you in which he  
 4 describes in the third paragraph -- sorry, it's the  
 5 second paragraph:  
 6 "Having completed a thorough search of all our  
 7 patients notified as at risk of vCJD."  
 8 The third paragraph:  
 9 "We have notified the UKHCDO and, as a result,  
 10 a similar exercise is being carried out across the  
 11 whole country since it is clear that others may have  
 12 made the same mistake that we did. Close examination  
 13 of the information that came to us in 2004 shows that  
 14 the order was given to notify all individuals who had  
 15 received UK plasma-based products made from plasma  
 16 collected between 1980 and 2001. However, it was less  
 17 than clear that during the period 1999 to 2001 there  
 18 were BPL products in circulation made from [other] UK  
 19 plasma or US plasma which only differed" --  
 20 SIR BRIAN LANGSTAFF: It's "either", I think.  
 21 MS FRASER BUTLIN: Apologies, sir.  
 22 "... there were BPL products in circulation made  
 23 from either UK plasma or US plasma which only differed  
 24 in appearance by the addition of single letter to the  
 25 labelled batch number. In the last six years, no-one

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1 else has noticed the error which was picked up by  
2 Debra's sharp eye when reviewing your daughter's case  
3 file."

4 So there had been an error in notifications and  
5 this letter is to apologise for that, but most  
6 significantly in the last paragraph of this letter  
7 Dr Tuddenham says:

8 "We remain deeply sorry for the distress and  
9 anxiety that the mistake has no doubt caused you both  
10 on her behalf. We are relieved that it was not  
11 compounded by giving her the wrong information to  
12 worry over herself and your decision to keep it from  
13 her has been fully justified."

14 So Dr Tuddenham in that letter confirms what you  
15 had said to him, that you were not going to tell your  
16 daughter about the vCJD risk?

17 A. Yes.

18 Q. That makes you particularly upset you have said about  
19 the letter that we looked at a moment ago from Dr Lee.

20 A. Yes.

21 Q. But for you personally, Mark, the issue of vCJD is an  
22 added worry?

23 A. Yes.

24 Q. Can you tell us about what you feel.

25 A. It's just one of them things, isn't it? With all this

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1 A. I rest my case.

2 MS FRASER BUTLIN: Sir.

3 SIR BRIAN LANGSTAFF: Well, unless there's anything else  
4 that you want to add, can I just thank you very much  
5 indeed for coming to give your evidence. It's never  
6 easy, and thank you.

7 A. Thank you.

8 SIR BRIAN LANGSTAFF: We'll take a break, slightly shorter  
9 than yesterday, and come back at 2.05.

10 (1.19 pm)

(Luncheon Adjournment)

12 (2.10 pm)

13 SIR BRIAN LANGSTAFF: Our next witness is Annette.

14 MS FRASER BUTLIN: Annette, sir.

15 SIR BRIAN LANGSTAFF: Annette, please.

ANNETTE HILL-STEWART, sworn

Questioned by MS FRASER BUTLIN

18 Q. Annette, you are here to tell us about your late  
19 husband Angus, Angus junior. You met him through work  
20 in 1998?

21 A. I did.

22 Q. What was his work at that time?

23 A. He was a horologist.

24 Q. You have given us two pictures of --

25 A. Shall I explain what a horologist is because not many

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1 scandal you don't know what's -- you know. They just  
2 lie. People just constantly lie to you. You can't  
3 believe anyone, you know. They tell you one thing and  
4 then tell you another. It's just -- it's a scary old  
5 thing, you know what I mean.

6 Q. Mark, those are the questions I have for you. Is  
7 there anything else you would like to say?

8 A. No.

9 Q. I am just going to turn to Mr Stein who, as you know,  
10 represents you. (Pause)

11 Just give me a moment, Mark, there's two  
12 documents that Mr Stein wants me to highlight to you.

13 Could we have document 1000020, please. We've  
14 looked at both of these documents before. Mr Stein  
15 just wants to highlight the connection. We looked at  
16 the last paragraph of the letter in which Dr Tuddenham  
17 said:

18 "Necessarily my opinions are based on written  
19 records and discussions with colleagues but I've done  
20 my best to understand what went on here before my  
21 time."

22 You said in response that he was your treating  
23 doctor during the time, and Mr Stein just asks that we  
24 look again at document 1000019 and, at the bottom of  
25 the page, 1981 we can see an entry from Dr Tuddenham.

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1 people would know.

2 Q. Of course.

3 A. His profession was actually manufacturing and making  
4 watches, old-fashioned watches.

5 Q. You have given us two pictures of Angus that you would  
6 like up during your evidence. The first of which is  
7 1001013, please, of him at his work bench and the  
8 second 1001019 and you have described this photo as  
9 how you want to remember Angus.

10 A. I do.

11 Q. We'll keep that photo up during your evidence.

12 A. I did actually have a photograph that I asked to be  
13 shown ten days before he died actually.

14 Q. We will come to that as well, absolutely. We will  
15 come back to that a little bit later.

16 A. Thank you.

17 Q. When you met Angus, you were aware that he had  
18 von Willebrand's disease?

19 A. We were friends at first. He'd worked at -- I'm in  
20 the watch business myself and we'd met previously and  
21 then we met again and we became good friends and the  
22 rest is history. But, yes, I knew before we entered  
23 into a full relationship that he had haemophilia, yes.

24 Q. What was your understanding of how much it affected  
25 him on a day-to-day basis?

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1 A. Not at all. Angus was a guy, larger than life. He  
 2 walked into a room and held a presence. He was very  
 3 tall and fit and handsome, magnetic personality and  
 4 that's why I fell in love with him. But it was very  
 5 apparent that he wasn't a sickly person. Now and  
 6 again he would have nose bleeds and sometimes at work  
 7 but that was it.

8 Q. You married in 2001. Can you tell us what your life  
 9 together was like at that time?

10 A. We were a couple who had just got married, had  
 11 a wonderful wedding in Scotland, and we bought  
 12 a house. Angus loved his home. I did too. We were  
 13 really home birds. We were joined together at the  
 14 hip. Wherever he went I went and vice versa. He  
 15 wasn't a football man that would watch football at the  
 16 weekend or go out with his friends, and the same with  
 17 me. We just always wanted to spend time together.

18 We loved cooking, we loved travelling, we  
 19 loved playing golf, we loved bicycling, walking, and  
 20 we had -- we worked hard. We both were ambitious  
 21 people at that time and we both worked very hard and  
 22 from that we managed to buy a beautiful home, house  
 23 and lovely holidays and it was wonderful. It's  
 24 a cliché to say he was my best friend, but he was.

25 Q. You obviously didn't know Angus when he was infected

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1 then a note from 1 December 1980 which records that  
 2 Angus had further nose bleeds and that he was treated  
 3 with Lister VIII and thereafter was to have liver  
 4 function tests.

5 If we look at 1001006, please, we have a list of  
 6 treatments that Angus had and we can see in the list  
 7 1 December 1980 is the first time that Factor VIII  
 8 concentrate is given.

9 From your discussions with Angus before he died  
 10 and with his family, were they ever warned of any  
 11 risks involved in him changing to Factor VIII?

12 A. No.

13 Q. Was there any discussion with them about making that  
 14 change?

15 A. No.

16 Q. If we look again at this document on the screen, we  
 17 can see that Angus was given Factor VIII on four  
 18 occasions, and then on 13 October 1982 his treatment  
 19 changed to DDAVP.

20 Having looked at these records and other parts  
 21 of Angus' medical records, you're concerned about  
 22 whether Angus was used as a guinea pig and why he was  
 23 ever given Factor VIII?

24 A. Correct.

25 Q. Can you explain to us what that concern is and why.

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1 with hepatitis C but since he died, you've obtained  
 2 his medical records and talked to family a lot about  
 3 what happened.

4 A. Mmm.

5 Q. From 1978 when he was 13 he was treated at the Royal  
 6 Free hospital under Dr Kernoff and he had recurrent  
 7 nose bleeds. Your understanding is that he was  
 8 usually treated with cryoprecipitate; is that right?

9 A. Correct.

10 Q. Please can we have document 1001003, please. It's  
 11 a handwritten entry in the notes -- it's 003, the  
 12 second page, please, Paul -- there's an entry on  
 13 28 November 1980 and I will read it out because it is  
 14 not entirely clear on the screen. It says:

15 "Treated today with cryo times 10 for epistaxis.  
 16 Developed a moderately severe transfusion reaction,  
 17 generalised erythema, urticaria and rigor which was  
 18 aborted with hydrocortisone. Piriton had been given  
 19 before infusion. All future treatment should be  
 20 changed to NHS Factor VIII concentrate", and that is  
 21 underlined. "Try 700 units in the first instance",  
 22 and it goes on to require liver function tests before  
 23 treatment and weekly liver function tests for eight  
 24 weeks after the first infusion.

25 If we look at the bottom of the page there is

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1 A. Yes, I had a concern which I was obviously going to  
 2 view today but in light of what my brother-in-law has  
 3 given as evidence this morning, my husband was patient  
 4 number 19 and he was knowingly, by the clinicians but  
 5 not by Angus or himself, given a product that they  
 6 knew was contaminated and it seems to be that was for  
 7 some type of clinical trial or -- I'm not sure. I  
 8 would like to know more about that document. It's the  
 9 first time I knew about that today.

10 Q. But even before you saw that document this morning in  
 11 Mark's evidence you were concerned even then.

12 A. Even then.

13 Q. Can you explain what your concern was then.

14 A. It was very clear. Angus was given Factor VIII  
 15 initially in December 1980 and by then it was very,  
 16 very clear that Factor VIII was contaminated. It  
 17 wasn't heat-treated and it would cause infections and,  
 18 indeed, there was a verbal interview given by  
 19 Christine Lee, I believe in June 2015, when she said  
 20 towards -- there was a -- I can't recall the specific  
 21 time but they knew that giving patients Factor VIII  
 22 100 per cent of them would be infected by hepatitis C.

