1		Friday, 1 November 2019	1		Questioned by MS RICHARDS
2	(10	.00 am)	2	MS	RICHARDS: Mr AW, you were diagnosed with leukaemia at
3		(Proceedings delayed)	3		the age of 18 in December 1992?
4	(10	.14 am)	4	A.	Correct.
5	SIR	R BRIAN LANGSTAFF: Now, our first witness this morning	5	Q.	And you were treated at Luton and Dunstable Hospital
6		is anonymous and will be known as Mr AW.	6		and at University College Hospital London.
7		Let me read out the restriction order	7	A.	Yes, correct.
8		guaranteeing his anonymity.	8		You've explained in your witness statement that
9		The name and address of witness W3023 that's	9		between December 1992 and May 1993 you received range
10		Mr AW to you and me and any other identifying	10		of different treatments. At Luton and Dunstable in
11		information, such as the names of members of his	11		December 1992 you received a transfusion of five units
12		family, as well as the witness's image or	12		of platelets and two units of blood.
13		a description of their appearance, cannot be disclosed	13	Α.	(Nodded)
14		or published in any form unless express permission is	14		Then at University College Hospital, between
15		given by me, or by the solicitor to the inquiry acting	15	٠.	December 1992 and May 1993, you received 14 units of
16		on my behalf.	16		blood and 15 units of platelets.
17		Witness W3023 must be referred to only as	17	Δ	Yes.
18		"Mr AW".	18		Then we can also see just from some records that you
19		This order remains in force for the duration of	19	Œ.	received some further treatment in July 1993.
					•
20		the Inquiry, and at all times thereafter, unless	20 21		Henry, could we have 3023015 on screen, please.
21		otherwise ordered, and I may vary or revoke this order			We can see here it's a letter of 7 July 1993,
22		by making a further order during the course of the	22		and it says:
23		Inquiry.	23		"I am grateful to you for arranging a local
24		Mr AW, would you come forward, please.	24		top-up blood transfusion with two units of leucocyte
25		MR AW (sworn)	25		depleted blood for this 19-year-old lad with ALL."
		1			2
1		Then if we have 3023016, please, we can see from	1	Q.	It was then ten years later, in 2003, that you
2		your notes that in addition to the treatment you have	2		received a letter from Luton and Dunstable Hospital.
3		identified in your witness statement, you received in	3		Now, we don't currently have a copy of that letter,
4		June platelets on a number of occasions, through into	4		but what can you recall it saying?
5		early July, when you received two units of packed red	5	Α.	There was a letter I received where from the
6		cells.	6		previous appointments I had been seen at the
7	Α.	Yes, that's following the bone marrow transplant,	7		haematology department where they'd noticed some
8		which was the final part of my treatment.	8		raised some liver issues, shall we say, in terms of
9	O	The bone marrow transplant you had in May at	9		the results in the blood. And then I was going to
10	œ.	University College Hospital.	10		actually see a different haematologist, a different
11	A.		11		name, someone I hadn't seen before to go on
12		In April 1993, the tests showed that you were clear	12		an appointment I didn't know too much about, really.
13	w.	from leukaemia, and you essentially got on with your	13		For me it was a complete surprise.
		life after that.	14	^	·
14		Yes.		Q.	So you went along to this appointment, and what did
15	_		15 46	Α.	the consultant say to you?
16	Q.	You had check-ups initially monthly but afterwards on	16	A.	I do remember the words vividly. I think the first
17		an annual basis.	17		words that he mentioned were, "Do you actually know
18	Α.	Correct, yes, yes.	18		why you're here?" And I think that was at that
19	Q.	You felt pretty well.	19		point in time, okay, what's there was a bombshell
20	A.	I think it took a bit of time to get back to	20		about to be dropped. So, yeah, I vividly remember
21		normality, just as a teenager of that age. It took me	21		those words being mentioned to me. Just me myself,
22		a little while to get up to what I felt normal,	22		a consultant I hadn't seen before, never in all the
23		comfortable, confident in myself. So probably I'd say	23		different visits I'd had to the appointment, never
24		a year after the treatment had finished I'd actually	24		seen this chap before. So that's when he said gave
25		say I was back to my normal health.	25		me the news, he said, "Unfortunately it looks like
		3			4 (1) Pages 1 - 4

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A. I was, yes.

Q. We can see what's said there:

1 you're hepatitis C positive." risk factors for hepatitis C are clearly the multiple 2 Q. Can you recall if you were given any information at 2 transfusions he would have had in 1993, when having 3 3 that stage about prognosis or treatment? treatment for ALL. At present, he is completely well 4 A. Not a great deal, really. I think when you get hit 4 and has no symptoms of liver disease. I have arranged 5 with health news -- this wasn't obviously the first 5 for him to have hepatitis C PCR and deliver 6 6 time, this was ten years plus after having the ultrasound, and assuming the PCR is positive and the 7 leukaemia side of things -- your brain goes into a bit 7 ultrasound normal, we will arrange for a liver biopsy 8 8 of a fog, shall we say. But I don't really remember thereafter." 9 9 too much information. I think in my head So we can see from that you're described as hepatitis C -- didn't know too much about what 10 unfortunately unclear as to the reason for your 10 11 hepatitis C was. I think probably I banded it in as 11 attendance. 12 something similar to what HIV is, essentially, and how 12 A. Mm. and why essentially was kind of buzzing around in the 13 Q. You are told that you have hepatitis C, but that you 13 14 14 were found to be positive in September of 2000. 15 Q. We're going to look at a couple of documents related 15 A. Three years earlier. 16 to that appointment. 16 Q. Was there any discussion with you at that first Henry, could we have 3023005, please, first. We 17 appointment as to why you were only being informed of 17 can see it says this. It's dated 16 April 2003. It 18 18 this in 2003? 19 relates to a clinic on 14 April. It says: 19 A. With it being such a long time ago, I can't really 20 "Thank you for referring this 28-year-old man to 20 remember -- recall why the reason for the time lapse 21 clinic. He was unfortunately unclear as to the reason 21 22 22 for his attendance, and when I explained it was I do actually -- one thing I do probably recall 23 because his liver function tests were abnormal and 23 at the time, that the consultant mentioned that 24 that he had been found to be hepatitis C positive 24 because it being a slow acting thing, it's -- we don't in September 2000, he appeared rather shocked. His 25 25 have to kind of catch things quickly. I think that 6 1 was kind of his reassurance, that okay, it's not too 1 Then it says this: 2 2 much of a bad thing those years have passed as such. "At first diagnosis of ALL he received blood 3 So I do remember that being mentioned, trying to put 3 transfusions and blood products, and this is the 4 my mind at rest, shall we say, but didn't seem to as 4 likely source of transmission of hepatitis C." 5 5 You've seen a number of doctors in different 6 Q. We'll just look also at the consultant's records of 6 hospitals in relation to this. The impression created 7 7 that attendance. by your records is that all are of the view that the 8 8 Henry, it's 3023007, please. cause of your hepatitis C are the transfusions you 9 9 It's the first entry for 14 April 2003, "Has received in late 1992 or 1993. A. Correct, yes. 10 C" -- or it might be, "Hep C positive 2000. Didn't 10 Q. No one suggested to you that there's anything about 11 know why here!" No explanation in the records of that 11 12 appointment as to the delay in informing you. 12 your life or lifestyle that would lead to a view of a 13 So from your perspective, you were told out of 13 different cause. the blue that you had hepatitis C. 14 14 A. No, no. 15 A. Yes. 15 Q. If we then have up on screen, please, 3023003, please, 16 16 Q. If we have up on screen, please, 3023002, we can see Henry. 17 this is a letter written by a consultant at the Royal 17 We can see this -- it's a letter of referral to 18 Free Hospital where you were subsequently referred, 18 Professor Dusheiko at the Royal Free hospital. You 19 and we can see the consultant's view again set out as 19 were referred there by the consultant you saw at Luton 20 to what the cause is or was of the hepatitis C. 20 and Dunstable after the clinic in which the news was 21 "Many thanks for referring this 28-year-old man 21 broken to you.

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and sending his liver biopsy slides for review. He

first became aware of hepatitis C virus infection in

April 2003. This was discovered as part of his

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routine follow-up for ALL."

8 (2) Pages 5 - 8

"I wonder if you would be kind enough to see

this somewhat anxious 27-year-old who has recently

1 been diagnosed with hepatitis C related liver disease. says: 2 He was treated in the 1990s for ALL and had a bone 2 "I wonder if you would see this 28-year-old 3 3 gentleman. He remains in remission from the leukemia, marrow transplant in 1993, when he obviously had a number of blood products. He is well from that 4 4 but more recently I have noticed that his liver 5 point of view now, but the haematologist noted that he 5 function tests show a raised ALT." 6 6 was hepatitis C antibody positive." Then it says: 7 Then it says this: 7 "Looking back in his notes, he was hepatitis C 8 8 "In fact, they found this on a blood test from positive when checked in September 2000, when the 9 9 three years ago, which only came to light this year. first abnormality in his liver function test was 10 10 [Mr AW] is rather upset that this has taken a long detected." time to discover." 11 11 So it would appear that in early 2000, 12 Then there's references to liver function tests 12 consultants looked at your notes and picked up upon showing a persistently raised ALT at 170, and a liver 13 the 2000 record in the context of considering abnormal 13 14 biopsy showing features suggesting early cirrhosis. 14 liver function tests. 15 Is it correct to say you were rather upset it 15 A. Yes. 16 had taken three years to tell you of your results? 16 Q. Had you been told that there was anything abnormal 17 A. Yes, pretty much. 17 about your liver function tests prior to 2003? 18 Q. Had you been aware in 2000 that you were even being 18 A. Nothing at all. There was a point probably around 19 tested for hepatitis C? 19 about the 2000 period, from memory, and the only thing 20 A. Not in the slightest. 20 that was picked up at that point in time, which is 21 Q. Now, could we have up on screen, please, Henry, 21 quite a common thing from the treatment, the blood 22 3023006. 22 transfusion being given, the body and the liver stores 23 This is a letter from January 2003, and it may 23 too much iron, so the iron levels were quite high and 24 be that this helps explain why a letter was then sent 24 dangerously high, I think, to a degree. The normal to you inviting you to come in to see the clinic. It 25 25 thing for that procedure then is just to give blood. 10 1 So it was around 2000, would you say roughly? 1 failure to attend an outpatient appointment at the 2 2000, 2001 period. Where probably on a quarterly 2 time the result first came available and several 3 basis I'd have to go in just to give blood and over 3 appointments before and after." 4 time they would check and just see to make sure those 4 Then it goes on to say: 5 iron levels had come down to sort of a normal level. 5 "When the oversight was recognised, you were 6 So that was something -- the only thing, shall we say, 6 promptly informed and referred to the gastroenterology 7 7 that around that time I was given sort of notification clinic." 8 8 of and some action against those, but nothing else. We'll look then at the previous years and see 9 9 Q. We'll have a look and see what opportunities there whether what's said here could be correct. 10 might have been between 2000 and 2003 to tell you of 10 Could we have, please, Henry, first of all --11 the diagnosis earlier. 11 **SIR BRIAN LANGSTAFF**: Just pausing there for a moment. 12 We'll start, please, Henry, with 3023008, which 12 So far there have been two explanations for the 13 is a later letter. It's dated March 2006, and it's 13 delay: one that it was -- I think that was 003 -- only sent from a haematologist to the legal services 14 14 just come to light, when it appears it had been in the 15 department within the trust. The context for that, 15 records all the time; and this, that it was his fault 16 16 I think, is you approached solicitors and there was for not attending an outpatient appointment when it 17 some consideration being given to the possibility of 17 might have been discussed. But it goes on to say that 18 bringing a claim. 18 when the oversight was recognised, he was referred to 19 A. Yes, yes. 19 the gastroenterology clinic. 20 Q. And we can see this: 20 I thought the inference from the documents you 21 "We cannot deny that the hepatitis C infection 21 have shown us a moment or two ago was that the reason

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enzymes.

say.

informed of this result until April 2003."

Then it says this:

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"However, this was at least in part due to his

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was detected in September 2000 and [Mr AW] was not

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MS RICHARDS: Yes, that appears to be what other letters

for his referral was because of his high liver

(3) Pages 9 - 12

1	SID	R BRIAN LANGSTAFF: So this is a different view of what	1		the letter as to what the blood tests were for.
2	Oiiv	took place.	2	Α.	
3	MS	RICHARDS: That would seem to be the case. We are	3		You did go in response to this letter to the pathology
4	1810	inviting the hospital to respond to Mr AW's statement	4	w.	department and you did have the blood tests?
5		in this documentation.	5	Α.	
6	SID	R BRIAN LANGSTAFF: Yes, thank you.	6	Q.	
7		RICHARDS: So, Henry, could we have 3023014.	7	w.	they'll write to you again. Did you ever receive
8	IVIO	We can see this is a letter from September 2000.	8		a letter telling you the results of
9		·	9		those September 2000 blood tests?
10		It says:	10	۸	No.
		"Dr Rejman has asked me to write to you as we have sent several appointments to you but you failed	11	Α.	
11				Q.	We'll look then at your next attendance, which was
12		to attend."	12		in February 2001.
13		So there were non-attendances prior	13		Could we please have, Henry, 3023009.
14		to September 2000. This says:	14		This is a later letter in the context of the
15		"He would like you to have a further blood test	15		litigation, but it gives us some dates. It says:
16		and I am therefore enclosing the necessary forms.	16		"I first saw [Mr AW] on 21 February 2001. He
17		Please could you come to the pathology department to	17		had missed a number of clinic appointments since
18		have these tests done at your own convenience."	18		12 January 2000."
19		Then the second paragraph says:	19		So, again, clinic appointments earlier.
20		"When we have the results of these tests, we	20	Α.	
21		will write to you again. In the meantime, we will be	21	Q.	, , , , , , , , , , , , , , , , , , , ,
22		sending you an appointment for January 2001, which	22		"He had come up for a blood test on
23		will be your next review in the clinic."	23		18 September 2000 but without actually being seen."
24		So that's the invitation in September 2000 for	24		You haven't been invited to be seen, you've just
25		you to come and have blood tests. No explanation in	25		been invited to go to the pathology department for
		13			14
1		a test.	1		completely normal, given you an annual follow-up. So
2	Α.	A blood test, yes.	2		no reference to anything to do with hepatitis C blood
3	Q.	Which is exactly what you did.	3		result, no reference to anything to do with abnormal
4	Α.	Yes.	4		liver function tests.
5		Then the doctor continues:	5	A.	
6		"When I saw him, I didn't appreciate the fact	6		If we look at the notes Henry, it's 3023017,
7		that he had not been told his hepatitis C result	7	•	please we can see that the entry for
8		previously."	8		21 February 2001, they have your new address now, we
9		Then refers to subsequent visits and rising ALT	9		see halfway down the page, we can see you obviously
10		liver enzyme levels.	10		attended in February 2001, various matters there set
11		So the doctor who saw you on 21 February says	11		out, but nothing to do with hepatitis C.
12		here that that doctor did not appreciate you hadn't	12	Α.	
13		been told your hepatitis C result.	13		That was February 2001.
14	Α.	Mm-hm, yes.	14	Œ.	You attended in fact again in October of that
15		If we just look at the record of the notes of the	15		year, October 2001. It's 3023012, please, Henry.
16	w.	attendance well, we'll look at two documents.	16		You had gone for a check-up on 15 October 2001
17		We'll look at a letter first of all to your GP	17		in view of your previous history in relation to the
18		following that clinic. 3023013, please.	18		leukaemia and the bone marrow transplantation, and
		·	19		•
19		So we can see the haematologist writing to your			you're seen in the haematology department. There's
20		GP. Again, there's the reference to you having been	20		a discussion of your leukaemia. No evidence of
21		lost to follow-up, but that's all	21		recurrence and a normal blood picture.
22		before September 2000.	22		Again, October 2001, you're seen again. Yes.
23		Then it says you remain completely asymptomatic,	23		
24 25		you have been completely well in the last year, weight	24 25	W.	No one tells you anything about liver function results
25		is stable, refers to examination, full blood count	25		or hepatitis C.
		15			16 (4) Pages 13 - 16

1	A.	No, no.	1	Q.	and nothing was said to you.
2		If we have 3023020, please, Henry.	2	A.	(Nodded)
3		We can see here in the first half of the page	3	Q.	That was March of 2002. You were seen again
4		the clinic notes for that attendance in October 2001.	4		in December of 2002. 3023010.
5		Hepatitis C not referred to there.	5		We can see it's a letter of 21 December 2002.
6		So we've had February 2001, October 2001. We	6		It refers to a clinic on 18 December, and we can see
7		come on to March 2002. Could we have, please, Henry,	7		in the first sentence you've attended for your routine
8		3023011.	8		review earlier because you were starting a new job in
9	A.	Yes.	9		the January and you wanted to get the appointment
10	Q.	This is again a letter from the haematologist to your	10		done.
11		GP. It refers to a clinic on 6 March 2002. So you've	11	Α.	Yes.
12		attended, you've had your annual review in the	12	Q.	We can see there set out you are described as
13		haematology clinic:	13		clinically and symptomatically well with no clinical
14		"He remains well and has been free of infections	14		problems. There's a reference to haemoglobin and
15		over the last one year."	15		platelets, and a reference to discussions about the
16		Refers to blood count, blood film, clinical	16		possibility of starting a family.
17		examination, and that you're in complete remission.	17	Α.	Yes.
18		Next review will be in a year's time.	18	Q.	If we go to the notes for that appointment we can
19		If we look again at the clinic notes, 3023020,	19		see in the letter there's no reference to hepatitis C
20		this time the bottom half of the page, we can see	20		or liver function tests of any kind. But can we look
21		again that you've been seen there. These are the	21		at 3023018, please, Henry.
22		records that have been recorded by the doctor. A	22		The notes show a different picture.
23		further opportunity to tell you of the blood result,	23		18 December 2002, we have various things there set
24		the hepatitis C	24		out. Starts new job in January, et cetera. All well,
25	Α.	Yes.	25		no problem, fertility discussed, see one year. Then
		17			18
1		someone's written we don't know whether it's the	1		Then it says this:
2		same date or a later date, the handwriting does look	2		"It is pleasing to note that steps have been
3		as though it might be different:	3		taken to improve the review and follow-up of the
4		"Hepatitis C positive September 2000. Rising	4		laboratory results."
5		ALT. Refer to hepatologist."	5		Has the hospital explained to you what steps
6		Was that drawn to your attention	6		have been taken to improve the review and follow-up of
7		in December 2002?	7		laboratory results or
8	A.	No, not at all.	8	Α.	No, this one is an interesting one. So in terms of my
9	Q.	So nothing until that April 2003 appointment that	9		records, certain things you just glare and jump out
10		we've looked at?	10		at you, and this one in particular was interesting
11	A.	Yes.	11		because obviously this memorandum must have some sort
12	Q.	If we have one further document on screen, please,	12		of information based on me, myself. So it would be
13		Henry. It's 3023019.	13		helpful to kind of see what reference is actually made
14		This is a letter, again written perhaps in the	14		in this in terms of what was done to improve those
15		context of the threat of a legal claim because it's	15		steps.
16		from the hospital's litigation adviser to the	16	Q.	I understand you would like to both see the memorandum
17		haematologist. It says:	17		and also know what had led to the identification of
18		"Thank you for your memorandum dated	18		a need to improve the review and follow-up of
19		9 September 2004. Your comments are noted."	19		laboratory results.
20		Pausing there, you've not seen, I think, a copy	20	Α.	Very much so, yes.
21		of that memorandum.	21	Q.	Now, if we then go back to April 2003, when you were
22	A.	No.	22		given the diagnosis of hepatitis C.
23	Q.	Then it refers to a potential claim against the	23		You say in your statement that the constant
24		hospital in respect of the failure to inform you of	24		thought you've had and have had since then and not
		the result of the hepatitis C blood test.	25		been able to expel is about whether there are others

(5) Pages 17 - 20

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1 in the same position as you. Could you elaborate upon 2 that? 3

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- A. Yes. So I think for me, for definite, it was having -- a strange one, almost like fortunate to have been found and know I have that, and in my head I have this kind of image of all the times when I had the transfusions given, and there's potential that there was someone next to me in a hospital bed in a ward, someone had maybe some sort of bike accident, needed two or three pints of blood given to him, and that person -- same blood type, and then let's just say they go on, fit, healthy life, lifestyle, 10/15 years, nothing's wrong at all, and all of a sudden certain things start to change, they go to see the GP, the GP says, "Okay, maybe we need to do some tests on you", and that person, or persons, who knows, then has that terrible news and finds out they're 15 years plus, whereas for me, for myself -- that for me didn't seem right. Could I actually just be that one person? It just didn't seem right. And I had that fear, is
- don't get to know, and I did? So, yeah. 23 Q. I want to ask you a little about the impact of the 24 diagnosis on you.

You describe in your statement how you became

some -- are there other people in that same boat that

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1 on top of what I was having.

> So me in my stubbornness, I guess, was just to go -- let's concentrate on this issue first as opposed to the mental side of things, really. Obviously things have changed a hell of a lot now, we're in a different world when it comes to mental health and how it's perceived, but for me my core focus was getting over the treatment and getting through the treatment.

- 10 Q. Did you receive any offer of counselling or 11 psychological support?
- 12 A. Not from memory.
- 13 Q. Now, you physically had felt okay. You weren't, as far as you know, experiencing any physical symptoms of 14 15 hepatitis C.
  - A. Absolutely not.
- 17 Q. But you were told that there were potentially signs of 18 moderate liver damage, and so you were referred, as 19 we've seen in the correspondence, to Dr Dusheiko. You 20 had your liver biopsy and ultrasound scan.
- 21 A. Yes.
- 22 Q. Then in October 2003 you were seen at the Royal Free. 23 You were told your genotype, which was 3A.
- 24 A. Mm.
- 25 Q. It was recommended to you that you embark upon

very introverted, in a deep place.

2 A. Yes, yes. Probably just after my 30th birthday, and 3 I do remember at the time one vivid instance of going to a certain friend's birthday party, and at the time 4 5 I had just started the treatment. Mentally, being in 6 a social environment did have an effect on me as 7 a person. Confidence, just being in a social 8 environment with other people, in a gathering area, 9 did they -- I did tell the close-knit friends that 10 I had at the time. I think some of those did 11 understand and obviously knew what happened to me ten 12 years earlier, but I don't think they fully understood 13 what hep C was as a condition.

> And I do remember in certain instances just from a mental perspective it definitely changed me as a person. The mental impact was hard.

- Q. You said in your statement you didn't take antidepressants, but in retrospect you've wondered whether you should have done and that they might have helped.
- 21 A. Yes. I think definitely from my side, having the 22 treatment I went through ten years prior and the drugs 23 you're given at the time, I suppose really for me, 24 knowing I had to take two sets of drugs for hep C, the 25 last thing I probably wanted was additional medication

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1 pegylated interferon and Ribavirin.

- 2 A. Mm.
- 3 Q. You say in your statement that the potential 4 side-effects were spelt out to you by the doctor at 5 the Royal Free.
- 6 A. Yes, they did say that obviously there's a variety of 7 side-effects, and everyone is different in terms of 8 how those side-effects hit you as a person, so kind 9 of, you know, what was going to come. But, yeah, 10 I had no idea in terms of how it would affect me and 11 obviously everyone is different.
  - Q. You started the six-month course of treatment in August 2004. How was that?
- 14 A. The -- to know -- it was going into the unknown again, 15 really. I suppose in some ways being of a -- wouldn't 16 say call it a benefit as such, but having the 17 treatment I had ten years prior, having to take more 18 medication for a prolonged period, how it's going to 19 affect you as a person, how it's going to affect the 20 people around you, having to inject yourself.

So, yeah, it's not just how it's going to affect you, but it's how it's going to affect the people around you as well, and then the unknown, once use start taking them, what sort of side-effects are going to come and be seen. Obviously for me the

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(6) Pages 21 - 24

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side-effects did build and they got to a point where I
think, of the six-month period, I had to stop the
treatment probably five months in.

Q. You've described in your statement physical symptoms;
loss of appetite, loss of weight, fluctuating thyroid
functions.

A. Yes.

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- Q. After about four months you felt so ill, you were having severe palpitations.
- A. I think the palpitations were the ones which wereprobably the big thing, really, so it's not nice.
  - Q. That led to your decision to stop the treatment early.
- A. Yes, through the -- through the consultant I was seeing at the time at the hospital. The reaction my body had given to the drugs, clearing the virus
  I think fairly early on, they were confident in thinking really at that point in time it would be a good point to stop rather than going for the full six-month cycle.
  - Q. Your mum's provided a statement to the Inquiry, and she talks about the psychological effects of the treatment on you. She said it made you angry. You could fly off the handle. We've heard descriptions of mood swings and anger from a number of witnesses who have undergone this particular course of treatment.

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1 on your relationship with your wife.