23 Q. In your statement your particular concern was also  
 24 about Angus' father, Angus senior?

25 A. Mmm.

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1 Q. In your statement you said that at the same time as  
2 Angus junior was changed to Factor VIII, Angus senior  
3 was also changed to Factor VIII.  
4 A. I think it was a matter of a week between the two.  
5 Q. And both Anguses were said to have had a transfusion  
6 reaction?  
7 A. Out of the blue. My Angus, Angus junior, had  
8 successfully been given cryoprecipitate for many years  
9 and he'd never, ever had a reaction to it and then all  
10 of a sudden he has a reaction to cryoprecipitate.  
11 Now, there was a line in his medical records  
12 stating, you know, Angus had a reaction to this.  
13 I'd like to know what was the reaction. Did they  
14 investigate it? What caused it? There was nothing  
15 else pertaining to why all of a sudden he became  
16 allergic to cryoprecipitate and, as it happens, you  
17 know, I have seen some of Angus senior's medical  
18 records and it's exactly the same. All of a sudden  
19 his father became allegedly allergic to  
20 cryoprecipitate too.  
21 Q. You are also concerned in your statement about why  
22 DDAVP wasn't used instead of Factor VIII.  
23 A. Correct. It was readily available and Angus was  
24 treated with it after being given Factor VIII four  
25 times and successfully, so I'm quizzed -- I would like

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1 of Biological Standards and Control as required by our  
2 full product licence. Therefore, any material not  
3 tested by NIBSC cannot be covered by our product  
4 licence and is only available for use on a named  
5 patient basis. We would, therefore, request you sign  
6 the attached letter and return it to say you fully  
7 understand the conditions under which we are making  
8 this particular supply of Haemate P available to you."  
9 If we go back to the first page there is then  
10 a letter from the doctor to the sales operation  
11 manager indicating that he had read and noted the  
12 content:  
13 "... and I understand that as such this  
14 particular supply of Haemate P is not covered by your  
15 product licence and I accept responsibility for the  
16 use of this product in the therapy of these patients."  
17 A. That's nice of him.  
18 Q. As far as you are aware, was Angus ever told that  
19 Haemate P he was being given was unlicensed?  
20 A. No.  
21 **SIR BRIAN LANGSTAFF:** Was he ever told that the doctor  
22 accepted full responsibility for the use of the  
23 product?  
24 A. No, and of course this is my understanding from Angus  
25 who is not here to obviously represent himself and

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1 to know why he was all of a sudden given Factor VIII.  
2 But, as I say, going back to the evidence I've heard  
3 this morning, to me there was reason behind it and it  
4 was due to some sort of medical investigation.  
5 Q. Another aspect of your concerns arise from a letter in  
6 Angus' medical records that you came across from  
7 July 1994 and it's 1001011, please, Paul, and if we  
8 can start on page 2 of it.  
9 It's -- this part of it is a fax from the sales  
10 operations manager of Hoechst about Haemate P and it  
11 says this, it's from 14 July 1994:  
12 "You will be aware of the close scrutiny that is  
13 applied to blood products and those where human blood  
14 is used in their manufacture. Haemate P has been  
15 prepared from large pools of human plasma nonreactive  
16 for hepatitis B surface antigen. However, such plasma  
17 may contain one or more causative agents of chronic  
18 hepatitis. Haemate P is heated to 60 degrees  
19 centigrade for ten hours in solution form.  
20 Nevertheless, no procedure has been shown to be  
21 totally effective in removing hepatitis infectivity  
22 from anti-haemophilia factor."  
23 It goes on to say that:  
24 "Haemate P is usually available in the  
25 United Kingdom after testing by the National Institute

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1 also his mother and it was very clear that he was  
2 never informed of that.  
3 **MS FRASER BUTLIN:** Going back to 1981, please, can we have  
4 document 1001004, please.  
5 We have here the record of the doses that had  
6 been given to Angus on 27 February 1981 in that entry.  
7 There's the note that doses of NHS concentrate on  
8 1 December 1980 and 20 January 1981 AST followed  
9 prospectively and that it became abnormal on  
10 20 January 1981.  
11 Then if we look at -- sorry, can I just have one  
12 moment.  
13 If we look at the bottom of that page, there's  
14 an entry from 11 December 1981 which flags that there  
15 was a flare up of symptoms around 23 November 1981.  
16 What your concern is is if we go over the page  
17 we have an entry from Angus senior's medical records  
18 at the bottom of the page, 11 December 1981, which is  
19 exactly the same as the entry in your Angus' medical  
20 records.  
21 You say in your statement you are rather  
22 concerned that there are identical records in the two  
23 individual patients' records of what was going on.  
24 A. How can you have two separate patients with exactly  
25 the same comments? That's my question.

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1 Q. As far as you are aware, do you know which Angus, if  
2 either of them, had a flare up of symptoms at that  
3 time?  
4 A. Well, I have no idea.  
5 Q. And the family can't work it out.  
6 A. No, none of us can, and indeed actually it actually  
7 looks like this was, obviously we're going back a long  
8 time ago before computers and also to note that the  
9 Haemophilia Centres always keep their -- they are what  
10 I know are the only departments in the hospital that  
11 keep their patients' records, which is very handy for  
12 them.  
13 It looks like this entry has been cut and  
14 paste like a piece of paper over the top of it which  
15 concerns me too because I didn't get the originals,  
16 I had scans. So I couldn't look and investigate  
17 that any further.  
18 Q. When you met Angus and when you got together with  
19 Angus he told you he had hepatitis C.  
20 A. It wasn't until we entered into a relationship that he  
21 told me that he had hepatitis C.  
22 Q. He also said to you that he felt there was a delay  
23 between his being diagnosed with hepatitis C and when  
24 he was actually told about it but going back through  
25 the records you are not entirely clear what the delay

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1 "You may know that we are trying to find out  
2 more about the hepatitis C virus which many of our  
3 patients acquired during the late 1970s and early '80s  
4 before clotting factor concentrates were sterilised.  
5 Many of our patients have been asking at their reviews  
6 if there's a risk of transmitting the virus sexually  
7 to their partners. We think that this risk is very  
8 small but do not have enough evidence to give definite  
9 advice at present."  
10 That was 1992, but by 1998 when you and Angus  
11 entered a relationship, what were you both told or  
12 understood about the risks of sexual transmission of  
13 hepatitis?  
14 A. Well, as partners, we actually at that time hadn't  
15 been into the haemophilia department to discuss this  
16 but Angus was clearly a very caring and thoughtful man  
17 who before he'd met me he had had children, and he had  
18 asked to see the clinicians prior to him having  
19 children to the possibilities of passing over his  
20 von Willebrand's, which indeed I have to also mention  
21 was moderate, and also hepatitis.  
22 He was never told that the hepatitis would be  
23 a problem. So when we met, you know, we used  
24 condoms when we first met as we just started  
25 a relationship and then, of course, as you fall in

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1 was or what was going on?  
2 A. No.  
3 Q. But his sense was that there had been a significant  
4 delay?  
5 A. Absolutely.  
6 Q. When you first entered a relationship with Angus, what  
7 was his understanding of how serious hepatitis C was?  
8 A. At that time not particularly serious. It was  
9 starting to become more apparent that hepatitis C was  
10 an issue but he just hoped, because he was a very  
11 positive man, that he wouldn't be inflicted or  
12 affected by it too much.  
13 Q. In your statement you say at that point he wasn't  
14 particularly worried by it.  
15 A. No, because he'd never been told that there was  
16 anything to be concerned about. He hadn't been pulled  
17 in by any of the clinicians or the doctors. He didn't  
18 deem it to be too much of a problem and he felt that  
19 if it had have been, he would have been called in. He  
20 had the utmost trust at that time with his doctors and  
21 the Haemophilia Centre.  
22 Q. Can we have document 1001023, please. It is a letter  
23 from May 1992, so before the two of you were together.  
24 It addresses the question of sexual transmission of  
25 hepatitis C. It says this:

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1 love with somebody you don't want to do that and  
2 Angus was clear because we'd talked about it that he  
3 was told that hepatitis could not be transmitted  
4 sexually and, of course, I trusted and believed him.  
5 I always have.  
6 Q. In about 1999 you felt unwell and had a test for  
7 hepatitis C. What was the result of that?  
8 A. It was positive.  
9 Q. What's happened for you about hepatitis C since then?  
10 A. I cleared it naturally, very fortunately.  
11 Q. In 2002 Angus' father, Angus senior, died of liver  
12 cancer. How did that affect your Angus?  
13 A. Oh, it killed him. He was completely devastated. You  
14 know, his father was his mentor and he also was in  
15 a state that, actually, Angus at that time, he'd got  
16 a job that actually incorporated lots of international  
17 travel and he was due to go to the Far East and the  
18 clinicians had said -- he questioned whether he should  
19 go, the clinicians said, "It's fine, your Dad will be  
20 with us for a while", and he'd only been away for  
21 three days and we had to call him and ask him to come  
22 back. Indeed, he got back two or three hours too late  
23 and his father passed. So not only did he struggle  
24 with the death of his Dad, Angus, he also really  
25 struggled with the guilt that he wasn't there with

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him. He was the only member of the family. We were all there. Angus' Mum asked us to all come to the house and we were all there when Angus senior passed and my Angus wasn't and he really never forgave himself for that.

**Q.** You have also said in your statement that it made you acutely aware of the potentially devastating consequences for Angus of his hepatitis C.

**A.** I think Angus saw it not so much the hepatitis C but just how much valuable life was and then he considered his hepatitis C and at that time, you know, we had started to hear in the press and, of course, the inquiries and et cetera and campaigns that it was a killer, and then it was at that time that he said to me, "I have a death sentence over my head. You know, there's a time clock ticking down. I don't know when it is that it will stop but we now really have to do something about this".

**Q.** In 2005 Angus became unwell. Can you tell us about that. He was becoming more tired?

**A.** Yes, actually, because previous to that he had been into hospital a couple of times with something else he'd contracted through bacteria actually when he was on a trip. But he began to feel more fatigued. He was terribly moody, would out of the blue just start

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that would go out drinking, not at all.

**Q.** In 2006 he was treated with ribavirin and interferon?

**A.** Sorry, can I just go back to the cirrhosis bit. It seems to be habitual that clinicians like to write that somebody has a problem with drink and that's why they have the cirrhosis. You hear this in the hearings and also they actually did this to -- they wrote this in Angus' father's notes at all and I have to say I never ever saw Angus' father ever drink at home, ever, never did, and he hardly went out the house. So it seemed to me that one clinician writes in something and they all tend to pick up on it and decide to continue to write that afterwards.

So I just have to -- yes, I have to make that very clear that I just feel that the blame of the cirrhosis, it was very evidently the hepatitis C but they were passing it on to alcohol.

He could not have been an horologist. He had a firm hand. I'm surprised I've got one at the moment but he had an absolute firm hand and he couldn't afford not to have that for his career.

**Q.** 2006 Angus underwent treatment. How was he during that time?

**A.** It was like, one of his friends actually said to me one day, it was like the walking dead. He was pale,

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an argument, very confrontational, never physically abusive but verbally abusive at times, and he would be mortified afterwards, you know. He would be really upset and he was also very nauseous, he was actually making himself sick as well at times and it was very clear that something wasn't right.

**Q.** In his records you found a number of entries

suggesting that Angus had liver problems because he was or had been consuming excess alcohol.

**A.** Mmm.

**Q.** In the time you knew him, is that accurate?

**A.** No, not at all. I was horrified when I read that. I have never, ever seen Angus with a beer in his hand, a spirit in his hand. We have -- he was not a pub visitor. He hated pubs, wine bars, nightclubs, and indeed when we used to go on holiday we would frequently fall out because I would want to go to something special after and he would be adamant, "No, we're going back to the room by 10.30", and there we would be in the most exotic location and he wanted to go back to the room.

In the whole time that I knew Angus he would like a glass of wine, we'd cook together and have a glass of wine and go out for meals and have a glass of wine but he was not the type of person

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he was thin, he had no personality. You know, as I say, Angus was full of life, always laughing, always joking, and everybody fell in love with him. He was charming. But at that time when he was going through the, you know, the education he was just a different person and, of course, he wouldn't eat and he was very sick, mood swings.

It was awful for him, but he was persistent.

Angus was a very strong character and he was adamant. I've never known anybody that wanted to live so much and he continued to take the treatment. He went all the way through it and he still worked and I don't know how he did it. Once in a while we'd have to call him in sick but he was a proud man.

**Q.** Towards the end of the treatment by May 2007 he had finished the round of treatment and he sent an email to his treating doctor. If we can have 1001008, please. It is the email at the bottom:

"Sorry for the late reply, only I've just returned yesterday from the States and I'm getting [I think it should say ready to return to China]. I'm scared in calling you that you are going to tell me the hep is back or I have cancer. Please reply and advise what the problem is and then I'll call you.

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I don't think I could handle bad news at the moment with my brother on the treatment and the scandal of the NHS in all the papers. Regards Angus."

Were you aware that was how Angus was feeling by May 2007?