- A. Exactly, as well, so --
- Q. We'll come on to your employment in a few minutes, but you weren't during the treatment working, and your wife ended up reducing her full-time employment to part-time in order to assist you.
- 7 **A.** Yes.
- 8 Q. So it was financially hard.
- 9 A. Yes, it was. Yes.
- 10 Q. In mid-2005, following further blood tests, you were11 told that you were clear of hepatitis C.
- 12 **A.** Yes.
- Q. What follow-up in terms of monitoring of your liver
   have you received since the hepatitis C treatment was
   completed?
  - A. So from kind of being discharged off from the Royal Free, from the treatment for the hep C, there was no follow-up from beyond that point.

Up until recently, we're only talking in the last sort of six months where I'd had two phone calls, evening phone calls from my GP surgery. One was an out-of-the-blue call, "Very quick question we just need to ask you, were you ever informed or told or have any evidence that you were fully cleared and discharged from the hospital where you had the

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She says you felt unclean.

A. Yes, I think the uncleanness is probably that early kind of -- the mental side of things, and as I mentioned that scenario there of being out in a social environment, how you're perceived, the paranoia was a big thing.

That's the vivid thing my mind, the paranoia, being out and -- I think as well, it's -- since that point in time there's only certain people that probably have kind of known about the hepatitis C and I've actually told. So it's not something that I've kind of divulged in -- only to certain people, really. It's sort of kept in -- even my friends probably at the time, if I was to -- they probably won't even know about -- I've mentioned to one or two close friends about the Inquiry and everything, but it's -- yeah, it's not something you -- I feel I can kind of talk about too much really.

- 19 Q. You were worried you might have infected your wife.20 You hadn't, but it was a cause of concern.
- A. Yes. That spun through my head, that moment of
   sitting with the consultant and, "Do you know why
   you're here for?" and that was very ... yeah. Just
   think straight off the bat and -- yeah.
  - Q. You were worried about the strain that it would place

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treatment?"

And quizzically getting a call from the GP in the evening randomly out of the blue was enough of a shock anyway, so that started putting sort of questions in my mind and the cogs start turning again saying, "Okay, what's happened here?"

This was probably from a timing perspective, I would say, probably six to three months prior to the Inquiry starting, so that -- I probably put two and two together potentially.

More recently I've had a few trips to the GP -- GP surgery. I'm not tied into a dedicated GP there. I tend to have two or three GPs which I kind of trust in. One of these was a new gentleman, quite newish to the surgery, and I went for different symptoms at the time, and he was just looking through my notes and said, "Regarding hepatitis C, when were you last tested?" And I said, "Well, I haven't been tested", and he said, "Okay, I think it might be just good for you potentially just to have a random test just to make everything's okay in that area". I was taken aback by that a little bit, thinking, well, this was 15 years prior, could it return? Can it return?

So I did have a blood test done and from that there was nothing found. Obviously, the antibodies

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still remain in the system, but they did say, "Oh, we've found raised levels in the liver", the ALTs I think it was, or FTs, I'm not sure which one, but he said, "I need to refer you to the gastroenterologist", and I thought, "Okay, this path, where is this leading to?" So I had to go and have an ultrasound.

The ultrasound was done probably talking three months -- yeah, in the summer this year, so went to have the ultrasound done, and then back to see the GP, and the GP said, "Okay, we've noticed from the ultrasound results that the liver is quite bright, it's quite bright", so from that he said, "I need to get you referred to the gastroenterologist."

So a few weeks after then I went to see the gastroenterologist at the hospital. Again, that was a kind of a moment thinking we're going into a situation again where you're just going to be given that kind of bombshell news.

So there was a little bit of apprehension, yeah, yeah, what was going to be found, shall we say. The good news really was reassured straight away that there was no scarring found on the liver, so they said the scarring -- there's no visible scarring there.

The brightness in the liver from the ultrasound probably would be down to a number of different

1 a route of IVF.

- A. Correct, yes.
  - Q. You needed to do that anyway, that wasn't due to hepatitis C. But your hepatitis C diagnosis did cause problems in terms of where you could have your IVF.
  - A. It did, yes. So with the fact that the hepatitis C antibodies obviously were found in me, you're restricted. So the first thing we were kind of told was we can't freeze any embryos or -- from my side -- from us, essentially, there are only two clinics available for you in the UK that would actually allow you to go and have the IVF treatment, [redacted] ... Okay, it was two clinics, and Chelsea and Westminster was the one of choice we went with eventually. But, yes, having that kind of -- be told again, you are hitting another hurdle and it felt like, okay, what -- another kind of kick in the teeth that something you want to have and being restricted down to two clinics, or the other alternative would've -- alternative would've been obviously to seek further afield.
  - Q. Your mum again in her statement explains how everything that you've described caused you to lose confidence and self-esteem. She says it wasn't really until you saw a Panorama programme in 2017 that you began to be able to speak a little more freely about

things, could be down to cholesterol, which has happened, my cholesterol is slightly raised, it could be down to blood pressure, but it's more a case of a dietary change or just a health style change, really, so there's nothing there. She said, "I don't really need to see you for many follow-up from that side."

But this is only really recently. We're talking the summer of this year.

- Q. So between 2005, after you'd cleared hepatitis C andyou'd been told you cleared it --
- 12 A. Yes.
- **Q.** -- from that point until 2019 --
- 14 A. Correct, yes.
- 15 Q. -- there was no follow-up in terms of liver.
- A. Like I said there, to have that kind of brought back
  into the foreground again, saying, okay, it -- yeah,
  it was -- definitely that kind of fear factor started
  to creep back in again, thinking, hang about, should
  I have not been every year in the same way as
  leukaemia, you're given a outpatient view of things,
- but, no, given nothing at all.
- Q. You and your wife had wanted to have children, but
   because of the cancer treatment you'd had, the
   treatment for your leukaemia, you had to go down

- 1 what had happened.
- A. Yes. Just sitting watching that programme was -- not
   just probably me watching that, but many others out
   there, just seeing that was incredible.
- Q. You also saw or heard evidence given during the first
   week of the Inquiry hearings --
- A. Yes.
- Q. -- in which there was a witness who spoke about
   infection with hepatitis C, again through transfusions
   post the autumn of 1991.
- **A.** Yes, yes.
- 12 Q. When you heard that evidence, you felt I think less13 alone in what you'd experienced.
- A. Yes. We just were sitting watching the News at 10.
  Probably first/second week of the trial. It was just
  the moment of ... just sort of blown away. It was
  a new -- for me, it was like, I knew I wasn't the only
  one. Yes.
- Q. What was the effect of the hepatitis C diagnosis and
   the treatment that you then had to go through on your
   wife, your partner, and on your parents?
- A. Yeah, I -- it's not something probably I've talked
   about enough with them, but I know that -- like I said
   before, it's not just you that are having to deal with
   it; you have that periphery around you that are having

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- 1 to see the effects it's having on them. Yeah.
- 2 Q. We have a statement from your mum to the Inquiry as 3 well in any event, which we've read.
  - A. Okay.

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- 5 Q. What happened in terms of your employment? You had 6 been in work at the time of your diagnosis. What then 7 happened?
  - A. At the time I had started in the January of 2003 with an IT company at the time. It was my second job post-university. Probably from a company perspective very small. I probably was in probably not a fantastic company to be in at the time to be supportive, shall we say, of my scenario. I mean, since that point in time I've worked for a lot -let's say bigger companies and companies that kind of can know and understand, and I've seen people in situations where they've been given support, time off, things like that. So I was in this small company and obviously I told them my situation, the diagnosis, and I would probably need time off work as such. It wasn't long after that I could see things changing, and I was put in a position where literally I was, shall we say, pushed out of the company. So they're talking -- only been there sort of five months at that point in time.

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1 ability to get life insurance.

> A. Yes. That's been a challenging one. I think it's a combination of both, so with the leukaemia plus the hepatitis C, life insurance in the very early days of -- once we'd got our first house, a few years after, looking at insurance policies, you go through -- you get to -- asked the standard questions. When those questions get ticked, that's it, "Sorry, we can't take things further."

It's got to the point really that thinking after such a window things would be made easier, they haven't, so to the point now where I've -- I have got life cover, shall we say. It's kind of based on an American company that I've gone with, so it's not your standard -- yeah, it doesn't cover you for that kind of -- the illness side of things. So I have some cover as such, but -- yeah, so that's been another challenging thing, ringing through. You can't -again, you're sort of deemed as a second class citizen in some ways and there's that blocker there.

- 21 Q. You were not eligible for any payment from the 22 Skipton Fund.
- 23 A. Correct.
- 24 Q. We can see a letter at -- it's a different reference, 25 please, Henry, it's 2926003, and it's page 3, please.

So then knowing you're jobless and at the same 2 time having to then deal with a condition -- about to 3 have treatment for a condition as well, it's not 4 a nice scenario to be in.

- 5 Q. You were worried that you would not be able to get 6 further employment because you didn't know how you'd 7 explain your 14 months out of work.
- 8 A. Yes, yes, that was the other thing I was thinking: 9 okay well, at some point I need to get myself back 10 into employment, how -- you are going to be looked at and say, "Okay, what's happened in this window? Why 11 12 have you been out of work for that point in time?" If 13 I mention the hepatitis C, how is that going to come 14 down on a prospective employer? Does it make me 15 employable still? So, yeah, that was a constant kind 16 of worry in your head as well.
- 17 Q. You have happily been able to obtain subsequent 18 employment.
- 19 A. Yes, I think the blessing for me was in February 2005 20 I started again with a small IT company, but this one 21 was a very, very good one, and there was no -- no 22 look-back, shall we say, of my kind of history. And 23 I've spent five and a half years at this company. 24 It's probably the best company I've ever worked with. 25
  - Q. One of the other problems has been the effect on your

We can see it's a letter written by the Department of Health, Jane Ellison, to your mum's MP, and it says:

"I am sorry to read that [Mr AW] is not eligible for the Skipton Fund. As your constituent highlights, only those who have contracted hepatitis C as a result of receiving blood or blood products from the NHS prior to September 1991 are eligible to apply. This is because the Skipton Fund was set up with a specific purpose of providing ex gratia support to those who were infected before blood donor screening tests were introduced.

"As [Mrs AW] suggested that her son was infected with hepatitis C during the course of his treatment for leukaemia from December 1992, he is over 15 months away from this point of eligibility."

And I understand you've since approached the EIBSS but had a similar response.

- A. Yes, my mother's -- yeah, she's gone down that path, and from a timing perspective obviously post-1991.
- You've referred in your statement to a letter from a legal adviser representing the National Blood Authority. It's dated 8 July 2005. We don't have the letter at the moment, but you've quoted from it, and it says this:

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1		"We understand from our client, the National	1		"Was it really just a freak accident and the
2		Blood Authority, that the transfusion history	2		blood donor just slipped through the net?"
3		indicates significant donor exposure. Unfortunately	3	Δ	Mm.
4		our client is unable to investigate all of these	4		Those are the questions I have for you. I am going to
5		donations and such an investigation is in any event	5	٠	ask Mr Snowden if there's anything else he would like
6		likely to produce a definite conclusion."	6		me to ask.
7		You've said in your statement you think that's	7		There's nothing further. Is there anything you
8		a typographical error in the letter.	8		would like to say?
9	Δ	Yes.	9	Δ	Just a thank you, really, to my family for their
10	Q.	It should be "unlikely to produce a definite	10	Λ.	support, their patience for me as a person.
11	w.	conclusion."	11		Especially my mother. She's been fantastic in
12		So there has clearly been some contact	12		terms of what she's done, taking things this far.
13		I think it may have been through your mother with	13		Obviously my wife as well and what she's had to
14		the legal adviser to the National Blood Authority back	14		go through with myself.
		in 2005.	15		Probably too probably this is a bit of
15 16			16		a strange one at the moment, for someone to thank MPs.
		You're not aware of there having been, I think, any more recent contact with the transfusion service?			
17 18	۸	No.	17 18		I'm going to thank two MPs. For Diana Johnson, what she's done. She's been immense in what she's done to
19	Ų.	You say this, Mr AW, in your statement. You'd like to	19		promote the message of what's happened. And
20		know if there's anyone else in your situation who is	20		Andy Burnham as well. So those two MPs, to thank them
21		infected so late, post the 1991 screening, and you	21		for their efforts in taking things to where things
22		would like to know what happened and how it happened	22	840	have got to now.
23		to you.	23	IVIS	GRICHARDS: Thank you.
24		Yes.	24	O.F.	Sir Brian.
25	Ų.	You pose this:	25	SIF	R BRIAN LANGSTAFF: What you've described to us is
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1		a sense of anxiety, apprehension, which has been added	1		lunch, will both be fully available on the stream, but
2		to by a sense of isolation until recently. You	2		not the next.
3		described yourself at one stage almost as being	3		11.30.
4		paranoid.	4	(11	.05 am)
5		We are very grateful that you've overcome those	5	•	(A short break)
6		feelings, and it can't have been easy to come here	6	(11	.30 am)
7		today, even with the protection of anonymity, and tell	7	SIF	R BRIAN LANGSTAFF: Well, our next witness, as you
8		those who are here what you find difficult to tell	8		already know, is anonymous. She will be known as
9		some of your friends.	9		Mrs AX.
10		It's important to hear evidence like yours for	10		In her case too I make the same type of order as
11		all sorts of reasons. Thank you very much.	11		I made earlier, but let me read it out so that you all
12	A.	Thank you.	12		hear it.
13		BRIAN LANGSTAFF: We'll take a break until 11.30.	13		The name and address of the witness W0507
14	MS	RICHARDS: Sir, I should say that there will be no live	14		that's Mrs AX to you and me the name of her late
15		streaming of the next witness, who is also anonymous.	15		husband and any other member of her family, and any
16		Her evidence will not be live streamed.	16		other identifying information, such as the witness's
17	SIR	R BRIAN LANGSTAFF: So if anyone is watching remotely,	17		image or a description of their appearance, cannot be
18		they should know that the next witnesses, the	18		disclosed or published in any form, unless express
19		remaining witnesses of the day	19		permission is given by me or by the solicitor to the
20	MS	RICHARDS: No, just the next witness.	20		inquiry acting on my behalf.
21		R BRIAN LANGSTAFF: The next witness.	21		Witness W0507 must be referred to only as
22		RICHARDS: Then the live stream will be on again this	22		"Mrs AX".
23		afternoon.	23		This order remains in force for the duration of
24	SIR	R BRIAN LANGSTAFF: Yes, I was going to say the next	24		the Inquiry and at all times thereafter, unless
25		witness, after lunch, and the two witnesses after	25		otherwise ordered, and I may vary or revoke the order
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		<del></del>			40 (10) Pages 37 - 40