- A.** Yes, I was. We were very, very close. He always tried to be strong in front of me and we always tried to be positive and always prayed for a miracle but, yes, I mean, of course, he was just beside himself with worry, especially after he lost his father and then Mark was on the treatment and he was scared.
- Q.** Unfortunately we can see from the email above that the virus had come back. He wasn't in remission at that point. Angus then had a battle for a further course of treatment to be funded.

What can you tell us about that?

- A.** Well, of course, you know, it was devastating news to be informed that his treatment had not worked and the hepatitis C was still there. So, of course, he wanted to go through another treatment and he was told that that wasn't possible. They didn't have the funding, so Angus wrote to our MP at the time who actually was really very good and was always very prompt in answering Angus with his letters, et cetera, and indeed, you know, he pushed for Angus with our local

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Of course, you live by your means so we were used to having Angus' income coming but we knew we had to start to make some adjustments in our life and so he said, "Well, okay, you know, I really should look at being self-employed and then I can work when I want to, et cetera", and he sent the feelers out to different people and said, you know, "I've left, I'm open for business", and within days he had quite a few of his previous customers and people that were selling to the company that he was working for, so it was music to our ears, you know, "We've wanted to work for you for a long time". He was inundated with offers of contract work.

So, yes, for a while before he fell really ill, he was able to work, but it wasn't until he really couldn't work that we decided to seek funding, you know, some sort of help.

- Q.** During this time of your marriage you had made the decision not to have children?

**A.** Mmm.

- Q.** Can you tell us of the ongoing impact of that on you.  
(Pause)

I can read something from your statement if you would prefer?

- A.** (Nodded)

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PCT to have further treatment and it was approved.

- Q.** Throughout this time, as you say, Angus had kept working but in November 2007 he resigned?
- A.** Yes, he did.
- Q.** Why was that?
- A.** He just couldn't take it anymore. He was in a really high pressured job and he was travelling an awful lot and he was tired and he was scared and he wanted to be at home and he wanted to be with me. We wanted to be together and, yes, I said to him, "Just leave it. Go. Give up. Stop what you're doing. We'll manage, we'll get through it", so he left his employment.
- Q.** Financially what was the impact of this?
- A.** It was huge. He had a fabulous position and he'd worked very hard in his career and he was a senior member of a very big company in the UK so the impact was massive, of course, on the money that was coming in every month.
- Q.** He'd just started up his own business and was trying to get things up and running but he'd also applied to the Department of Work and Pensions?
- A.** What actually happened was he -- we talked about him resigning. I said, "Absolutely, you must", and at the time I was fortunate -- I also had -- I did have a good job and so, you know, I could cover to a point.

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- Q.** "Angus and I very much wanted to have a child. However, after discussing this at length I decided not to. Neither of us knew what the future would hold for Angus and it would be more responsible not to. Therefore, because of the hepatitis C infection and also the uncertainty of Angus' future life we decided not to have any children together. Whilst this was probably a sensible decision, it was totally devastating for me as I've never had children and desperately wanted to have a child with Angus. Angus already had three children when we met but he did also very much want to have one with me if it was possible."

You have alluded to it a moment ago but early 2008 Angus became very unwell and was diagnosed with liver cancer.

- A.** He was.
- SIR BRIAN LANGSTAFF:** If you want a break ...
- A.** No, I'm fine. Thank you.
- SIR BRIAN LANGSTAFF:** Are you sure?
- A.** Thank you for asking.
- SIR BRIAN LANGSTAFF:** Not at all.
- MS FRASER BUTLIN:** Angus was diagnosed with liver cancer.
- A.** He was.
- Q.** You are concerned that there was a delay in that

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1 diagnosis.  
2 A. Yes.  
3 Q. Can you tell us about that.  
4 A. I believe there was. Angus actually was at the Royal  
5 Free Hospital in September and in his notes it's  
6 actually pointed out when he came to clinic that day  
7 he was very jaundiced and didn't appear to be very  
8 well and to me that's not rocket science. There was  
9 something clearly wrong.

10 When Angus' father died, there were  
11 certainly -- there didn't seem to be any urgency to  
12 really watch Angus. It was evident afterwards that  
13 his father died of the hepatitis and then had cancer  
14 but there didn't seem to be any urgency to, you  
15 know, every three months pull Angus in for scans or  
16 biopsies or anything at all and in the September he  
17 went in and, yes, it was clearly noted by one of his  
18 doctors that he was looking jaundiced and unwell.  
19 I just don't understand to this day why they didn't  
20 take that any further. They just didn't act on it  
21 at all.

22 Q. He wasn't diagnosed until early the following year.  
23 A. It was -- we'd actually been away and he wasn't at all  
24 well when we were away and so it's just -- it was two  
25 or three days after we got back, something like that.

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1 But they left it far too late and, indeed, it wasn't  
2 until he became unwell and we actually went into A&E  
3 that he was told he had cancer.  
4 Q. Angus underwent embolisation and was very unwell. You  
5 have said there were difficulties with getting the  
6 embolisation appointments?  
7 A. Well, Angus was admitted and it seemed to take an age  
8 really for them to actually confirm to Angus that he  
9 had cancer, and they were doing lots of different  
10 scans and they were always very hesitant to say,  
11 Angus, you have cancer or we think it might be but  
12 we're not sure, which is very strange, and so then  
13 they said, "No, you have cancer", and Angus -- he left  
14 the hospital, we went home and then we had to  
15 obviously wait for a follow-up to know what was going  
16 to happen and where we used to have to chase  
17 constantly, you know, what actions do we take next,  
18 what can we do next and there was nothing. So, yes,  
19 we had to -- I know I wrote and Angus wrote and  
20 emailed and, gosh, Angus I think had managed to -- he  
21 was such a charmer he managed to get the mobile  
22 telephone number I think of everybody in that hospital  
23 so he was constantly texting, constantly emailing.  
24 But we had to really push for the appointment for him  
25 to go in and have the embolisations.

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1 Angus was always reluctant to go to the hospital  
2 towards the end of his life but I persisted and indeed  
3 we in the end went to A&E. He had oedemas. He was  
4 very swollen in his body, cold sores and just very  
5 fatigued and very tired and, yes, it was found  
6 a couple of days later that he then had liver cancer.  
7 Q. Angus was told he wasn't eligible for a liver  
8 transplant.  
9 A. Mmm.  
10 Q. What was the impact of that on Angus?  
11 A. Oh, he was -- he was devastated but, you know, then of  
12 course that sinks in and then, of course, you get  
13 really angry. The hospital knew the history of his  
14 father and yet history seemed to be repeating itself  
15 with Angus and nobody had taken any diligence or any  
16 care of monitoring him and I do wonder, you know,  
17 Angus was refused a liver transplant due to the Milan  
18 criteria because his tumour was too big and he had too  
19 many, and I always asked myself if they had scanned  
20 Angus in the September when it was very apparent that  
21 he wasn't well, would they have then found the cancer?  
22 We don't know. This is me clutching at straws really.  
23 But, indeed, you know, if he had have had the cancer  
24 would he have then fitted into the Milan criteria so  
25 then he could have been put on the transplant list?

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1 Q. Then in May 2008 you were told that a liver from  
2 a live donor was available as part of a domino  
3 transplantation procedure?  
4 A. Mm-hm.  
5 Q. How did Angus respond to that news?  
6 A. Well, of course, to him it was a lifeline and had to  
7 take it, had to grasp it, and so he did. But, you  
8 know, the liver that he was given was from a live  
9 donor, so it was a domino procedure so -- and the  
10 liver that Angus was given was from a patient who was  
11 suffering with amyloidS. So Angus was actually  
12 given -- and I don't want to sound ungrateful -- but  
13 a liver that was not healthy in itself otherwise the  
14 other patient wouldn't be having a new liver. So that  
15 patient was actually having a liver from a cadaver.  
16 Angus said to me, "I'm probably not going to be here  
17 in a couple of months' time. We have to take this  
18 chance", and so he -- it was totally his decision and  
19 he said, "No, I really have to go with this".  
20 Q. Initially the transplant was a success?  
21 A. Mmm.  
22 Q. And what was Angus told about the hepatitis C after  
23 the transplant?  
24 A. That it was no longer apparent.  
25 Q. Then in April 2010 Angus was in the hospital and was

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1 reading his notes and he saw that the hepatitis C had  
2 returned. Until that time, had Angus ever been told  
3 in person or by letter that the hepatitis C had  
4 returned?

5 A. No.

6 Q. Please can we have document 30940012. It is  
7 a exhibit, thank you. We can see on the top right  
8 corner clinic date 20 April 2010, so in accordance  
9 with what your recollection is of Angus finding the  
10 note, and then if we go down into the body of the  
11 letter we can see that it says:

12 "I saw this patient today in clinic with my  
13 colleague, Dr Rowlands, at Welwyn Garden City. He was  
14 upset to hear that his HCV was positive having been  
15 told that his HCV RNA was negative previously. In  
16 fact, going back through his results on one of our  
17 reporting systems there are two instances where his  
18 HCV RNA was reported as negative with a positive level  
19 in between times."

20 So as far as Angus was concerned, he hadn't been  
21 told anything about this until he saw it and it was at  
22 this clinic that it was raised by Angus himself.

23 A. He was looking through his notes, as I say. You know,  
24 he -- at this point, well way before this, he didn't  
25 trust anybody and we used to have to lug his notes

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1 just showed Angus' personality, he actually had just  
2 come out of theatre and he flopped himself on Angus'  
3 bed and said, "I can't believe what I'm about to tell  
4 you", and he said, "Your operation has been  
5 cancelled", and Angus obviously asked why, and it was  
6 actually Mr Eric Lim, who was fabulous, he is a superb  
7 surgeon, and he said, "Angus, the management have  
8 deemed you at high risk".

9 So he said, "Okay, what, because of the  
10 hepatitis?" He said, "No, CJD, so I'm not allowed  
11 to operate on you here", and this was at the Royal  
12 Brompton Hospital.

13 Q. In your statement you had thought that it was the  
14 Royal Free where some of that had gone on and so the  
15 Inquiry put the statement to the Royal Free. We have  
16 had a response from Debra Pollard from the Royal Free  
17 Hospital in which she said it was not a decision of  
18 the Royal Free. It was a decision of the Royal  
19 Brompton and that is now being put to the Brompton  
20 Hospital.

21 But she's also provided an email in relation to  
22 this. It is 30940017 and it's the second page of it.  
23 The particular doctor involved in this has got their  
24 name redacted out at this stage because, of course, we  
25 have only just received the email and it needs to be

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1 around from department to department because he had so  
2 much going on and, yes, indeed, one day we were  
3 sitting -- it was actually in the waiting room,  
4 I think, and he was flicking through and he said, "Oh  
5 my God, the hepatitis is back. Nobody told me", until  
6 he read it.

7 Q. From the time of his transplant through to  
8 January 2012, which we'll come to in a moment, what  
9 was Angus' health like?

10 A. He really reacted well to the transplant, and he just  
11 always wanted to prove everybody wrong. He wanted to  
12 beat the record of being the person with a transplant  
13 that was going to get out the hospital the quickest,  
14 you know, and the physio would say, "Angus, climb one  
15 step of the stairs", and he would climb three. It was  
16 fabulous and he had a new lease of life. We thought  
17 that he would live to a lovely age.

18 Q. In January 2012 Angus was diagnosed with lung cancer.

19 A. Mmm.

20 Q. He was due to have surgery on 7 February 2012 to  
21 obtain a sample to see what was going on?

22 A. Mm-hm.

23 Q. What happened with that surgery?

24 A. Well, to cut to the chase, it was cancelled. The  
25 surgeon who actually became a very good friend, and it

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1 dealt with through the criticisms process, sir.