1 by making a further order during the course of the 2 Inquiry. 3 As you know, there will be no live streaming, 4 either visually or orally. 5 With that protection, may we have Mrs AX, 6 please. 7 MRS AX (sworn) Questioned by MS FRASER BUTLIN 8 9 MS FRASER BUTLIN: Mrs AX, you are here to tell us about 10 your late husband, and you are going to refer to him 11 by his name, [redacted], because it's too hard not say 12 his name when we're talking about him, but just to make it clear that his name is covered by the 13 14 restriction order and mustn't be used outside of this 15 room 16 You met in 1972. Can you tell us a little bit about what your husband was like before he became 17 18 unwell? 19 A. He was just a normal, hardworking man. He had his own 20 business. We had nice holidays. We were just 21 a normal couple. 22 Q. He loved to ski. 23 A. He loved to ski. We had lots and lots of skiing 24 holidays before he became ill, and summer holidays, 25 and we just had a nice lifestyle. 41 A. Yes. 1 2 Q. Can you tell us about that process? 3 A. What do you mean? 4 **Q.** What did [redacted] have to go and do? 5 A. Oh, it's a form of dialysis, but he just used to go to 6 the local renal unit once a fortnight and they would 7 draw off his old -- his plasma and give him new plasma 8 from a donor. 9 The old plasma then was drained off and that 10 seemed to work for a while, stopped the kidneys from 11 failing, you know. It was a gradual failure and it 12 seemed to slow things down a little bit. 13 Q. You have a particular recollection of what the new plasma looked like. 14 15 A. Yes, it looked like peach melba. Q. And the new plasma had "Baxter" written on the bags. 16 17 A. I think it was "Baxter". You know, it's a long time 18 ago. I can't -- I remember it being in a clear -- it 19 was clear fluid in a bag that was fed through 20 a dialysis machine. 21 Q. The old stuff coming off looked like peach melba --22 A. The old stuff coming off looked like peach melba. 23 Q. -- and the new was clear. 24 A. Yes. 25 Q. You said in your statement that you recall that

1 November 2019 Q. In July 1985, his ankles started to become swollen and 2 he was tired all the time. 3 4 Q. What did the doctors find that was the problem? 5 A. Well, the GP was -- she didn't know what the problem 6 was, so she referred him to the local hospital and 7 they did various blood tests, and eventually said that 8 he had glomerulonephritis. 9 Q. Which is a kidney condition? 10 A. A kidney condition, yes. 11 Q. He always had to clear his throat. 12 A. Yes, he always had -- not a sore throat, but he always 13 had this sort of (Demonstrated) whenever he was 14 talking, and he had had that from being a child. He'd 15 had his tonsils out but it didn't make a difference, 16 but he'd always had that and they said eventually 17 that's where the infection could've come from. It's 18 like a meningitis type infection. 19 Q. They thought he had had an untreated streptococcal 20 throat infection, which had then affected the kidney 21 function. 22 A. That's correct, yes. 23 Q. He started receiving steroid treatments, but after 24 a while that was deemed to be unsuccessful, and he was 25 started then on plasma exchange. 42

1 "Baxter" was written on those bags.

2 A. I think it was "Baxter", yeah.

3 Q. Your husband had that treatment every fortnight for 4 about 18 months?

A. Yes.

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6 Q. But over time, as you say, his kidney function did 7 gradually decrease.

8 A. Yes, he carried on -- he was still running the 9 business, we were still having holidays, he kept 10 filling up with fluid obviously, but -- because his 11 kidneys weren't working properly.

> So, yeah, for 18 months we just tried to carry on as best we could, but then they started to fail.

Q. His kidney function went down to just below 14 15 20 per cent.

16 A. Yes.

17 Q. And at that point he became more unwell, I think.

18 A. Yeah, yeah. And the consultant at the time said he 19 thought that he would need full-time haemodialysis.

20 Q. In your husband's medical records there's a laboratory 21 report from April 1993 that we're just going to put up 22 on the screen. It's a different witness number,

Henry. It's 3807003, please.

We can see in the bottom right-hand corner there the date of report, 26 April 1993, and it indicates

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that he was positive for hepatitis C.
Were you or your husband aware in 1993 that he
had tested positive for hepatitis C?
A. No.
Q. Now, in your statement you thought your husband had discovered he was hepatitis C positive in about 1995.

Q. Now, in your statement you thought your husband had discovered he was hepatitis C positive in about 1995, but having looked at some records, you think it was actually 1996.

9 A. Yes.

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10 Q. Can you tell us about how you came to find out?

A. It was a routine renal appointment. We used to go every three months because we were dialysing at home then, so it was just a routine clinical appointment, and they did routine bloods. We had the consultation and then he said at the end, "Oh, we just need to take these bloods", so he got the blood forms out and then he got a category 3 risk sticker out of his drawer and stuck that on and I asked him why he was doing that, and he said, "Oh, I don't really know", and he sort of flicked through the notes and said, "Oh, it looks like you've got hepatitis C."

Q. Because at that point -- we won't explain your role -you actually worked in the hospital, so you understood what category 3 risk stickers were.

A. Yeah.

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Dr Throssell. There is a general discussion about your husband's condition, and if we go over the page, there is a single line: "Counselled re hepatitis C."

That consultation was then followed with a letter to the general practitioner, which we'll have a look at. It's 3807005, please. We can see it's dated 12 April 1996.

There is general discussion about your husband's renal failure and being on home haemodialysis, and then in the very last paragraph -- thank you -- it simply says:

"Routine screening has shown him to be hepatitis C positive, and I explained the significance of this to him today."

What do you recall of being told about hepatitis C at that appointment?

A. Not a lot. It made it more difficult because I did know a little bit about hepatitis C anyway through my job, and although Dr Throssell was really nice, I don't think he knew as much about it as I did, and he sort of dismissed it as, you know, saying, "But there's nothing for you to worry about". And that's when I questioned him about whether or not he ought to see a gastroenterologist, you know, to have his liver checked, and he more or less said, "Well, you can if

Q. We asked the doctor, Dr Throssell, to respond to your statement, and he said he can't now recall specific details of what you discussed at the appointment, but he provided us with some of the medical records and we've correlated them with those that you had.

6 A. Yeah.

7 **Q.** He noted the 1993 test results and he indicated that the next note in the clinical records is the document 3807004.

We can see it's in different handwriting to the rest of the page. It's dated 1 March 1996. It says:

"To discuss and counsel re hepatitis C positivity on next attendance. Needs category 3 stickers on samples."

So it doesn't appear that this was a consultation in March 1996, but that there was a note of the need for those stickers that you recall.

18 A. Mm-hm.

Q. You've provided us with the medical records, and
 Dr Throssell has obviously looked at them as well, and
 there isn't anything else between the 1993 result and
 this note in 1996 that has any reference to
 hepatitis C.

We then come to the next entry in the notes, which is 10 April 1996. It is an entry made by

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you want, but I don't think it's going to be -- it's
 not going to help you in any way, you're not going to
 die of it", I think were his words. "Hepatitis C
 won't kill you," he said, "it will be something else."

So we just waited then for the appointment to go and see the gastroenterologist.

7 Q. In terms of that referral to the gastroenterologist,
8 Dr Throssell responded and said he thinks it may have
9 been in relation to an appointment you had a year
10 later with a different doctor.

11 A. Mm.

Q. You're not entirely sure whether it was Dr Throssell
 or whether it was in fact a year later with
 a different doctor.

15 A. I can't remember.

Q. What you do know is that at the appointment when you
raised the question of going to see
a gastroenterologist --

19 A. Yes.

20 Q. -- that was the response that a doctor gave you.

21 A. Yeah, yeah.

Q. When your husband was referred to the
 gastroenterologist, he had an ultrasound of his liver
 and he was told there was no scarring to it. What's
 your recollection of what happened in relation to

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- 1 having a liver biopsy and the discussions around 2 having treatment for the hepatitis C at that point.
- 3 A. As I don't think he -- the way it was explained to us 4 was a liver biopsy would determine if there was any
- 5 damage to the liver, but it also came with
- 6 complications, and I think we decided at the time he'd
- 7 got enough going on, he'd got end stage renal failure
- 8 and everything else that goes with that, and it was
- 9 just something else that, you know, if it wasn't
- 10 affecting him and it wasn't making him ill, then we 11 didn't want to do it.
- 12 Q. Because you were also advised alongside that the
- prospects of success of interferon treatment --13
- 14 A. Were very low.
- 15 Q. -- were very low.
- 16 A. Yes.
- 17 Q. Your husband obviously had the renal failure, and he
- 18 also then had to have his parathyroid removed. You've
- 19 wondered whether the hepatitis C exacerbated his
- 20 renal failure, but you're not very sure.
- 21 A. I don't know.
- 22 Q. But it is a concern you have.
- 23 A. Yes, yes.
- 24 Q. He also had to have a hip replacement.
- 25 A. Yes.

- 1 Q. Can you tell us a little bit about the emotional 2 effect of the diagnosis of hepatitis C on your 3 husband?
- 4 A. Well, it -- like I said before, it was just something 5 else to deal with at the time, you know, you -- with 6 any chronic illness, you -- it's not something -- it's 7 not going to get better, so you adjust your life 8 around that. And then when somebody else comes along 9 and says, "You've got this as well" -- I'm sorry ...
- 10 Q. [Redacted] changed as a person.
- 11 A. Massive change. Yeah. He was -- he was horrible to 12 live with. He was just like a different person. And
- 13 I think he felt that, you know, life had been so
- cruel, and he just didn't deserve to have something 14
- 15 else as well, you know, with everything else that was
  - going on. Yeah, he changed a lot.
- 17 Q. He became more insular.

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- 18 A. Very, yes. He never told anybody he'd got
  - hepatitis C, because at the time I think people
- 20 thought -- they associated it with HIV, and there was
- 21 a lot of stigma, you know, people thought they could
- 22 catch it by being -- touching you or whatever.
- 23 I mean, I knew different, but other people didn't
  - know. And so we just lived in our own little world.
- 25 Yeah, we just got on with it.

- Q. Again, you've wondered whether the hepatitis C 2 affected his bone strength.
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- Q. What particularly made you concerned about that?
- 5 A. Well, when he had the hip replacement, the surgeon 6 told us that when he went -- when he went in, he put 7 his hand in and the bone just disintegrated in his 8 hand, literally just disintegrated.

9 He made a good recovery, made a really good 10 recovery, but, you know, we -- I think we were a bit 11 shocked at the time as to how bad it was. We 12 didn't -- I mean, he was in a lot of pain, he was in 13 a wheelchair, you know, he couldn't walk. So, you

know, he needed to have it done. But I don't think we

realised at the time the extent of the damage.

- 15 16 Q. Your question has arisen, you don't know, but was 17 there a link to it being particularly bad because of
- 19 A. A link, yes, yes, that made it worse, yes, yes.
- 20 Q. You've said earlier in your evidence that when your
- 21 husband was having the dialysis and dealing with the
- 22 renal failure, he had carried on working.
- 23 A. Yes, he ran his own business.

the hepatitis C?

- 24 Q. And life had carried on for the two of you.
- 25 A. Yes, yes.

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- 1 Q. Not even the rest of the family knew.
- 2 A. No.
- 3 Q. Nobody knew.
- 4 A. No. [Redacted] knew, but [redacted] is a nursing 5 sister that dealt with -- well, we've been friends 6 55 years. So she's like my sister.
- 7 COMPANION: A big sister.
- 8 MS FRASER BUTLIN: And that feeling of isolation and of 9 stigma was made worse because of changes to how your 10 husband had his dialysis.
- A. Yeah. 11

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- 12 Q. Can you tell us --
- 13 A. Very much so.
- Q. -- about that? What happened? 14
- 15 A. We -- for -- well, I dialysed him at home for 16 21 years, and -- but when he started to deteriorate,

17 we had to attend the hospital renal unit. But when 18 we'd gone abroad on holiday, we obviously had to tell

19 them that he'd got hepatitis C.

So we were isolated from all the other patients, and sometimes in not a very nice area. You'd be pushed into a little corner somewhere with the oldest machine, the oldest chair, no TV, no contact with anybody else, and just made to feel, you know, like you'd got some contagious disease. It was awful.

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- 1 Q. Sometimes your home dialysis machine would break.
- A. Yes.
- Q. You'd then have to go into the hospital in thiscountry.
- 5 A. Yes, yes.
- 6 Q. And much the same thing happened.
- 7 A. Yeah, I mean the -- it was an isolated -- you were in 8 isolation again, and you're on dialysis 4 hours 9 45 minutes, three times a week. It's a hell of a long 10 time to sit there on your own, you know, with no --11 I mean, I used to sit there with him, but, you know, 12 it's not -- just not -- it's not really nice to have 13 to do. And then if you're not feeling well anyway, 14 you know, the way that you're treated, because they 15 need to isolate you, you know, and everybody used to 16 come in all this protective gear, you know, and it was 17 just awful.
- Q. There was one particular occasion when you were going down to the coast and wanted to be -- [redacted] would obviously need to be dialysed down there. What happened?
- A. He could only go two days without dialysis, so if we
   were going for any longer than that, he had to dialyse
   wherever we were, and his mum lived in Paignton at the
   time, and he hadn't seen her for a while. We were in

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1 **A.** Yes.

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- Q. What can you tell us about how he came to be diagnosedwith renal cancer?
  - A. He was getting short of breath, and they advised us to see a consultant cardiologist. So they made the he had various tests, appointments, and then we went back, and I thought it was just a routine follow-up appointment, and when we actually got into the consultant's it was a consultant I'd never seen before, it was the first time I'd met him, and he'd never met [redacted] before, and he was just he was just looking through his notes and said, "Well, I'm sorry to say it looks like you've got renal cancer". And we were absolutely flabbergasted. We'd got no idea

Then of course everything gets set into motion about surgery and to remove the kidney. I mean, up to that point, he did have cysts on his kidneys, but they'd been beneficial because, without getting too technical, dialysis patients don't make erythropoietin, which is in your blood, which keeps your haemoglobin high, stops you feeling tired all the time, and his cysts were producing EPO on their own, so he didn't need to have it as an injection. So they were a good thing.

Sheffield, so, you know, it's a long way. By the time we got there he would've needed to dialyse.

So the renal unit in Sheffield contacted Exeter, which was the nearest hospital, and said could they dialyse them, and they said no, because of his hepatitis C, they hadn't got -- they hadn't got the facility -- they hadn't got a machine that they could

So she came -- she -- I mean, I wish she hadn't have done it, but the renal nurse that tried to fix it up said that his -- [redacted]'s mother was dying, so he needed -- that's why he needed the dialysis, and they relented and they said they'd do it. But I didn't know any of this and when I got there she said, "I'm so sorry to hear about your mother-in-law", and I had no idea what she was talking about. It was only when we got back to Sheffield that she'd told me what she'd done. She said, "If I hadn't have done that, they wouldn't have dialysed you."

- Q. Your husband was on the renal transplant list, but hishealth continued to deteriorate.
- 22 A. Mm-hm.
- 23 Q. He took early retirement in 2001.
- 24 A. Yes.
- 25 Q. Then in 2006 you were told he had renal cancer.

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But then one turns rogue or whatever it does, but then they assured us, they said, "If you're going to get it, it's the best cancer to get because it's isolated in the kidney, it's not going anywhere", you know, so we were a little bit reassured, you know. I mean, it's still a devastating diagnosis.

But we just sort of said, well, we'll -- you know, just go along with whatever they advise -- you know, advising you to do.

- Q. He was then referred to the oncology department to look at surgery to remove the kidney.
- 12 A. Yes, correct.
- 13 **Q.** What were you told?
- 14 A. In --?
- Q. What were you told originally about the removal of thekidney?
- A. That they would just take it out, you know, they would
   remove the kidney, and then -- there was no mention of
   chemotherapy or anything. That was it, really. They
   just said they would remove it and dialysis would
   carry on as normal.
- carry on as normar.
- 22 Q. There were then some concerns about his lungs.
- 23 A. Yes.
- 24 Q. Because he had got some fluid on the lungs.
- 25 A. Got some fluid on his lungs, yes.

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1 Q. So what happened in relation to that? 2 A. He was referred back to the Northern General and to 3 a cardiology lady, who they put a tube in his back and drew off all this fluid. It was quite a lot of fluid, 4 5 apparently. And they said they would test the fluid 6 that they'd taken off and they would ring us. He was 7 in hospital for about three days or something. 8 And I can remember getting the phone call at 9 home, and this lady rang and said, "There's no cancer 10 in the lungs, you Know, the fluid was clear". You 11 know, it's sort of good news and we thought -- we were 12 sort of, "Oh yay, at last some good news." 13 Q. So you went back to discuss the removal of the kidney. 14 A. Yes. 15 Q. And what happened between the August and the October? 16 A. I can't remember. Nothing happened, you know --17

Q. You kept phoning.

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A. I just kept phoning and saying, "Have we got a date for the surgery? You know, when is it going to happen?" And I kept getting fobbed off with, you know, "Oh, there's problems with the theatre because of his hep C. They can only do it either at the end of the day or" -- yeah, it was the end of the day, that's the only time they could do it and the theatres were full, and then they were only available on

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A. Absolutely. 1 2 Q. -- element of it. 3 A. Yeah, yeah. 4

Q. Your husband had been given some treatment to try and slow the cancer down, but as you say, by the October it had spread into the renal vein and into the lymph nodes.

8 A. Mm.

9 Q. It was also into the lungs.

10 A. Yes.

11 Q. Your husband remained on medication to try and slow 12 the course of the cancer, even though it was 13 inoperable, but he died on [redacted] 2008.

14 A. My birthday.

Q. You've said in your statement you had to stay strong 15 16 while your husband was alive and you were caring for 17 him, but that after he died you didn't want to see 18 anyone.

19 A. (Indicated dissent)

20 Q. And you stayed off work for three months and couldn't 21 face the world.

22 A. Except this one (Indicates).

23 Q. We talked earlier that you didn't particularly want to 24 say any more than that, but then there were 25 difficulties as well with the undertakers, and you did

certain days, and they had to co-ordinate it with his 2 dialysis, and -- you know, it just seemed like it was 3 just too much trouble.

Q. When your husband finally went back in in the October of 2006, what did they find in relation to the kidney? What were you told?

7 A. That the cancer had spread, you know, and that it was 8 inoperable, and it had spread to his lungs. And we 9 said, "Well, you know, we've already been told that 10 there was no cancer there", so it's -- this must have 11 happened between being told there was no cancer to 12 waiting for the surgery.

> Q. Within your husband's medical records there's quite a lengthy letter explaining what was going on during that time. We haven't got it up on the screen, but the explanation in relation to the delay from mid-August to October was:

"... a problem we have with organisation of lists across the two hospitals and the need to access the dialysis unit. There is quite a considerable administrative problem organising and getting access to the theatre lists."

There's no reference to hepatitis C being an issue but you recall in your conversations that that was a significant --

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ask me to read a couple of paragraphs from your statement about the difficulties you had in relation to the funeral arrangements. I'll do that now, okay?

"My husband's hepatitis C infection affected his funeral arrangements. I have a good friend of more than 50 years who is a clinical nurse specialist and who worked at the hospital and in the course of her job dealt with death all the time. When my husband was dying, she held his hand and tried to make his final moments less traumatic. She also advised me not to go to the funeral home because the undertakers would refuse to prepare his body due to his hepatitis

"My husband always dressed very smartly and he had several beautiful suits. I picked out a lovely suit for him to wear, but the funeral home wouldn't allow them to dress him, and he was cremated in his hospital gown, with his suit laid on top of him."

That's something you found particularly upsetting.

21 Yes. A.

Q. The final part I wanted to ask you about.

You and your husband received one payment from the Skipton Fund at some time between 2003 and 2007, but since then you've heard nothing further from the

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SIR BRIAN LANGSTAFF: 1.20. 1 Skipton Fund, and nothing from the new scheme, the 2 EIBSS. 2 (12.05 pm) 3 3 (Luncheon adjournment) A. No. 4 Q. In fact, you're not even particularly aware of who the 4 (1.20 pm) 5 EIBSS is. 5 SIR BRIAN LANGSTAFF: Our next witness is David. 6 6 A. I didn't know it existed. MS FRASER BUTLIN: That's correct, sir. 7 Q. Until I asked you whether you'd heard from them. 7 SIR BRIAN LANGSTAFF: David, please. 8 8 DAVID RANKIN (sworn) 9 9 Q. Mrs AX, that's all I have to ask you. Is there Questioned by MS FRASER BUTLIN 10 10 anything else you would like to say? MS FRASER BUTLIN: David, you have haemophilia A, and you 11 A. No. 11 started bruising when you were very young. You had 12 MS FRASER BUTLIN: Sir. 12 been adopted, so there were concerns that your 13 SIR BRIAN LANGSTAFF: It's really important that you've 13 adoptive parents were mistreating you. 14 come to give this very moving evidence, and one of the 14 A. That's correct. 15 features of giving evidence orally is it is not just 15 Q. But then you were diagnosed with haemophilia by 16 what is said, but how you say it. And sometimes what 16 a family friend, GP, who spotted the signs, and you 17 17 isn't said, but how you say it nonetheless, tells you were told that it was severe initially. 18 18 everything you need to know which words couldn't A. Yes. 19 convey. In my view, that's what you've shown us 19 Q. But subsequently that was changed down to moderate. 20 today. 20 A. Yes. In the 1970s, late 1970s, there was 21 So thank you very much. 21 a re-diagnosis from mild to moderate. 22 22 While you were growing up as a child, what impact did A. Thank you. 23 SIR BRIAN LANGSTAFF: We'll take a break. We'll take 23 the haemophilia have on your life? 24 a break until 1.20. 24 A. I was prevented from doing a lot of things. I was MS FRASER BUTLIN: Thank you, sir. 25 25 encouraged not do any activities that could 61 62 1 potentially cause me harm. The main impact would've 1 treatment with cryoprecipitate between August 2 2 been at school, when I was prevented from any sort of and September 1969, and it indicates that: 3 physical activity. So I believe teachers didn't want 3 "This centre is taking part in a survey arranged 4 4 the responsibility of being in charge of me when by the MRC cryoprecipitate working party in order to 5 an injury occurred. 5 discover whether transfusion jaundice occurs in 6 For instance, I was very keen to play football 6 patients suffering from haemophilia or Christmas 7 7 as a young lad, but prevented from doing so because of disease who have been treated with blood, plasma or 8 8 the risk of injury. However, I was given a linesman's plasma concentrates." 9 9 kit and encouraged to run the line. Not the same The doctor is then asked to indicate whether or 10 thing. My hero was Gordon Banks and I wanted to be 10 not jaundice had occurred following your treatment 11 a goalkeeper. 11 in August and September 1969. 12 Q. You were initially treated with plasma, then with 12 As far as you're aware, did your parents consent 13 cryoprecipitate until about 1983. 13 to being part of that study? A. Yes. 14 A. I actually think this document came to light fairly 14 15 Q. We'll come to the 1983 point in just a moment. 15 recently as opposed to when my mother was trying to 16 16 Your mum passed away about five years ago, but obtain records, because I'm sure she would've reacted 17 when she was still alive, she organised for your 17 somewhat differently to that, had she known about it. 18 medical records to be obtained, and you had a chunk of 18 As far as I'm aware, my parents were not made 19 them at that point. 19 aware of this study, and certainly I -- the first 20 A. Yes. 20 thing I knew was when this letter came to light fairly 21 Within those documents there was a document from 1969. 21 22 22 Q. As you were growing up, there were discussions about We're just going to have a look at that. 23 23 It's 3742005, please, Henry. you going to Treloar's, but your parents didn't want 24 We can see that it's a letter to your family 24 you to go there. 25 doctor at the time saying that you had received 25 A. No.