2 But the email to Dr Lim says this:

3 "Thank you for your recent email regarding  
4 yesterday's frozen section in this complex case."

5 That was the operation that Angus was due to  
6 have.

7 A. Mmm.

8 Q. "I completely understand and I'm sorry for the  
9 distress delaying this procedure has caused the  
10 patient. However, this situation is extremely unusual  
11 and outside the experience of our laboratory. Given  
12 the risks of infection to members of our staff  
13 associated with performing frozen sections, we had to  
14 ensure we made an informed decision as to whether or  
15 not we could perform a frozen section on this  
16 patient's tissue in our laboratory. The preliminary  
17 advice we obtained in the time available yesterday  
18 morning was that a frozen section should not be  
19 performed."

20 Further down:

21 "I understand the patient's status as at risk of  
22 vCJD has been provided by his Haemophilia Centre, and  
23 I presume this is as outlined in the 2010 HPA document  
24 re vCJD which categories patients having been treated  
25 with certain blood products between 1980 and 2001 as

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at risk of vCJD without further distinction."

Then the doctor goes on to suggest a different methodology, a different operation that could be done, a way of dealing with the samples that would be obtained.

Just before that email, there is also, on the first page of it, a note from Angus to Debra Pollard saying:

"I'm still having the operation next Tuesday", so it had been postponed. "I must say, Debra, I'm now finding the whole thing rather hard to swallow at the moment."

You've said in your statement that you and Angus were outraged.

**A.** Oh, we were completely disgusted. Angus not only, you know, was he infected with hepatitis C, at that time we didn't know if he had been infected by CJD and he was infected by the Department of Health, National Health, whoever, and they were not taking responsibility for their actions at all so, yes, we just couldn't believe what was happening. But the doctor fought and indeed Angus did get his operation.

**Q.** In relation to the vCJD, I want to just ask you a couple of questions about the documents in Angus' records that you're now aware of.

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the new form of CJD infects the lymphocytes, a type of white cells found in the blood, blood products don't contain white cells. That's not the issue, is it? The issue was whether blood products transfer whatever it is that is damaging the lymphocytes in the bloodstream.

**MS FRASER BUTLIN:** Precisely, sir.

**SIR BRIAN LANGSTAFF:** So it is not really answering the question that it was supposed to be answering, is it?

**MS FRASER BUTLIN:** That's one way of reading it, sir.

**SIR BRIAN LANGSTAFF:** I will be interested to know what other ways there are of reading it in due course.

**MS FRASER BUTLIN:** Sir, I was trying to be entirely neutral because it is obviously something we will need to investigate further.

**SIR BRIAN LANGSTAFF:** Yes.

**MS FRASER BUTLIN:** Then if we go to 1001026 we have a form that Angus has filled in in November 2004 where he said he does want confirmation of whether he received UK sourced plasma in person, he would like to know if he received an implicated batch, and he would not like a specific consultation to discuss the implications of the issue.

**A.** Can I just mention I think the reason why he didn't want an appointment was because it took forever and

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**A.** Mm-hm.

**Q.** It takes us back initially back to 1997, 1001024.

This was the letter that Angus got on 3 December 1997 from Professor Christine Lee, Dr Pasi, and Dr Perry indicating that:

"You may have heard or read about CJD and the concerns that the agent causing this may be transmitted by blood transfusion and blood products. At the present time there is no evidence for this. The basis for scientific speculation is that the new form of CJD, new variant CJD, infects the lymphocytes, a type of white cells which are found in the blood. Blood products used for the treatment of inherited bleeding disorders do not contain white cells.

"As a consequence of these concerns and as a precautionary measure there have been two recent recalls of BPL Factor VIII batches because it was found that a donor had not met the current health requirements for CJD. According to our records, you have never been treated with these batches."

Then it explains that the issues are complex and that they would ensure that further information would be provided.

**SIR BRIAN LANGSTAFF:** I don't for the moment understand the first paragraph because it seems to be saying that

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a day to get one and, you know, Angus was always on the phone or emailing. So specifically to me he wanted an immediate response to this. He wasn't prepared to wait for an appointment and, indeed, it follows later.

**Q.** So if we go to 1001027, the first page is an email from Angus to Professor Lee just checking that his forms had been received. The following page on 6 December 2004 we have an email from Christine Lee saying:

"I have not seen these forms", and on the same day, the following page, Paul, please, 6 December 2004 an appointment has been arranged for him to see her on 19 January despite him having said he did not want an appointment.

Then the following page, on 15 December 2004 -- so before the appointment -- he receives in writing confirmation that he had received UK sourced plasma and the following letter that he had not received an implicated batch.

So in 2004 the information that Angus had received was that he had not received an implicated batch and yet, as you say, in 2012 that was the reason why they postponed his operation.

**A.** Seems so.

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1 Q. Following the operation in February 2012 it was  
2 confirmed that the tumour in the lung was cancerous.  
3 A. Mm-hm.  
4 Q. Angus went on to develop secondary tumours.  
5 A. He did.  
6 Q. Can you tell us a little bit more of what happened to  
7 Angus.  
8 A. Yes. I mean, it was very invasive and very quick.  
9 Initially Angus had the lower lobe taken away from his  
10 left lung and obviously we hoped that the cancer  
11 hadn't seeded and spread. Indeed he was discharged  
12 from the Royal Brompton because his scans and  
13 everything seemed okay.  
14 Then it was some time after that he had  
15 a general scan on one of his check-ups and he had  
16 some shadows in his lungs and it wasn't just the  
17 left lung where he had previously had the cancer, it  
18 was in both, and it was very apparent that it was  
19 everywhere.  
20 Q. It had gone into his shoulder, his arm --  
21 A. Yes, it then extended to his hip and he had  
22 radiotherapy for his hip and his shoulder, indeed, he  
23 had a tumour that was literally the size of  
24 a grapefruit and you could literally see this growing  
25 every other day. It just got bigger and bigger and

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1 for Angus because they affected his eyesight.  
2 A. Yes, they did.  
3 Q. And he lost feeling in this fingertips.  
4 A. Yes, he lost -- they did say the duration of Angus  
5 having the chemotherapy that he would probably feel  
6 sensations of pins and needles and he'd feel the cold  
7 and certain drinks, that to be careful what he was  
8 drinking, cold liquids, et cetera, and that he would  
9 be supersensitive and that those may not go away those  
10 side effects and with Angus it didn't.  
11 You know, his sight really deteriorated and he  
12 lost the feeling in his finger tips which was really  
13 important to him as horologist. At that time, he  
14 wasn't working but it was a hobby that he liked to  
15 do. It kept him busy. He loved it. He devoted his  
16 life to studying and working to be horologist and  
17 when he was really unwell he would love to sit in  
18 his office and he'd had this lovely horologist work  
19 bench made and designed for him and it was a way --  
20 put the radio on and it was a way for him to just  
21 forget about what was happening and he couldn't do  
22 that anymore.  
23 Q. You have said that had a huge impact on his mental  
24 state as well.  
25 A. It did. He always, always, always tried to be

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1 also it affected the bone in his arm as well and it  
2 was just destroying and deteriorated all of the bone  
3 in his left arm.  
4 Q. You think he may well have had a brain tumour as well  
5 because of the headaches.  
6 A. He was complaining of headaches before he passed away,  
7 yes. You know, sort of five or six weeks before he  
8 passed, yes.  
9 Q. You have described that the physical pain Angus was in  
10 was horrendous.  
11 A. It was terrible. Angus didn't react very well to  
12 opiate medication and so he always, you know, refused  
13 that and he was sent to the pain clinic and he was  
14 prescribed other types of medication but it got to the  
15 point where it actually really didn't help.  
16 Q. He had some chemotherapy?  
17 A. He had chemotherapy, he had radiotherapy which was  
18 really invasive and brutal. He had burns actually  
19 where he had had the radiotherapy and it actually got  
20 rid of the tumour on his back and in his hip but he  
21 did go on a course of I think it was FOLFOX, actually,  
22 which at first seemed to -- it destroyed some of the  
23 tumours and stopped the growth of some of the others  
24 but it wasn't without him having side effects.  
25 Q. And those side effects were particularly devastating

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1 positive and when he went to the hospital it was an  
2 act, but as soon as we'd get in the car, we'd get home  
3 and he'd be in pieces about the situation, yes.  
4 Q. Angus deteriorated very significantly in October 2013  
5 with a gastrointestinal bleed. He wanted you to take  
6 a photo of him when he was near the end.  
7 A. He did. Yes, he never had any faith in any of the  
8 campaigns or inquiries. This is just Angus. He said  
9 nothing is ever going to happen, nothing seems to be  
10 ever happening, but if there ever is a chance that an  
11 inquiry will come out you need to record what's been  
12 happening. So we did. We took photographs of him all  
13 the time when he was in hospital with different  
14 treatments, operations, et cetera, and he did ask me  
15 to take a photograph, and it was ten days before he  
16 passed away.  
17 Q. If you feel comfortable, we'll show it. 1001018,  
18 please. This was taken ten days before he died.  
19 Angus died on 28 December 2013.  
20 A. He did.  
21 Q. Can you tell us something of the impact of Angus'  
22 death on you and the family?  
23 A. Well, very obviously it completely devastated us.  
24 None of us were expecting him to die so quickly and it  
25 was a shock to all of us, quite frankly, when he did.

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I don't know if any of us really accepted that he would die. There's always hope that some miracle again would happen.

You know, of course, it broke the family, especially the Stewart family. Their father died and Angus died and, of course, Mark was infected and my family were completely devastated. My father, who is a funny charismatic Scotsman didn't go out the house for about three weeks. We were really worried about him and he said he felt he'd lost his son. Well, he had.

When Angus died I just felt I had to be dignified and together to make sure that, you know, all of his -- he was very specific in his funeral arrangements and what he wanted and I wanted to make sure that that was carried out properly and then people were just breaking apart around me and I felt strong -- I felt I had to be strong for them so ... and I was still in shock and it didn't really affect me for some months afterwards.

Q. But then several months later it hit you.

A. Yes. I mean, I went back to my employment part-time at first in the March, probably far too quickly. Angus had passed away in the December. But I continued with my job and continued to succeed. In

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and so his friend said, "Of course, I will", and this gentleman was French descendant, but everybody who knows Angus will say to you he had the driest funniest sense of humour and I have to finish on something but it's also very sentimental to a point, so I'd written to our friend after the funeral and said, "Thank you very much for a fabulous eulogy", and Angus used to talk to him an awful lot about history, and he came from French lineage and Angus Scottish and they used to a joke about that quite a lot.

So anyway I thanked Christopher and he said, "Annette, I'm sure on reflection I could have done much better as there was plenty to say about Angus, but if you want, voilà, here you go". His eulogy read, you know:

"Angus was charismatic, indomitable, courageous, witty, intelligent, determined, canny and much besides. The mark of a man. As a haemophiliac, he suffered from a disease that was compounded by the tainted blood which gave him hepatitis C (or hep C as he described it), then liver cancer, lung cancer and bone cancer. Most human beings with afflictions of this sort would have been broken psychologically long before the diseases overcame them but not so with Angus. He

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fact, I had to throw myself into that and, of course, I was the breadwinner then and I had to keep our lovely home. It was expensive. We bought it together, and it was just me on my own. I wanted to keep everything together and I was seemingly doing so and then I think my mind was on autopilot and my body just gave in and I suffered skin conditions, et cetera, and it really then started to take its toll.