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- 1 Q. What was their thinking? 2 A. When I was initially adopted and it was discovered 3 that I had haemophilia, an offer was made to take me 4 back and replace me with somebody else, and my parents 5 fought to keep me, fortunately. So my parents always 6 had this attitude that I should stay within mainstream 7 education and grow up with other people, normal 8 people, and whilst Treloar's offered the opportunity 9 for excellent medical care, my parents felt that being 10 in a school that was exclusively for people with 11 medical conditions, that that possibly wasn't the best
- 13 Q. With hindsight, you're very glad that you remained 14 where you were.
- 15 A. Indeed, the statistics for haemophiliacs from 16 Treloar's do not make good reading.

way forward for me.

17 Q. We'll come back to that feeling of being very 18 fortunate to be here in a moment.

> You wanted to join the RAF as you were growing up.

21 A. I did.

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- 22 Q. You wanted to fly jets, so you tried to join the 23 school Cadet Force.
- 24 A. Yes.
- 25 Q. And they declined.

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and set off in the very early hours of the morning from Truro station, about 5.30 in the morning, I remember, to get to Biggin Hill in Kent. I arrived at Biggin Hill, presented myself to the guard room, and my name was not on the list. So I was guite insistent and I said I had travelled all the way from Cornwall, I had the letter with me that was the initial acceptance letter.

So after a little bit of digging around, somebody came to see me and said I wasn't on the list because they had sent me another letter saying that in view of the haemophilia, which I had declared, I would not be suitable for service in the RAF. That letter had obviously arrived after I left to get to Biggin Hill.

On the strength of me being quite keen and insistent, they said, "Seeing as you're here, you might as well undertake the testing."

- Q. And you passed. A. So the way it worked is at the end of the weekend, the list was read out, first of all for pilot, then for navigator, then for those who were lucky enough to pass the aptitude test for both pilot and navigator. The list was read out in alphabetical order, and first list for pilot, my name was not on the list; for

A. I went to Portsmouth Grammar School and they had 2 a combined Cadet Force unit, and attendance was 3 compulsory. You needed to do a minimum of a year, 4 attend an annual camp and one weekend camp and 5 complete a proficiency certificate, so initial 6 training syllabus. I assumed I would be joining it, 7 and when I was excluded I wanted to know why. They 8 felt, again, that the risks involved in cadet training 9 were not appropriate for somebody with haemophilia.

I did not want to be excluded from the activities that my peer group were undertaking, and so, with my parents' support, I argued and eventually the school said "Okay, join the CCF", and I elected to join the RAF section of the CCF.

- Q. Your parents subsequently moved down to Cornwall and there you were able to join the local Cadet Force.
- 17 Yes. Α.

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- 18 Q. At 16 you applied to join the RAF itself.
- 19 A. Yes.
- 20 Q. What happened?
- 21 A. So at that stage you could apply for a test in 22 advance. So at 16 you could apply to the RAF, test in 23 advance and they would test -- it was a short test, 24 a weekend at Biggin Hill to test your aptitude for 25 pilot and/or navigator. I applied and was accepted,

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1 navigator, my name was not on the list; for pilot and 2 navigator, my name was not on the list. So at that 3 point I figured I'd made a complete and utter fool of 4 myself. 5 However, because I was not on the list, my name 6

was read out last, having passed both the aptitude test for pilot and navigator.

- Q. But subsequently the chief medical officer declined to allow you to go forward because of the haemophilia.
- 10 A. So initially I received a letter saying, despite the 11 pass for the aptitude test, in view of my medical 12 history, I was deemed permanently unfit for service. 13 I argued that such characters as Douglas Bader had successfully flown with the RAF, despite being 14 15 a double amputee, and at the time -- I cannot remember 16 the name of the pilot, but somebody had undergone 17 fairly major heart surgery and had also continued to 18 fly with the RAF.

So eventually I was invited for an interview with the chief medical officer at Goodge Street in London. I argued my case, he argued -- not his case, but the case on behalf of the accountants, who didn't want to run the risk of training me, only for me to be run over outside the base and be unable to fulfil my duties.

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After a lot of toing and froing, he did offer me a desk job, which I, in the pride of a teenager, declined, rather foolishly. I subsequently realised that if I'd taken the desk job, I probably could've transferred over into a flying role at a later date.

- Q. That meant you had to decide on something you've described as your plan B for your career.
- 8 A. Plan B had already been initiated. The process of
  9 arguing with the RAF took some six years, so I didn't
  10 really give up arguing until I was 21/22. In the
  11 meantime, I had elected to find a job, and I found
  12 a job with National Westminster Bank.
- Q. Your parents then moved away from Cornwall and youwent with them.
- 15 A. Yes.

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- 16 Q. And ended up working in a bank in London.
- 17 A. Initially in Crawley, and then I got transferred to 18 the Haywards Heath branch, where I ran into a chap 19 called Dick Simmons, who subsequently became the 20 training manager for the area. He spotted something 21 in me which I hadn't spotted, and he got me a job or 22 got me on a training course for a role in London in 23 the insolvency and debt recovery office. So, yes, 24 I ended up working in King's Cross.
  - Q. That timeline of being in Cornwall, then moving on up
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1 A. The swelling was no longer increasing. The bat had 2 walloped me. I hadn't lost consciousness. It had --3 it had broken the joint between the cartilage and the 4 bone, but it wasn't to my mind a severe injury. Yes, 5 looking back at it today, it was a head injury of 6 sorts. But as I say, I wasn't suffering from any 7 nausea, the bleed seemed to be under control, it 8 seemed to be sorting itself out, and I would've 9 preferred to have waited 24, 48 hours. My usual MO 10 for bleeds was I would clot and either it would hold 11 or it wouldn't hold. So subsequent to this I'd often 12 leave things for 24 hours before doing anything about 13

- Q. When you received the Factor VIII, were you warned of any risks involved in receiving it?
- A. I had no recollection of being told that there was a risk with the treatment, and I have had this conversation subsequently with my parents and neither of them remember it being mentioned at the time, because although I was over 18, my mother was accompanying me because obviously I wasn't fit to drive myself to the hospital, so she had driven me.
- Q. You've tried to obtain your medical records from
   Treliske Hospital, but you were told they've been
   destroyed.

eventually to London helps you pinpoint the date on which you received Factor VIII --

- 3 A. Yes.
  - Q. -- that you believe infected you with hepatitis C.
- 5 A. I'd been very fortunate in Cornwall. So from the tail 6 end of 1979 onwards, I hadn't received any treatment 7 at all, and then I joined the bank on 2 August 1983, 8 a Tuesday. The following Monday I was playing 9 rounders with the local Rotaract club on the beach 10 near Trevose Head in Cornwall. I was second into bat, 11 and the person in front of me, rather than throwing 12 the bat on the floor, threw the bat over his shoulder. 13 I hadn't anticipated that, and it hit me in the face, 14 cracking my nose, my cheek and blacking my eye.

So I ended up at Treliske Hospital in Cornwall, just outside Truro, with a half-open packet of peas clutched to my face, hoping that they'd have a look at it and sort it out for me.

- 19 Q. That was August 1983.
- 20 A. It was, it was August 1983.
- Q. At that point when you went in, you receivedFactor VIII products.
- 23 A. Yes.
- Q. You believe that they weren't necessary on thatoccasion. Can you tell us why you think that?

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A. My mother did that on my behalf. So when I started to become ill in the mid-1990s, I deteriorated slowly, but mentally a little bit quicker than physically, and my mother took it upon herself, as was in her character, to try to find my medical records to pinpoint when this infection must have happened.

She was told by Treliske Hospital that my records were no longer available and that they had been destroyed. She did enquire whether they had any records of the treatment that they'd used and what they'd had and what they'd done with it, and they said no, they didn't have those records either.

- Q. Subsequently there is an entry in your UKHCDO record --
- 15 **A.** Yes.
- 16 Q. -- of the treatment.
- 17 A. Yes.
- 18 Q. Did you ever receive Factor VIII again after that19 incident as far as you know?
- A. I think possibly I did. I'm not certain. The next time I can recall receiving treatment will have been when I'd moved back to the south-east and was registered with St Thomas', and the first time I can recall requiring treatment, expecting to get Factor VIII. I was offered either DDAVP otranexamic

25 Factor VIII, I was offered either DDAVP otranexamic

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- 1 acid, which surprised me until I was told that they 2 thought they had some issues with Factor VIII.
- 3 Q. So you'd gone in expecting Factor VIII at that point.
  - A. Yes.

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- 5 Q. You were offered something different, and what exactly 6 did you say and what did they say?
- 7 A. I was suffering from nosebleeds and I was expecting to 8 be treated with Factor VIII, and St Thomas' said, "No, 9 we'd rather go down the route of trying these 10 alternatives". And in the end, for that injury, my 11 nose was cauterised.
- 12 Q. Did they say specifically what they were concerned 13 about in the Factor VIII?
- 14 A. I cannot recall that. All I know is that my 15 recollection is that there was an issue with it.
- Q. In 1990, you were working in London and went for 16 17 a routine check-up at the Haemophilia Centre.
- 18 A.

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19 Q. You received a phone call a few days later.

20 Can you tell us what was discussed on that phone 21

A. So I can't remember the day but, yes, I'd been in for a blood test, and they telephoned me and asked -- they said they'd got some interesting results and they wanted to enquire whether I had been drinking the

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A. Unfortunately I've not been able to obtain my sickness record card, but I can visualise it and the entries were regular for flu-like symptoms. So I would ring up and say, "Look, I'm sorry, I'm unwell and it's

> These flu occurrences were happening more and more regularly, and I didn't think an awful lot about it, but some of my colleagues sort of said, "You don't seem yourself, you don't seem to have the same amount of energy, the same vitality". And so it wasn't a huge surprise when the diagnosis was eventually given that I had hepatitis C.

- 13 Q. With your move north, your treatment transferred to Birmingham. 14
- 15 A. Yes.
- 16 Q. And you were asked to have blood tests.
- 17 A. Yes.
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- Q. What happened after that? 19 A. So I received a phone call saying that they'd like me 20 to come in as a result of the blood test. So 21 I attended the hospital. I wasn't able to see the 22 person in charge, Jonathan Wilde. A junior doctor 23 spoke to me in a corridor and delivered the death 24 sentence that I had hepatitis C. He went on to say

25 that he felt it was as a result of my lifestyle

night before. I said yes, there had been somebody's leaving do and I had three or four pints, and they said, "Oh, okay, that possibly explains the results that we've got."

I enquired what that was and they said, "Some of your liver function enzymes are elevated", and that was the end of the conversation. I was reassured by the fact that they thought it was possibly down to having a couple of beers.

- 10 **Q.** From then until your diagnosis, was there any 11 follow-up of those blood tests that you are aware of?
- 12 A. Not that I recollect at the time. I know from 13 subsequent conversations that in addition to the blood 14 tests, they were also testing for at least HIV, and 15 I think subsequently they did mention they were 16 looking for non-hep A, non-hep B as well.
- 17 Q. But as far as you're concerned, at the time, between 18 1990 until you were diagnosed, there weren't regular 19 checks of your liver function tests that you knew 20 about?
- 21 A. No, not that I knew about.
- 22 Q. You then moved north because you received a promotion.
- 23 A. Yes.
- 24 Q. And in 1992, you started to struggle at work. What 25 was happening?

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- 1 choices and that was pretty much the tail end of the 2 conversation. I was left to drive myself back from 3 Birmingham to [redacted].
- 4 Q. That news was delivered in the corridor.
- 5 A. In a corridor.

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- 6 Q. With other patients around?
  - A. And people walking past, yes.
- 8 Q. After you had driven home, you then subsequently met 9 with Dr Wilde, Jonathan Wilde, and what did he say to 10 you?
- 11 A. So he apologised for the way the news had been 12 delivered. He was very sincere in his apology. He 13 went on to say that it was his choice to let patients know, his patients know, that they had hepatitis C, 14 15 and that other clinics and other trusts were not 16 telling their patients because they had nothing to 17 offer them in the way of treatment.

He went on to say that he didn't have anything to offer, but there was a hope that there might be something available in the future, and as soon as there was, he would let me know.

- Q. You've recorded in your statement that he said that he felt compelled to share the information with patients.
- 24 A. He felt it was important that his patients, that all 25 patients, should know the conditions that they were

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1 suffering from in order that they could make either 2 arrangements or changes in their lifestyle 3 accordingly.

Q. You received a letter following up from that discussion with Jonathan Wilde. We're just going to look at it. It's 0357002, please.

We can see the letter in the middle saying:

"We are currently reviewing all our patients who have received coagulation factor concentrates in the past to see whether they have evidence of chronic inflammation of the liver caused by the hepatitis C virus. It is well recognised that prior to heat treatment of concentrates hepatitis C virus was very readily transmitted in factor concentrates. In some individuals, the virus settles in the liver and causes chronic inflammation. It has recently been shown that the drug interferon can eradicate the virus in some people."

Then it goes on at the end to indicate:

"We are setting up a joint clinic with the liver doctors so we can discuss hepatitis C infection with you further and, with your agreement, take the opportunity to perform the new blood test to establish the situation for you."

SIR BRIAN LANGSTAFF: And the new blood test is that

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1 resignation letter.

- 2 Q. So we'll come back to that.
- 3 A. Yes.

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- 4 Q. But in 1996, you became unwell, and then did start 5 treatment, and you went on interferon and Ribavirin.
  - A. Yes.
- 7 Q. What was that like?
  - A. Not enjoyable at all. The Ribavirin was supposed to attenuate some of the side-effects of the interferon, not too successfully. The main side-effects of interferon are mood swings, violent mood swings. You know it's going to happen, but there is absolutely nothing you can do about it. Additionally, night sweats, increased flu-like symptoms. It's not a nice process at all.
  - Q. By then you were married.
  - A. Yes.
- 18 Q. And you've said you were surprised that your wife put 19 up with you at that point.
- 20 A. My then wife had previously been out with 21 a haemophiliac who tragically died, so she was aware 22 of some of the things with haemophilia. We had the 23 discussion before we were married. After my 24 diagnosis, we had a further discussion, and at all 25 stages up to the point we actually got married, I said

referred to in the last sentence of the first 2

paragraph?

3 MS FRASER BUTLIN: It is, apologies, sir. Yes, exactly.

SIR BRIAN LANGSTAFF: Thank you. 4

5 MS FRASER BUTLIN: You attended for that blood test.

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- 7 Q. And you were confirmed to be PCR positive.
- 8 Yes.
- 9 Q. You didn't start treatment at that point, but 10 treatment came later.
- 11 A. My recollection is that it was still very much 12 a trial. So it was a fight to get on that trial. My 13 viral load at the time indicated that the trial would 14 potentially not be successful, and obviously the trial 15 was expensive, so there was a struggle to get me on 16 that trial with interferon.
- 17 Q. But at around this time, you decided to resign from 18 the Cadet Force that you'd been part of all of those 19
- 20 A. That was actually a little later than this.
- 21 Q. Ah, apologies. Sorry, your statement had -- can you 22 tell us when you did resign from it, was it after 23 treatment?
- 24 A. Once I moved back to Sussex in early 2000 -- I believe 25 2002/2003 springs to mind. I'd have to find my

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- 1 to her, "If you want to back out of this, I will 2 understand entirely". And she chose not to.
- 3 Q. You've described in your statement that you were 4 a very difficult person to live with during that time.
- 5 A. I didn't like living with me and I can't imagine that 6 anybody else would've found it in any way an enjoyable 7 experience.
- 8 Q. You continued to work during the treatment.
- 9 A. Yes.

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- 10 But a senior manager at work tried to remove you.
- 11 A. My immediate line manager had noticed difficulties, 12 and I had mentioned to him what was going on and he 13 was extremely sympathetic. I was then approached by 14 the clerk to this senior manager, and the clerk said 15 that this senior manager wished to interview me. He 16 then went on -- we had worked together, this clerk and 17 I, and he went on to say a warning, more than anything 18 else, that he felt that she intended to use the interview as a means of dismissing me, or perhaps

19 20 start the process of dismissal.

21 So forewarned, I went into the interview. 22 A statement had been prepared for me and the interview 23 was along the lines that I must know that my 24 performance was not of a standard that was acceptable,

> and that therefore I should sign this witness 80

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statement to that effect, and that would then be the mainstay of the dismissal process. I declined to sign that statement. I felt it was inequitable and unfair and incorrect. This senior manager wasn't particularly happy about that, but there was very little that she could do about it at that point.

Q. Then what happened in relation to work?

A. My line manager suggested that the health -- the occupational health nurse, who was due to visit anyway, should speak to me. I spoke to the occupational health nurse. She was most sympathetic and she said, "Go and pack up what you got from your desk and go home". I said, "What do you mean?" She said, "Go home. We'll take it from here. You will be paid sick for a minimum of six months. If I can organise it, it will be a year. During that period of time, we'll refer all of this to the bank doctor. He may wish to see you, he may not, and a decision will be taken "

The bank doctor was most sympathetic. He phoned me up and said, "Look, there's no need to drag you all the way down to London. If you're happy for me to speak to your medical team, I'll do that and I'll keep in contact with you and let you know what the decision was."

bed. You can have brief bursts of activity, but it's a general deterioration in both physical health and consequently mental health. I certainly became extremely lethargic, tendency to become melancholy or depressed, and uncommunicative.

- Q. And in 2001, your marriage broke down.
- **A.** Yes.
  - Q. Partly because of the strain of her working all day, you being retired, and all the mental effects that you were suffering from.
  - A. You know, I understand entirely, it must be extremely difficult to work all day to support somebody who initially -- you got married, we're going to support each other. To leave the house with this person still in bed being miserable, come home perhaps to find them in the armchair, sat in front of the TV having done nothing all day in the way of housework, contributing to the household. I was offering absolutely nothing and, yeah, it took its toll. I do not blame her, and hopefully she doesn't blame me too much either.
  - Q. One sadness from that time is the fact that you never had children.
- A. The period of time this happened was absolutely the sweet spot for most couples to start a family, and that didn't happen for us, which is possibly

And the decision was very favourable. NatWest was a fantastic employer. It was a case of, "No, no, we understand entirely, most unfortunate set of circumstances, we'd like you to retire early through ill-health. We'll increase your service from 14 years to 20 years for pension purposes. You may draw down your pension immediately, and whilst you continue to live, you will have full staff benefits."

I did take the precaution of showing this offer to the union, and the union said, "It's the best offer we've ever seen, you should rip their arm off at the shoulder". So I was very, very grateful to both the bank's doctor and the senior management at NatWest.

14 Q. In terms of that first round of treatment, it was15 unsuccessful.

16 A. Yes.

Q. How were you told about that?

A. Essentially, it was a phone call to say, been
unsuccessful, no, they were taking me off the trial,
so that was it. A little bit of hope disappeared.

Q. What was your health like when you finished thattreatment?

A. I think anybody whose had hepatitis C, it is -- it's
 described as flu-like symptoms. Severe malaise. You
 don't want to do anything, you'd much rather stay in

fortunate, the difficulties with being ill, and also
the awareness that I might not be around to father any
children for very long was very much in the forefront
of both of our minds.

Q. You've described that between 2003 and 2005, youbecame very insular.

7 A. Yes

Q. Do you want to tell us anything else about that period of time in your life?

A. It's -- the slippery slope is one that you don't perceive at all when you're at the top of it. It's only really when you're well and truly going down that slope and you start to realise that, having had quite an active social life, various hobbies and activities, friends, parties, meals out, et cetera, et cetera, it just dawns on you that suddenly, through no fault of anybody else's but your own, you're sitting there on your own, hoping that nobody comes and knocks on the front door, not answering the phone, and just building a wall, is how I would describe it, and hoping to hide behind that wall until it all goes away or it's all 

Q. One of the activities you had withdrawn from was the Cadet Force.

25 A. Yes.

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1	Q.	Why had you stopped doing that?
2	A.	It was an activity I'd got so much out of cadets as
3		a young lad, I wanted to pay that debt back, and
4		I continued to try and do so until I realised that
5		I really wasn't doing the things that I should be
6		doing. I was now no longer physically capable of
7		doing those things. So, with much regret, I offered
8		my resignation. I felt it was no longer fair to the
9		young people. I couldn't do what I was supposed to
10		do.
11	O	In 2005, you went with some friends down to watch the

- 11 Q. In 2005, you went with some friends down to watch the 12 24-hour Le Mans.
- 13 A. I did.

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- 14 Q. On the second day, you became unwell.
- 15 A. I had usual flu-like symptoms on the way down. 16 I drove my car on the way down there, and the -- we 17 would go down several days before the race started, 18 set up camp, a large marquee tend, lots of individual 19 sleeping tents. We went to collect some firewood and 20 I was feeling more and more unwell, letting other 21 people do most of the donkey work, and then I just 22 took to my bed, and that was it. I never did get to 23 see any of the race. I heard it, but I didn't get to 24 see any of the racing.

I was in more and more pain. Not entirely sure

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Q. Looking back, sometimes you're not entirely sure what was really going on and what were the hallucinations and the paranoia that you were feeling.

- A. Certainly. I do know that I had already had the diagnosis of hepatic encephalitis, so that would have contributed to it, plus also large amounts of morphine.
- 8 Q. You stabilised and were allowed to go back to your 9 parents' house.
- 10 A. Addenbrooke's got me stable and they said, "Look, you 11 can wait here for a liver, but it's probably going to 12 be better for you if you're in a more familiar and 13 friendly environment". So I went back to -- rather than going back to my house, because I wasn't fit to 14 15 look after myself, I went to wait at my parents' 16 house, mainly bedridden.
  - Q. You were waiting for a call to say there was a suitable liver --
- A. Yes. 19
- 20 Q. -- transplant.
- 21 A. The process had been explained to me quite clearly, 22 that when a suitable liver -- I was fairly close to 23 the top of the list at this stage, and as soon as 24 a suitable liver -- for those who don't know, it's 25

where it was, it was just about all over, and so once we were due to come home, I was not in a fit state to drive. So I said to my friend, "I'm afraid you're going to have to drive home", and it was an agonising trip home for me.

Shortly after we got back I realised that things were not getting better, so the next thing was an ambulance trip from my house to St Thomas'.

- Q. And then subsequently you were moved from St Thomas' up to Addenbrooke's.
- 11 A. My recollection is there was some -- dispute is the 12 wrong term. My mother wanted me to go to 13 Addenbrooke's. I'd already been to Addenbrooke's for 14 my assessment prior to transplant, and my mother felt 15 that this was -- I needed to be in Addenbrooke's. St 16 Thomas' didn't think I was stable enough to transfer. 17 But eventually the point came when both hospitals 18 agreed that that was the way forward, so it was a trip 19 from St Thomas' to Addenbrooke's.

In the meantime, my reaction to the painkillers, mainly morphine, was that I'd become delusional, I think, certainly was having some very spectacular hallucinations. I've got -- I have got some relatively clear memories of that time, but they are pretty haphazard.

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as an O positive liver became available, they would give me a call and I would get myself up to Addenbrooke's, my dad would drive me up to Addenbrooke's, and then we'd go through the pre-operation process in preparation for a liver.

> And that's indeed what happened. We got a phone call. We did get told to treat it as a dry run because they weren't certain whether that liver would be in a fit state to transplant by the time we got the liver and me up to Addenbrooke's. I don't recall being told where the liver was coming from but they did say it wasn't sourced in-house.

I got to the hospital and they said, "Look, time-wise, it's still within the time frame, so we're going to go for it, with your consent". At that stage, it's not a case of consent; it's the only choice you've got. So prepared for the operation, told to get a little bit of sleep while they did the work, went down, premeds, lights out, and the next thing I knew I was coming round in the recovery room.

- Q. Initially it seemed like everything had gone fairly well, but after 48 hours you deteriorated.
  - A. Initial sense of absolute euphoria. I'm alive. All is good. And that was pretty much -- I was very weak. It's a huge operation, two surgeons having their hands

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inside you; one doing the removal, one putting the other one back in. I wasn't really aware of anything other than the faces of the medical team, looking more sombre than I would expect, and eventually it was explained to me that although the liver had gone in nice and pink and healthy, it hadn't started to do its job. So blood (inaudible) was still good, it wasn't dead, it wasn't being rejected, it just was not working.

Consequently, the only course of action was another liver transplant, and they hoped that another suitable liver would be available in time.

- Q. There was one particular Saturday afternoon when it was very solemn.
- A. So initially I was quite well, but I started to deteriorate. I ended up on the high dependency unit at Addenbrooke's and in an awful lot of pain. I was not healing, so as fast as they were trying to get units of blood in me, it was leaking out from all over the place, basically.

I had been in and out of consciousness, and it was a Saturday afternoon, and I remember coming to and seeing a lot of familiar faces, but the one thing that struck me was in amongst those familiar faces was the hospital padre, and none of those faces looked

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1 of it. Yes, I was aware of it.