Q. And you gave up your own job?

A. I did in 2016 and I was executive vice president of a Public Limited Company and it was a huge role. I had been with the business for 17 years and nothing really mattered anymore. I just wanted to find a different way of coping with life and, you know, the day-to-day dramas, silly dramas of a business really didn't fulfil anymore. And so I decided to hand in my notice.

Q. Before I ask you if there's anything else you want to say I am just going to turn and ask Mr Collins.

Is there anything else you would like to say?

A. Well, I'm going to try and read something just to, you know, talk about Angus and the person he was really. One of -- Angus actually asked one of his friends if he would write his eulogy. Angus prepared his funeral

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never surrendered. Despite the frequency of invasive medical treatments and pain and suffering, he remained hopeful. He fought the illnesses all the way, buoyed up by massive strength and incredible spirit and the support and love of Annette and his family."

He then says:

"I'm told his forebearers were the Stewarts of Appin, a band of Scottish clansmen celebrated for their fighting instincts and their physical prowess. He was a big man and larger than life itself."

Christopher says:

"May I read you an email that he sent me back in August last year, which shows his humour despite the gravity of his situation. Just in case you wonder, he is alluding to my French origins.

"Yes, fella, I'm full of chemo. They usually only give 85 per cent doses to we challenged patients but I told them I could handle the full 100 per cent again. It's tough but it's got to be done. Just mad Jock juice in these veins. See you soon, my small French ally."

And then he goes on to talk about lots of historic things and he says:

"You learn something useless everyday, right?"

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1 Then Christopher says:  
 2 "I met Angus when he worked for the company he  
 3 worked for. He was a horologist and a metrologist  
 4 of repute, writing papers for the BSI standards and  
 5 for the EEC. Angus had a huge zest for life. He  
 6 loved good cuisine, conversation and travel. And he  
 7 and Annette embarked every three months on exotic  
 8 locations all over the globe, and he especially  
 9 enjoyed Hong Kong and admired the Chinese culture  
 10 and lifestyle.  
 11 "In September last year, he emailed me about  
 12 his situation. 'Hi, Christopher. We saw the  
 13 oncologist and the liver consultant today. There is  
 14 no cure for this type of cancer. They are going to  
 15 start radiation treatment to reduce the bone tumour  
 16 in my shoulder. This are then going to start me on  
 17 a chemo that will try and stop or at least slow the  
 18 spread of the cancer. We are positive that at least  
 19 this gives us some more time together. Christopher,  
 20 you have been a good friend and I just want you to  
 21 know that. I hope to see you again as I will keep  
 22 fighting until the end'."  
 23 And then he read lovely poem, which I don't  
 24 think I can bring myself to read at this moment.  
 25 But what I have to say is very short and sweet.

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1 have been at times particularly difficult for you.  
 2 Thank you very much indeed for giving your evidence.  
 3 A. Thank you.  
 4 **SIR BRIAN LANGSTAFF:** We will take a break until 3.40 when  
 5 we will hear from Baroness Campbell.  
 6 (3.19 pm)  
 7 (A short break)  
 8 (3.45 pm)  
 9 **SIR BRIAN LANGSTAFF:** Our final witness of the day is the  
 10 Baroness. How would she like to be known?  
 11 **MS RICHARDS:** Jane.  
 12 **BARONESS JANE CAMPBELL, sworn**  
 13 **Questioned by MS RICHARDS**  
 14 Q. Jane, you are a campaigner and adviser in relation to  
 15 disability rights.  
 16 A. Yes, that's correct.  
 17 Q. We'll touch on that towards the end of your evidence  
 18 but you're here not primarily in that capacity but to  
 19 talk about your late husband Graham Armstrong  
 20 Ingleson.  
 21 A. Yes.  
 22 Q. Graham died as a result of AIDS in 1993.  
 23 A. That's right.  
 24 Q. Graham had severe haemophilia A but he was a very  
 25 active young man and that resulted in him having to

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1 I have numerous questions, especially as I now fully  
 2 believe that Angus was patient number 19 on  
 3 a clinical research paper, as just evidenced by his  
 4 brother Mark Stewart. Angus was given a product in  
 5 the 1980s already deemed unsafe. Indeed,  
 6 100 per cent of patients apparently would be  
 7 infected. The clinicians knew this. I call this  
 8 manslaughter.  
 9 The pharmaceutical companies who manufactured  
 10 the blood products were greedy and humane, we know  
 11 that, but the ministers, the Department of Health  
 12 and the clinicians who continued to purchase and use  
 13 contaminated blood products when they knew they were  
 14 infected must be held accountable and fully  
 15 investigated.  
 16 These departments and people had a duty to  
 17 assist the sick. Instead, in my view, they killed  
 18 them.  
 19 For decades, a web of lies and deceit has been  
 20 spun. We do not want lame apologies or excuses. We  
 21 want the truth, we deserve the truth, and we need  
 22 justice.  
 23 **SIR BRIAN LANGSTAFF:** You have given your evidence in  
 24 a very calm and measured way but I suspect that masks  
 25 a very real and deep and raw feeling, and so it must

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1 take a lot of Factor VIII products.  
 2 A. Yes, he was impossible. Anything that he shouldn't  
 3 have done, he did from a child all the time that we  
 4 were together, climbing trees, going up ladders, climb  
 5 roofs, anything to prove that he was -- probably to  
 6 prove that he was not a disabled person.  
 7 Q. How did you and Graham meet?  
 8 A. We met at Hereward College. We were both 16, just  
 9 over 16. This was a college that was built for  
 10 disabled people who got resident there while being  
 11 educated in segregated special schools and at that  
 12 time if you were a disabled person and you went to  
 13 a special school, you basically did basket weaving,  
 14 rudimentary mathematics, what I would call a primary  
 15 school education until the age of 16.  
 16 And, unfortunately, many of the kids there  
 17 were very bright, very able and very capable of  
 18 doing anything that any non-disabled person can do  
 19 but because you were a disabled person you were  
 20 treated differently and often less favourably.  
 21 So at the time, in the early '70s, the  
 22 education authorities decided that maybe it was  
 23 a bit not very good that they weren't teaching  
 24 a curriculum to disabled children in these schools.  
 25 So a special school, a special college was built so

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1 that children who had languished in these schools  
2 could get a proper education.

3 It was expensive but I was lucky to get  
4 a bursary to go there from my local authority and  
5 Graham was also. He was at a special school in  
6 Yorkshire and I was in a special school in Surrey and  
7 we both went to college at the same time and we were  
8 young, we were so hungry for knowledge and we were  
9 so hungry for a life outside the very cocooned  
10 environment of a special school that, well, we went  
11 a bit mad really. We just did everything and had  
12 just a wonderful time for three years.

13 Q. You went out together for three years but you went --

14 A. Not for three years. We probably went out together  
15 towards the first or the second year really and I was,  
16 you know, I was a bit shy and he didn't want to go out  
17 with a girlfriend in a wheelchair so it was, you know,  
18 we were just finding ourselves as young people and  
19 eventually we got together in the second year and we  
20 had tremendous fun. He was a pretty much able bodied  
21 and I wanted an able bodied boyfriend and I had my eye  
22 on him and, yes, he was my freedom.

23 Q. You then went off to university.

24 A. Yes.

25 Q. But you got together, you and Graham, a while later

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1 We were lucky to get a council house that was  
2 on the ground floor and, of course, after being at  
3 university and away for quite a number of years,  
4 I couldn't wait to get away from Mum and Dad.  
5 I didn't want to go and live back at home and he and  
6 I were desperate to have our own place and to build  
7 a life together.

8 He had to provide all my own care because,  
9 frankly, there wasn't anything out there. It was  
10 either home care that came in when they kind of can  
11 fit you in in the morning and put you to bed at  
12 6 o'clock and getting in my pyjamas at 6.00 wasn't  
13 much of a life. So he basically said, "Well, babe,  
14 it won't be a problem for us. You're as light as  
15 a feather and I'm fit, so let's get on with it".

16 Although he wasn't that fit because he had  
17 a lot of bleeds as a result of being quite a severe  
18 haemophiliac but he would just, as he put it, jack  
19 up every morning, so that would prevent his bleeds  
20 and so he needed that Factor VIII to lead a normal  
21 life, otherwise he would have definitely had to use  
22 a wheelchair because both knees would swell up and  
23 it was so, so painful. It was excruciating so to  
24 compensate for that or to avoid that he used to take  
25 Factor VIII quite a lot.

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1 when you met again at a party in London.

2 A. That's right. We decided after we left, I left with A  
3 levels and he left with A levels, he went on to do an  
4 engineering course in Yorkshire and I went to  
5 university in Hertfordshire and we were quite mature  
6 really for that age, but we decided that we needed to  
7 go and find ourselves further in the outside world.  
8 We'd never been amongst the open community, as it  
9 were. So we parted, which was the right thing to do,  
10 and I had a few boyfriends and he had a few  
11 girlfriends. We sort of parted but we always kept in  
12 touch. Yes, it was about four and a half years later  
13 that we kind of got back together again.

14 Q. You began a relationship again. You moved in  
15 together.

16 A. Yes.

17 Q. Graham provided all of your care?

18 A. He did, yes.

19 Q. And he was a very talented craftsman, so he also did  
20 a lot of refurbishment in your new home.

21 A. Yes. Again, you have got to go back in time and  
22 understand what it was like to be a disabled person in  
23 the sort of late '70s/mid-80s. There weren't any  
24 facilities for us. You could hardly get in a cinema  
25 or shop let alone find a house or bungalow.

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1 Q. Do you know whether Graham was ever given any advice  
2 or warning or information about any risk of infection  
3 with a virus?

4 A. No, not until a lot, lot later. He was actually  
5 encouraged to use Factor VIII prophylactically because  
6 it enabled him to seek and gain employment as  
7 a heating engineer and if you're a heating engineer  
8 you really shouldn't have haemophilia. But that, as  
9 I say, was definitely not going to stop him. He lived  
10 life to the full.

11 Q. In 1985, I think your first statement had thought 1987  
12 but we have been able to look back at Graham's  
13 records.

14 A. It was such a long time ago.

15 Q. Absolutely.

16 A. And, of course -- well, I can say loads of things if  
17 you like but I chose to put a lot of it out of my  
18 mind.

19 Q. In March 1985, Graham's medical records or the records  
20 that are left show that he was tested for HTLV3 and  
21 that test was positive.

22 A. Yes.

23 Q. And he was informed of this looking at his medical  
24 records some time in June of 1985.

25 A. Yes, that was the first time.

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1 Q. What you have said is that at that time you and Graham  
2 didn't really understand the seriousness of the  
3 diagnosis.  
4 A. Honestly, I mean, looking back in hindsight is  
5 a wonderful thing but when you are living in that  
6 moment and you've had such a protected life and people  
7 have always looked after you and always told you what  
8 was best for you and, unfortunately, that's what it  
9 was like for disabled people, and they told you what  
10 was best for you, they told you what they thought you  
11 should know and what they thought you shouldn't and so  
12 when Graham had the first result -- and I was with  
13 him -- they just said, "Oh, you have tested positive,  
14 your test was positive and it's nothing to worry  
15 about". I remember distinctly. He said, "It's  
16 nothing to worry about because it's not the same kind  
17 of AIDS that you're hearing about on the news. It's  
18 different for haemophiliacs". I do remember that  
19 distinctly.  
20 So we kind of said, "Oh, well that's good  
21 because we're going to get married soon and, you  
22 know, it will be fine", and they said, "We'll call  
23 you back if we have any other news", and they didn't  
24 call us back and we kind of got on with it.  
25 To be honest, maybe we put our heads in the

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1 and he was a really, really interesting and lovely man  
2 and he, I remember later him saying to me, you know,  
3 "They're killing my boys. I can't believe this.  
4 I told them. I told them". He was very, very  
5 distressed about what was happening to what he said  
6 were his boys.  
7 Q. You and Graham got on with your lives and you say  
8 this, in the same way that we had always minimised our  
9 disabilities you got on and tried to have a normal  
10 life.  
11 A. Yes. I mean, that's what we were all about. I think  
12 you have to understand the psychology of disabled  
13 people at that time. We were trying to prove to the  
14 world that we weren't other people, that we weren't --  
15 that we were capable, that we were just ordinary  
16 normal human beings and the stigma made disabled  
17 people hide everything. We hid our impairments, we  
18 hid our difficulties to everyone so that we could get  
19 a job or so that we would be allowed in a pub because  
20 at that time it was still lawful for people to -- for  
21 publicans or restaurant owners to say, "You can't come  
22 in here. You are disabled. I don't have the  
23 facilities for you".  
24 That was ingrained deep inside our psyche, so  
25 we were quite -- we -- sorry, we were rebelling

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1 sand but we were just so keen on getting on with  
2 life and being together and building this home and  
3 doing all the things that we'd been prevented from  
4 doing for so many years. We were quite similar.  
5 Q. You have said in your statement that you and Graham  
6 didn't make the link to the AIDS virus that you would  
7 read about in the press because that was primarily  
8 discussed in terms of affecting the gay community.  
9 A. That's right. Again, you know, I know so much more  
10 now, I'm such a different person now. I often can't  
11 believe that I didn't realise that that was  
12 ridiculous. But I suppose I just believed the medical  
13 profession. They said he'd be all right so he would  
14 be all right.  
15 Q. Graham's consultant at the time was Dr Savage --  
16 A. Yes.  
17 Q. -- at St Thomas'.  
18 A. That's right.  
19 Q. They had a good relationship and Graham reposed great  
20 trust in him?  
21 A. Yes, he was as crazy as Graham. He was mad. He  
22 really lived up to his name. I remember Graham  
23 laughing and joking because he used to come in in  
24 a white coat with blood all over it because he thought  
25 that would be a really good joke for the haemophiliacs

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1 against our stigma. So, yes, everything was  
2 minimised and even as a haemophiliac and a person  
3 who went through enormous excruciating pain when he  
4 had bleeds, he would just get on with it and he  
5 would never complain and that was the way that we  
6 lived our lives. Don't take any notice of your pain  
7 or your illnesses, just concentrate on living.  
8 Q. You got married in June of 1987.  
9 A. We did.  
10 Q. But some time in around that time in 1987 Graham was  
11 asked to attend a further appointment at St Thomas'.  
12 What can you recall about that?  
13 A. It was terrible really because it was -- I don't know  
14 how many months before we were married. It seems like  
15 it wasn't long because two very bad things happened to  
16 me within a space of a few months.  
17 First, Graham was told for the second time  
18 about his diagnosis and my father was later killed  
19 in a car accident and we were about to get married  
20 and it was all within that year. I remember that --  
21 I remember thinking, "No, this is meant to be the  
22 happiest day of my life and it's all going a bit  
23 wrong", so we went for the second appointment. We  
24 were recalled and it was a long time after we'd had  
25 the original test results and they called us in, and

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1 it wasn't Dr Savage, and we were taken into this  
2 room and there was a pot plant and a box of tissues  
3 and a new doctor and a nurse who later became our  
4 friend.

5 He said, "I've called you in because I'm  
6 reviewing all the -- all our haemophiliacs who have  
7 contaminated -- who have got contaminated through  
8 the Factor VIII product", and he then went through  
9 it and it was almost -- it was almost unbearable to  
10 hear.

11 He told Graham very calmly, very -- which  
12 seemed at the time, which I'm sure it was the only  
13 way that he could deal with the situation, but very  
14 coldly, very professionally, what he had, that it  
15 wasn't different to any other AIDS, that it was  
16 exactly -- although HIV, that it was exactly the  
17 same and he told Graham that he would probably get  
18 quite ill, that he would get chest infections and he  
19 would have other complaints that they did not yet  
20 know what they would be but they would come.

21 But that there was a drug that they were  
22 trialling and that they wanted to put Graham on it,  
23 and he told Graham all the side effects, and I just  
24 remember feeling the room was getting smaller and  
25 smaller, and then Graham asked one question, I know

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1 live, so we -- I mean -- Annette earlier was  
2 speaking and I'm sorry, Annette, if you are still  
3 here but I left because I couldn't really hear your  
4 story because it was too much but I wish I'd had  
5 Annette's fortitude to ask more questions and get  
6 more information or even thought to ask the  
7 questions that, of course, I would as an adult now,  
8 but things were so different then.

9 So, no, hepatitis was not part of our thinking  
10 or questioning. We were just trying to deal with  
11 the enormity of HIV and what that meant and, of  
12 course, at the time we'd still tried to tell  
13 ourselves that there would be a cure and he would be  
14 fine.

15 I don't think either of us could really quite  
16 take in the enormity of what the doctor said that  
17 day. It took a long time. Actually when we left  
18 the hospital, we didn't speak. We couldn't speak  
19 about it for a long time and probably never  
20 properly.

21 Q. Graham did start AZT.

22 A. Yes.

23 Q. And the side effects he experienced were so bad that  
24 he often considered coming off it.

25 A. Yes. I don't know other people's experience but AZT

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1 he only asked one question because he couldn't -- he  
2 didn't speak through the whole thing and he just  
3 said, "Am I going to die?" The doctor said yes.  
4 We left and nothing was the same.

5 Q. In terms of practical advice or support at that time,  
6 you said in your statement that the advice that was  
7 given was that Graham could approach the Haemophilia  
8 Society, that you should use protection during sex and  
9 to keep away from open wounds and, other than that and  
10 a discussion about the drug, which was AZT, there  
11 wasn't very much else in terms of any practical  
12 assistance or support.

13 A. There was nothing. There was nothing.

14 Q. At some stage, and we don't have sufficient records to  
15 identify when but at some stage later Graham was told  
16 by a doctor that he's also been infected with  
17 hepatitis C.

18 A. Yes. I mean, that was like -- when that was told to  
19 us, if it was told to us, I honestly can't remember,  
20 it was certainly not something that they sat down and  
21 went through with us, we didn't even know what  
22 hepatitis C was.

23 You have to remember we were so young, not  
24 just in age but in experience. We'd been cocooned  
25 for so many years. We were only just beginning to

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1 was a disgusting drug. He used to throw up a lot,  
2 practically every day. He would feel desperately  
3 tired. To continue as a heating engineer became  
4 harder and harder as the months went by and sometimes  
5 I'd think if the HIV virus didn't kill him, then AZT  
6 probably contributed to that because he was never well  
7 after taking it and, in a way, again hindsight if he  
8 knew what he knew now he probably wouldn't have taken  
9 it because it made his last few years, the quality of  
10 life for him after AZT was absolutely atrocious and he  
11 was such a well person beforehand. You know, he was  
12 a big hunky Yorkshireman. You know he used to go and  
13 work with his Dad on the grocery stall and on the farm  
14 before that.

15 After AZT he completely changed.

16 Q. You've described in your statement how over the years  
17 that followed physically he became more tired,  
18 frailer, thinner. When you married he was 14 stone  
19 and strong and he used to be able to hold you in the  
20 air with one hand.

21 A. Yes, he would throw me in the air. He would pick me  
22 up out my wheelchair and, you know, we'd dance round  
23 the room. It was, as I said, he was my freedom. He  
24 was like a big bear. It was just horrible watching  
25 it, horrible.

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1 Q. He lost over half his body weight in the years that  
2 followed?  
3 A. He did, yes.  
4 Q. The effect on him mentally and psychologically, what  
5 was that?  
6 A. He completely changed. He was completely without fear  
7 as I knew him before when we were courting, that he  
8 used to go courting. He was very fun-loving. He  
9 adored his family. Everybody loved him. It was quite  
10 annoying sometimes that everyone loved him and they  
11 were like, "Stop nagging him, Jane. He's too lovely",  
12 and he was just great and I was kind of like  
13 fiercely into my work and career.  
14 We both campaigned for disability rights  
15 together. He was just a huge man from Yorkshire.  
16 He had the most beautiful Yorkshire accent. We used  
17 to go up on the moors in Yorkshire. It was a life,  
18 it was a dream life for somebody who'd been in  
19 a wheelchair and not really gone anywhere or done  
20 anything, with him and the two of us together. As  
21 he used to say, "Yours brains and my brawn, we can  
22 do anything". Then just, it all changed.  
23 Q. He lost what you have described as his positive and  
24 sunny outlook.  
25 A. Yes.

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1 deteriorating at the same time. But I knew we had --  
2 I had to work because we didn't have any money. We  
3 were actually quite poor.  
4 Q. He became too unwell to continue being the provider of  
5 your care.  
6 A. Yes.  
7 Q. But you found it hard to find carers to come in and  
8 assist you in part because of the stigma of AIDS and  
9 you didn't know whether to tell people or not.  
10 A. That's right. I mean, I remember the nurse who  
11 supported us, a really good woman called Chris  
12 Harrington, she said, "You don't have to tell anyone,  
13 you know. They are not going to hurt themselves as  
14 long as they, you know, they just look after you".  
15 I don't know if I put it in my statement but  
16 I was also tested and I was tested to be -- to not  
17 have -- I was negative. Of course, when we realised  
18 the second time that it was real, the real McCoy,  
19 then that killed our marriage too.  
20 So I don't deny it would have been any danger  
21 to them but I didn't know if I should or shouldn't.  
22 I felt that they would find out sooner or later. So  
23 I chose to tell people and mostly they didn't want  
24 to work for us. But not only that carers, statutory  
25 carers at that time, wouldn't come at the time you

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1 Q. He became depressed and he became terribly worried  
2 about what would happen to you.  
3 A. Yes, that was the hardest part I think that, you know,  
4 we were just about to get married and we were so close  
5 and that one injection or however many it was that  
6 contaminated us, it contaminated our marriage, it  
7 contaminated our relationship, it contaminated  
8 everything we touched and also we couldn't tell  
9 anybody. That was the worst. I couldn't even tell my  
10 Dad.  
11 Q. Slowly Graham was able to work less and less and you  
12 became the breadwinner and that dependence financially  
13 on you was hard for him because you say he was a proud  
14 Yorkshireman and it was crushing for him?  
15 A. It really was. I tried to not let him feel that way  
16 and, you know, and I'd always tell him that I couldn't  
17 do any of this without him. I tried to make life as  
18 nice and comfortable for him as possible but it was  
19 really hard to work and also, you know, I was --  
20 I have a progressive impairment so I was getting  
21 weaker just because of my disability, as part of my  
22 condition. So when we first knew each other I could  
23 cook and I could wash up and he would just be the one  
24 to pick me up and put me to bed. He didn't have to do  
25 that much but as his condition degenerated, mine was

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1 needed them in order for me to go to work, so I had  
2 to find people to -- that I could pay myself  
3 personally out of my salary to come in to assist me  
4 and that's why I decided to campaign for community  
5 care direct payments because there were disabled  
6 people all over the country who were having to do  
7 what the services told them, which was preventing  
8 them from having employment, and I have been  
9 campaigning on this for some time and that  
10 fortuitously came into force towards the kind of end  
11 of Graham's life and I was able to have some money  
12 from the Social Services to employ my own PAs.  
13 But it was really hard so we had actually very  
14 little support and Graham would struggle to help me  
15 and I would struggle to help him. We struggled on  
16 together really. It was hard.  
17 Q. Sometimes --  
18 A. Can I have a drink.  
19 Sorry, I don't normally cry.  
20 Q. Sometimes, you have said in your statement, Graham  
21 would be too unwell even to make a cup of tea.  
22 A. Yes.  
23 Q. You were unable to and the two of you might sit there  
24 for hours without a drink.  
25 A. Yes. It was really tough.

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- 1 Q. When you did have people coming in to assist,  
2 particularly as Graham himself grew iller, there was  
3 the additional difficulty of there being strangers in  
4 and out of the house for Graham. Sometimes he  
5 couldn't find his way to the door to open the door as  
6 he would intermittently lose his sight.
- 7 A. That was the darkest time of our life. Yes, and I've  
8 only got one Mum who was getting older and I didn't  
9 want to burden her, and my sister was travelling all  
10 over the world so it was -- I think it was the  
11 loneliest time of my life. Yes, it was very, very  
12 lonely. It was -- and I was getting angry as well and  
13 I wasn't coping very well at that time. It had been  
14 about three years so, you know, weeks of that it wears  
15 you down.
- 16 Q. Graham's health continued to deteriorate. He got  
17 regular chest investigations which would sometimes  
18 lead to pneumonia?
- 19 A. Yes.
- 20 Q. Seizures, constant vomiting and headaches?
- 21 A. Yes.
- 22 Q. And you have described in your statement that he had  
23 a series of lengthy hospital admissions in St Thomas'.
- 24 A. Yes.
- 25 Q. On one occasion he had sepsis and you thought he was

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- 1 Q. And fewer and fewer people came to visit him when it  
2 became known he had AIDS?
- 3 A. Yes.
- 4 Q. Although one of his best friends or his best friend  
5 was there as a friend to the end.
- 6 A. Oh, he was wonderful. He was a wonderful man -- he is  
7 a wonderful man. He is also a haemophiliac and he had  
8 known Graham since they were at college together.  
9 They were both mad and crazy and they were very, very  
10 close and he luckily didn't get contaminated because  
11 as he used to say, "I've got pig's blood in me. I'm  
12 never going to get your disease". He used to tease  
13 Graham about it. They lived together, actually, as  
14 flat mates when Graham came down to live in London and  
15 he was a tonic to Graham and they were able to talk in  
16 the way I couldn't talk to Graham.
- 17 Q. Graham had a brother, Anthony.
- 18 A. Yes.
- 19 Q. Anthony was also a haemophiliac and Anthony was also  
20 infected with HIV through the use of Factor VIII  
21 products.
- 22 A. Yes.
- 23 Q. Can you tell us what happened to Anthony and how that  
24 affected Graham.
- 25 A. Anthony must have -- I don't know whether he was

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- 1 going to die.
- 2 A. Yes, he was covered in tin foil and I was called by  
3 the hospital. Luckily, I worked in County Hall.  
4 I worked for the GLC at that time or was it Camden?  
5 I might have been at Camden by then. I was working in  
6 local government as an equality trainer and adviser,  
7 and I was called at work and then I had to try and get  
8 a cab to the hospital and then I'd be at the hospital  
9 and that day I didn't know whether he was going to  
10 live or die. I didn't have anyone with me.  
11 I couldn't get in touch with my family.
- 12 Q. Graham was discharged home on that occasion after ten  
13 days in what you have described as a desperately weak  
14 state. You explained to staff that you weren't able  
15 to look after him on your own because of your own  
16 disability and you've said nobody seemed to care that  
17 we were both severely disabled and in need of help.
- 18 A. It was extraordinary when I think about it now. I'm  
19 sure that wouldn't happen now but at that time it  
20 seemed to be common. You know they thought that  
21 some -- I must have people looking after us. They  
22 wouldn't believe me.
- 23 Q. The last four months of his life Graham was confined  
24 to bed.
- 25 A. Yes.

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- 1 infected earlier than Graham. He went to another  
2 hospital. It's the hospital where I believe that  
3 Graham might have got infected, because Graham had  
4 a car accident when he was visiting them, going too  
5 fast of course because he was like that, and he ended  
6 up in Newcastle infirmary. I haven't the evidence but  
7 I have a strong feeling that's where it started.  
8 I don't think we are going to get any evidence at the  
9 hospitals. I did try to get far more evidence when  
10 all the inquiries started but stupidly after Graham  
11 died I binned it all because I was so angry I just  
12 wanted to get shot of everything and anything that  
13 reminded me of that time, which I regret so much now.
- 14 Q. Anthony had also been treated there.
- 15 A. Anthony had been treated in Newcastle Infirmary and he  
16 was younger than Graham. He was the baby boy and he'd  
17 just got married a year or two earlier and he had  
18 a little girl, just about that time he had a little  
19 girl when it became known that he had also been  
20 infected and he started getting ill before Graham.
- 21 So they both did the same. They both tried to  
22 ignore it, but when they couldn't ignore it any  
23 longer they started talking to each other and  
24 I remember Graham saying to me that it was  
25 unbearable watching -- not only watching his brother

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1 die but he was watching his future, and that was  
 2 a terrible thing. It affected him very badly.  
 3 Q. The family told people that Anthony had cancer because  
 4 of the stigma of AIDS?  
 5 A. Yes. You know, they lived in this small Yorkshire  
 6 village and at that time it was awful and a lot of  
 7 haemophiliacs were getting tanned -- you know, were  
 8 getting hate mail -- and people were being really very  
 9 nasty towards them and the stigma was worse than being  
 10 disabled, so it was a bit of a double whammy really.  
 11 So they decided that they would say that he  
 12 had cancer and they almost believed it themselves.  
 13 I mean, his mother really could not cope. It was  
 14 her two young sons and I know that it affected the  
 15 whole family very, very deeply.  
 16 Q. You and Graham went to Yorkshire to visit Anthony when  
 17 he was very ill and the brothers were able to spend  
 18 some time together talking.  
 19 A. Yes.  
 20 Q. When Anthony died about a year before Graham you said  
 21 the funeral was particularly hard for Graham as he was  
 22 watching his future.  
 23 A. Yes. By that time he was pretty ill. We had  
 24 a wonderful man who came to drive me to work and he  
 25 became very close to us and he took Graham up to see

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1 Q. He was 34 years old. You've said in your statement:  
 2 "We enjoyed five years of torture at such  
 3 a young age. No-one can imagine what that does to  
 4 your spirit and mental health and it was so much worse  
 5 for Graham who bore it so bravely and with such  
 6 grace."  
 7 A. Yes. He was like what people would say, I suppose, he  
 8 was the model patient. He never complained and he  
 9 suffered in silence. The thing is there was so much  
 10 silence it was unbearable.  
 11 He was so, so courageous I can't tell you how  
 12 courageous he was in light of the most terrible  
 13 things happening to him and knowing he said, "You  
 14 know, Jane, it's a cover-up. You know that this  
 15 shouldn't have happened". He knew, he knew that his  
 16 life would have taken another course had he not had  
 17 the Factor VIII.  
 18 Q. You had had very little by way of practical support  
 19 over those years. The two professionals you've  
 20 identified in your statement and you wanted to mention  
 21 were your GP who you said was a fantastic support.  
 22 A. Judy Munby. She was absolutely brilliant and she  
 23 supported us at home because the one thing that Graham  
 24 did not want and I promised it would never happen, he  
 25 did not want to go into hospital and he did not want

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1 his family. I paid for my driver to drive Graham  
 2 around at the end because otherwise he just wouldn't  
 3 be able to get out the house, so it was all -- I had  
 4 to work harder because -- and more, to pay for all the  
 5 extra things I wanted Graham to have at the end of his  
 6 life, although by that time we had been given what  
 7 they call an *ex gratia* payment from the Government  
 8 which I was so furious about, because I personally,  
 9 being in the business of equality and justice, wanted  
 10 to fight for his rights in court.  
 11 We did start proceedings but he was getting  
 12 worse and worse and they were -- we were being told  
 13 that if we accepted the money we wouldn't be able to  
 14 continue with any court case and we had to sign  
 15 something to say that we wouldn't take it to court.  
 16 So we thought about this for a long time and I said,  
 17 you know, to Graham, "You know, it must be your  
 18 choice. It's your life", and he said, "Well, Love,  
 19 we need the money", so we took the money.  
 20 But it felt like blood money.  
 21 Q. That's what you and Graham called it, I think: blood  
 22 money?  
 23 A. It's not anything else, is it?  
 24 Q. Graham died on 19 December 1993.  
 25 A. Yes.

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1 to die in hospital and she enabled us to get through  
 2 those last few months without having to go to  
 3 hospital. She was amazing, and Chris Harrington who,  
 4 goodness, if it wasn't for her I don't really know how  
 5 we would have survived.  
 6 Q. She stayed with you during the 24 hours in which  
 7 Graham died.  
 8 A. She did. She was -- she and I were just together and,  
 9 yes, I really can't talk about that time.  
 10 Q. After Graham's death, you began to experience panic  
 11 attacks and you were diagnosed after a while with post  
 12 traumatic stress.  
 13 A. Yes, that's what the panic attacks were. Funnily  
 14 enough, I went back to work and I just behaved as if  
 15 nothing had happened because that's what you do, you  
 16 know, especially as disabled people you swallow the  
 17 rubbish and you carry on.  
 18 I remember I was about to give a big speech to  
 19 disabled people at a rally in Trafalgar square, so  
 20 it was a huge audience of hundreds and it was  
 21 something that I could easily do when I was  
 22 campaigning on behalf of rights of disabled people,  
 23 so I was about to go on the stage and suddenly  
 24 I thought I was going to die. My heart just kept  
 25 pounding and it's like I couldn't breathe and I was

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1 so afraid. I didn't know what I was afraid of  
 2 because it was only a speech I've done hundreds of  
 3 them. And so I just shot off in my electric  
 4 wheelchair and hid. I hid behind the car.  
 5 Someone came to find me and I was just  
 6 a complete crazy woman, just crying and couldn't  
 7 stop crying and I was so afraid, I was shaking.  
 8 That was the first one. They came fast and furious.  
 9 Q. You had to take in the end some 18 months or so off  
 10 work?  
 11 A. Yes.  
 12 Q. You were living on your own deeply depressed and  
 13 financially very poor.  
 14 A. Yes. Although my Mum and sitter were great. They  
 15 helped me as much as they could.  
 16 Q. You have said in your statement you felt scared, you  
 17 couldn't sleep, you felt unable to leave the house and  
 18 it was ultimately the support of your Mum and sister  
 19 who helped you through that darkness?  
 20 A. Yes, and my friends and one particular person.  
 21 Q. You were eventually able to return to your work and  
 22 continue your career.  
 23 A. Yes.  
 24 Q. A number of years after Graham's death you remarried?  
 25 A. Yes.

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1 A. Yes.  
 2 Q. One was in relation to the Macfarlane Trust and the  
 3 position of women who were the wives and partners of  
 4 haemophiliacs who gave up work to care for their  
 5 husbands or partners were often widowed weren't  
 6 recognised by the Macfarlane Trust. What would you  
 7 like to say about that?  
 8 A. Well, I'd like to say in relation to women I'd like to  
 9 talk about that first and it struck me, actually, when  
 10 I came today it's the first time that I've heard  
 11 a woman, partner, wife, of a haemophiliac or somebody  
 12 who was infected, that's why I couldn't stay and  
 13 listen to all of it because I thought it was just --  
 14 it was touching upon so much of my own experience and  
 15 I'm sorry for that because I wanted to be here because  
 16 I wanted to hear it but I knew I was going to be  
 17 giving my own evidence and I didn't want to start  
 18 a wreck, even though I'm probably ending up one.  
 19 But what you have to understand is that as  
 20 a disabled person you are treated less favourably.  
 21 If you are a woman and you're a disabled person, you  
 22 are dealing with a double discrimination because  
 23 women are in my view and were, certainly at that  
 24 time, treated differently to that of the men. So  
 25 I was just seen as the supporter and the carer and,

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1 Q. And you've said that you know that Graham would be  
 2 happy for you on both counts.  
 3 A. Yes. I mean, I'm so lucky. I don't normally cry.  
 4 I'm normally a very jolly person. I feel although it  
 5 was a terrible, terrible thing to do and I have lots  
 6 of regrets and lots of things I wish I'd done and  
 7 I still have times when I -- well, this Inquiry hasn't  
 8 been the greatest but it's been the best, which sounds  
 9 ridiculous but I so want the truth because I believe  
 10 that if we have the truth then I won't feel like this.  
 11 Goodness, it was 30 years ago but I still  
 12 can't talk about Graham without going into this  
 13 squeaky voice and all these tears coming out my eyes  
 14 and feeling that goodness I hope no-one at work sees  
 15 this because I'm not this kind of person. I'm  
 16 normally very composed and I'm very bloody-minded.  
 17 You have to be in the House of Lords, for God's  
 18 sake. I'm dealing with Brexit!  
 19 But honestly that's nothing to what that time  
 20 was. It was so dark, it was so horrible and he was  
 21 so brave.  
 22 But I can't actually remember your question,  
 23 sorry.  
 24 Q. Don't worry. There were two particular points you  
 25 wanted to talk about.

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1 as a disabled woman, it was never recognised that  
 2 probably, you know, as women, as partners of  
 3 haemophiliacs and other people with contaminated  
 4 blood illnesses, we go through it with them.  
 5 We have to provide a lot of support, both  
 6 physically and economically and we were there all  
 7 the time. But nobody ever asked us, you know, if  
 8 they could help us, if there was anything they could  
 9 do to help us help them. It was never recognised  
 10 that we had to not be with our loved ones when we  
 11 should have been because we had to work and because  
 12 it was deemed that the women would look after -- in  
 13 my case I only knew the haemophiliac community,  
 14 which were largely men, but the women looked after  
 15 the men.  
 16 Graham got little enough support as it was.  
 17 When we applied for -- I don't know what they called  
 18 the fund but it was the Macfarlane fund but it was  
 19 like applying for disability benefits. You had to  
 20 say why you wanted it. You had to justify  
 21 everything that you wanted, and some of the things  
 22 that you couldn't explain it in financial terms.  
 23 Actually, all you wanted was bit of support. No  
 24 counselling was ever offered. Nobody ever sat down  
 25 and went through and explained to us more about the

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1 actual illness.

2 Nobody ever told us that it was possibly  
3 contaminated. We got all that information from the  
4 news. Nobody, not the medical profession -- sorry,  
5 within the NHS there was just a kind of silence and  
6 we tried to find out as we started the proceedings  
7 against those responsible for the blood products but  
8 evidence just wasn't forthcoming and it was then  
9 that we began to realise, oh, there's a big cover-up  
10 going on here, because that wall of silence was  
11 enormous and as a woman and as the women who were  
12 there for our men, our haemophiliac men, we were  
13 never really recognised for or supportive for what  
14 we had to do.

15 You know, of course we would do it. We loved  
16 them. But my God did we need the support and I just  
17 really wanted to say that on behalf of all the women  
18 and the mothers in this room and out there, well,  
19 sisters, it was rubbish and you have a right to feel  
20 angry and you have a right to feel unsupported  
21 because you were. So that's what I wanted to say  
22 about the role of women in all of this.

23 The other thing was ...

24 Q. The second point I think you wanted to mention and  
25 you've touched on it in part in your evidence already,

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1 They were not told things because it was felt by the  
2 medical profession that actually it would be better  
3 if they didn't know. I know that to be true, and  
4 they didn't want them to stop taking the blood  
5 products that they knew were infected or were  
6 possibly infected.

7 This is a rumour. Of course, I don't have  
8 evidence of this but I've heard stories from so many  
9 haemophiliacs now that it's confirmed in my mind  
10 that they were treated even less favourably than  
11 somebody -- anybody else, because they were deemed  
12 disabled people and disabled people who were going  
13 to die early anyway or, you know, this will be  
14 better for them than not giving them infected blood  
15 because they are going to die anyway.

16 So I believe there was a strain of disability  
17 discrimination at large at that time. So it's  
18 complex and that's why this Inquiry's so important  
19 because -- and you're so important and why I was so  
20 happy when the Government finally decided and, you  
21 know, there's not a lot I can thank Theresa May for  
22 but my God I thank her for her decision to do this  
23 because it was the best thing that she ever did. It  
24 was a courageous thing. It was the right thing and  
25 it's something that no other Government did before

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1 was the particular position of haemophiliacs as  
2 disabled individuals.

3 A. I just -- well, I did touch upon that earlier.  
4 I mean, I'm in the business of disability  
5 discrimination. That's my profession, human rights  
6 and equality, and the Equality Act and equality laws,  
7 you know, the rights of women, the rights of all those  
8 groups within society are discriminated, that's what  
9 I do. That's why I'm in the House of Lords and the  
10 more I learnt about this and the more I learnt about  
11 myself and my own oppression as a disabled woman, the  
12 more I began to understand about what happened to  
13 haemophiliacs in the '70s and '80s and '90s.

14 A lot of them went to special schools. A lot  
15 of them were treated like children. A lot of them  
16 were not even treated like -- in the way that they  
17 would have treated an able bodied adult. I have  
18 experienced that myself as a disabled person, in my  
19 relationship to the NHS, when they tried to give me  
20 a DNR, when I had a chest infection in hospital once  
21 because as they put it, "Well, in her condition, you  
22 know, it would probably be in her best interest".

23 I feel at that time haemophiliacs were treated  
24 differently because they were disabled people. They  
25 were not given the information that they deserved.

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1 because they felt it wasn't worth it. But she did.  
2 Maybe it's because she was a woman.

3 So that's why it's complicated and that's why  
4 I wanted it to be mentioned.

5 Q. Jane, those are the questions I have for you. Is  
6 there anything else that you would like to add?

7 A. Just a few things, if I may.

8 Q. Absolutely.

9 A. I'm just going to get my notes.

10 Firstly, I wanted to apologise to the campaign  
11 to get this Inquiry up and running and they have  
12 been fighting for a very long time. For a long  
13 time, for probably over 15 years I didn't do  
14 anything. I hid the fact that this was something  
15 that had happened to me because I'd just couldn't  
16 bear to do it anymore, and I know that I probably  
17 could have used some of my campaigning skills to  
18 help the campaigns that have brought about for the  
19 third time this Inquiry.

20 Today I am supported. Lord Morris, who was in  
21 the Lords with me, I've been in the Lords ten years,  
22 behind the scenes, but I never felt that I could  
23 make any personal commitment not just because it was  
24 so hard but I just didn't want this tragedy to  
25 define me and my work because my work is really

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important to a lot of people and I apologise for that.

But I decided -- when I decided to give evidence to this Inquiry I decided it was time to do something. So I hope by giving my statement and by writing an article in the Times today and by going on Radio 4 recently it's helped to raise the profile of the Inquiry and it will do some small bit to help those still living with HIV to get the justice they so, so rightly deserve.

I hope it will help in some small way to get to the truth because I think if we just have the truth then a lot of us are going to feel a whole lot better and if that's all we get that will be absolutely fantastic. So I wanted to thank the haemophiliacs and for those other families and campaigners who are people who have also suffered hepatitis and other really horrible illnesses as a result of being infected. I'm with you and I'll always be with you and I'm sorry I wasn't with you earlier.

I wanted to thank this Inquiry in particular and the Chair who has been brilliant at how he's enabled all of this to happen in such a different way to the other two inquiries, and I can only wish

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decades later but this can be helped if the unresolved questions of why and when -- of how, why and when are answered. I don't know about anyone else but for me the personal effects of secrets and lies has been deeply upsetting and it still haunts me and I absolutely know that the truth will enable me to finally make sense of that time.

Hopefully -- hopefully -- I won't feel the darkness which hangs over a huge chunk of my life.

Lastly, I just want to say if you knew Graham and I don't know but I gave you some photographs and I wondered if you were going to use them.

**Q.** I'm sorry, Jane, I haven't seen those but we can make that part of the record of your evidence.

**A.** That's good because if you look at the photographs of Graham when he was alive you would know that he absolutely deserves justice, even though he won't be here to see it. He deserves it and I want the same for all the people, every single one of the people who had his journey. He was the most fantastic human being and he was just beginning his life and so enjoying it. So, yes, justice. Thank you very much.

**Q.** Thank you.

**SIR BRIAN LANGSTAFF:** You've thanked us. Can I say that you have described yourself as a wreck. That's the

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you the very best and I know you've got a hell of a lot of work to do. I know that there are probably millions of bits of paper to go through and just if I can help in any way, then you know where I am.

I'd like to thank individual people, just a few, and one is Robert James who actually wrote to me this morning after reading my witness statement this week and he told me the name of the haemophiliac from the Birchgrove Group. And am I allowed to mention his name? He's dead.

**Q.** I'm afraid, I don't know. It is probably best not to but you can perhaps provide us with that information privately.

**A.** I just want to thank James for telling me his name because of what happened to James because that was a really wonderful thing to do.

And I wanted to thank Chris Harrington again for being the person who got me through most of that time, and this Inquiry is indispensably important for those still living with the effects of contaminated blood products, but it's also vitally important for all of us who supported, especially the women, infected loved ones during their period of deep suffering.

The effects of that trouble many us even

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one thing you most certainly are not. If you hadn't occasionally cried, I would have been really quite surprised with what you have had to tell us. But for me, it's been humbling listening to you and for all of us, I think, a privilege. Thank you.

Well, that is the end of the formal proceedings for today. Tomorrow we have anonymous witnesses.

**MS RICHARDS:** Sir, tomorrow all our witnesses are anonymous, yes.

**SIR BRIAN LANGSTAFF:** So tomorrow please, remembering my remarks at the start, take special care when you are in and around the building, and particularly with cameras or phones that take photographs, not to catch anyone unawares. Thank you very much.

(4.56 pm)

(Adjourned until 10.00 am the following day)

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1                                    I N D E X

2       LOUISE MARSDEN, sworn ..... 1

3       TREVOR MARSDEN, sworn ..... 1

4       Questioned by MS RICHARDS ..... 1

5       MARK STEWART, sworn ..... 65

6       Questioned by MS FRASER BUTLIN ..... 65

7       ANNETTE HILL-STEWART, sworn ..... 103

8       Questioned by MS FRASER BUTLIN ..... 103

9       BARONESS JANE CAMPBELL, sworn ..... 147

10      Questioned by MS RICHARDS ..... 147

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(50) all... - attendance

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<b>between [14]</b> 17/9 27/14 37/4 42/11 60/1 76/10 79/1 87/21 96/3 100/16 109/4 113/23 129/19 132/25 <b>beyond [1]</b> 92/5 <b>bicycling [1]</b> 105/19 <b>big [10]</b> 58/17 59/2
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(58) funeral... - happening



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(75) way... - witness



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(76) witness... - zest