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- Q. That continues to give you nightmares.
- A. I had some very, very bad nightmares at the time and, yes, it -- it's still somewhere that -- unfortunately your mind takes you back to these places when you least expect it and certainly you don't want it.
- Q. You were very weak after the second transplant.
- A. When I went into hospital, first of all, I weighed about 22/23 stone. When I finally left hospital in February 2006, I weighed just over 11 stone.

Physically I got to the point where I could do nothing for myself whatsoever. To pick up a plastic cup half full of water was almost all I could manage. So it really did take its toll on me.

I had become institutionalised. I was not getting any better, any worse. Although I did not fulfil the criteria to leave hospital, it was felt that the only way I would make any form of recovery would be back in, again, a familiar environment and not staring at the same walls in the ward that I had been for several months.

- Q. You say in your statement you had become a difficult and uncooperative patient.
- A. Yes. I've had counselling for this. I still haven't

particularly cheerful.

Slipped into unconsciousness, and on the Sunday morning I remember sort of coming to and croaking at the nursing staff and they all looked very surprised to see me. No breakfast had been ordered for me, and subsequently the medical team did say they had not expected me to make that Sunday.

- 8 Q. You had a second transplant --
  - A. Indeed.
- Q. -- at the beginning of December 2005. What can you 10 11 tell us about that?
- 12 A. I was incredibly weak by that stage. It was very 13 touch and go as to whether it was a waste of 14 everybody's time. But we did go ahead with it, and 15 that liver had actually been sourced in-house, so 16 Addenbrooke's were very confident that it would be --17 well, it'd be down to me physically whether I could 18 cope with it or not, and we went for it and here I am.

So I came to after the second operation -actually, in truth, I came to during that operation. I was in such a weakened state that the anaesthetist had tried to use the minimum amount of anaesthesia. and unfortunately I had slipped back into consciousness during the operation. It had been noted. I was subsequently asked whether I was aware

1 spells in hospital and had remained cheerful and 2 co-operative. On this occasion, I wasn't able to do 3 so, and I recognise that my behaviour was certainly 4 not what I would hope for myself, although obviously 5 the nursing staff were very understanding. When 6 I subsequently went back to apologise, they said there 7 was absolutely no need, but it's still something which 8 does not sit well with me.

- 9 Q. You've said in your statement logically you understand 10 that anyone else in the position would've been exactly 11 the same.
- 12 A. I would forgive anybody else, but I struggle to 13 forgive myself.
- Q. You were discharged back to your parents' house. 14
- 15 A. Yes.

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- 16 Q. And you say that the initial delight of being 17 discharged soon faded.
- 18 A. I hadn't smelt fresh air for -- well, since the middle 19 of October until the middle of February. So 20 I remember being wheeled out, because I wasn't capable 21 of walking, into the ambulance, and that just brief 22 smell of fresh air was quite euphoric again.

They got me home to my parents' house, lifted me in, and -- a combination of things. So obviously my parents had other things to do, so I didn't have the

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quite forgiven myself for it. I had had plenty of

1		nursing staff at my beck and call as I had done	1	little blob of material on the end, quite
2		before, and it was a long and painful process to get	2	sweet-tasting, and you get a very good initial hit
3		back to a state where I could look after myself.	3	from these things. They come in various strengths,
4	Q.	It took three months before you could walk again.	4	and at one stage I was on the strongest ones.
5	A.	Yes.	5	By all accounts from other people I'd become
6	Q.	It took until August 2006 when you managed to find	6	very talkative having got the initial hit, and it is
7		your car keys	7	phenomenally addictive, but I was not told that at the
8	A.	Correct.	8	time. I did notice that my use of these lozenges
9	Q.	and drive.	9	I was in pain, I did need to use the lozenges, but my
10	A.	Yes.	10	usage accelerated, which obviously, with the benefit
11	Q.	It took about a year before you could function	11	of hindsight, is a clear indication that not only was
12		independently.	12	my body becoming tolerant of it, but it was starting
13	Α.	Certainly. My mother would she really didn't want	13	to want and crave the drug.
14		me to go and live on my own again, but it was	14	It got to the point where I realised I had
15		important for me to do that, but I would have regular	15	a problem with them. I had the phrase I used to
16		visits, and she'd come round with food and with	16	choose to use was I had become dependent upon them,
17		housekeeping materials and so yeah, although I was	17	but in reality that's an addiction. I was addicted to
18		living on my own, it was certainly not unaided.	18	them.
19	Q.	While you were in hospital, you had been given a lot	19	I decided not to keep them in the house because
20		of opiates.	20	I would just consume them, so I kept them at my
21	Α.	Yes.	21	parents' house, which is some 6 miles away from mine.
22	Q.	You continued to use fentanyl after your discharge.	22	But I had a key, so I would sneak over there in the
23		Lovely stuff! Yes, I had been given lozenges,	23	small hours of the morning. So 2.30/3 o'clock, I'd
24		fentanyl lozenges. A bit like some of the candy you	24	drive over there, help myself to they come in
25		would have had as a kid, sort of a lollipop stick with	25	a strip of four and sneak off back home, and I'd
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1		probably demolish two of them on the journey on the	1	you had some fentanyl?" I said Friday. This is now
2		way home. So my consumption was rapidly accelerating.	2	Sunday. But I hadn't got any, and I had used the
3		It came to the point where I decided it was	3	stash at her house, unbeknownst to her, so she phoned
4		an issue, so I would stop using them. I can't	4	the local pharmacist who said, "I can't give you any
5		remember how many I was using at the time. But in my	5	fentanyl, I haven't got any, but I have got a patch,
6		wisdom, I decided to go cold turkey. A friend of mine	6	I'm willing to let you have a patch, which it will
7		asked if I'd help him collect a vehicle he had	7	take a while to kick in, but will tide you over until
8		purchased, an old ex-army fire engine from a place	8	we can get you some lozenges."
9		called Withams near Grantham on the A1. So	9	So that was it, straight back on the lozenges
10		I accompanied him, and on the way back I was driving	10	for another period of time. I did speak to my GP,
11		said fire engine. Lovely warm day coming down the	11	a very understanding man, but he said, "No, we're
12		M11, had both doors open on the side of it, and	12	going to step down the analgesic", and I wasn't
13		I started to shiver, and I became very, very shivery.	13	prepared to do that. So in the end, I went cold
14		I thought, that's a bit odd, obviously a bug of some	14	turkey again. I went on holiday with some friends of
15		sort.	15	mine to Spain without any lozenges. It was a torrid

By the time we got back to Plumpton -- quite a long journey -- I started to experience paranoia. I could feel my skin crawling. Local pub, I was quite convinced all these people -- I know everybody in there, but they were all staring at me, they all had some intent, I don't know what.

So I retreated home, spent a very uncomfortable night, and the following day I rang my mother to say, "I don't know what's going on, something's wrong".

She figured it out. She said, "When is the last time

19 Q. But it had taken you three years to --

20 A. Yes

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21 Q. -- be free of the dependency.

them since.

22 A. Mm.

Q. Since the second liver transplant, you've had regular blood tests for hepatitis C.

four or five days, more for them than for me I

suspect, but I did come home and I haven't touched

A. Yes.

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1 Q. And you are undetectable. A. Yes. 2 3 Q. The doctors are puzzled by that. 4 A. Puzzled would be an understatement, yes. 5 Q. Do you want to say what has been happening? 6 A. So I had an enormous viral load before my first liver 7 transplant and before my second liver transplant. 8 There is no other case on record of somebody with such 9 a high viral load no longer having any trace of 10 hepatitis C in their system. So it was 2005, the last 11 transplant, so we are now nearly 14 years on, and 12 regular six-monthly blood tests, no sign of 13 hepatitis C to date. 14 However, the medical team are not willing to 15 give me an assurance that that's the end of it, so 16 I still have that sword of Damocles hanging over my 17 head. 18 19 20 21 you mean by that? 22 23 24 25 fed up of driving 80 miles to be told, "You're still 97 1 2 your father received a further letter from them 3 providing further records. 4 5 6 up?" I said, "Yes, by all means". So totally 7 8 9 10 previous time. 11 12 to your mum, was: 13 we have additional information. If you want it, 14

Q. You've said in your statement that although doctors are keen for you to live as long as possible, they're also keen to make lifestyle choices for you. What do A. So we have had some discussions. I have always been overweight, fat, and so I stopped attending my annual check-up a couple of years ago simply because I was seem to be some missing, and then in August this year A. Yes, out of the blue he said to me, "I've had contact addressed to your mum, do you want me to follow it unsolicited on our behalf, somebody had done a trawl through the records and discovered that they did have some records that they claimed they didn't have the Q. The original letter, which, as you say, was addressed "We have recently become aware of the fact that 15 please email us." A. Yes. 16 17 Q. Your dad followed that up. 18 A. He did. 19 Q. We have the letter in response. It's 3742003, please, 20 Henry. Thank you. 21 It's from August 2019, and it says this: 22 "We are contacting you because you previously 23 requested a copy of the personal information held 24 about your relative at the National Haemophilia 25 Database. Following that request, we sent you all the 99

overweight, you need to lose weight". The 2 conversation regarding my blood work -- my blood work 3 has been constant for all of that time, so I elected 4 not to go anymore. 5 Q. Part of that was the discussion around weight, but 6 you've also said in your statement you struggle to 7 trust doctors. 8 A. I am far more cynical, sceptical, call it what you 9 will, now than I used to be. So I have no choice. 10 I need to trust the NHS, and I'm absolutely convinced 11 that every person I deal with has got my best 12 interests at heart. But it is difficult to 13 disassociate what has happened to me with current 14 15 Q. Another aspect of that has been the question of 16 records going missing and the availability of your 17 medical records. 18 A. Yes, yes. 19 Q. As we spoke about earlier, before your mum passed 20 away, she had tried to look for records and she 21 applied to the UKHCDO at that point. 22 A. I didn't know this, but yes, she had. 23 Q. You've now discovered that's what she had done. 24 A. Yes. 25 Q. And she received some documents from them, but there 98 information that was held on our electronic database. 1 2 It was assumed at the time that the electronic record 3 was a complete record. 4 "However, on recent inspection of the paper 5 archive, we discovered that some details, from paper 6 forms submitted to the database in the 1970s through 7 to the 1990s, were archived but not entered into the 8 electronic record. These forms were submitted many 9 years ago by your relative's Haemophilia Centre when 10 the database was held in Oxford, before paper 11 reporting was phased out in 2000. 12

"Please see the enclosed additional paperwork that we have found on your relative when going through this archived material. We apologise unreservedly that you were not sent all the information after your initial request and for any distress or difficulties that this may have caused."

With that letter, you were provided with some further documentation.

You've also said in your statement that you're now a very different person to who you were in the early 1990s.

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24 Q. Can you tell us a little of how you feel you've 25 changed?

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A. I suppose the initial thing I should say is that undoubtedly we all age and change. However, I think I've changed more than you would expect. Notwithstanding the insults both mental and physical.

> I was very gregarious. I was an active member of Round Table. I was involved in the Army Cadet Force. I was the chairman of the sports and social club at work, and, yes, my leisure time was full of activities involving other people. All of those things have been taken away from me.

I have rebuilt a life post-transplant, and the people I mix with now are very nice people, but it's -- it does strike me that an awful lot of the activities I undertake now are less social and less gregarious than they once were. I am a more melancholy person than I once was, certainly more cynical, less trusting. Yes, less full of the hope I once might have had.

- 19 Q. You're now engaged to Jan.
- 20 A. Yes.

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- 21 Q. You've tried to live together with her and her son, 22 but you've struggled to cope with that.
- 23 A. Yes. We have touched upon my building the wall. 24 Well, that happened again once I was back on my own, 25 so 2006 onwards.

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that support and encouragement has been repaid by huge amounts of anxiety and fear. No parent should stand by a hospital bed, watching their child essentially dying, repeatedly.

I have no idea of the anguish that my mother went through during those months up at Addenbrooke's. She effectively moved into a house up at Addenbrooke's while I was there, and nothing was too much effort for her. I would not be here without the effort of both of my parents, but in particular my mother.

The only satisfaction or the only glimmer of satisfaction, I suppose, is that she saw me come out of hospital and start to rebuild my life, something which I'm sure on more than one occasion she didn't think was going to happen.

- Q. You've mentioned that you've had counselling.
- A. Yes.
- Q. You had to seek that privately.
  - A. I did. I wouldn't have done so. It was at the insistence of a very good friend and my mother, who both said, "Look, we know you're going to be anti this", and I was, and they said, "But go and give it a go". And so I was on benefits at the time, so it was at a reduced rate, but no, it did cost me, and it was a very useful process. I embarked upon it merely

So when I first came out of hospital, my friends were very pleased to see me, lots of social activities were encouraged, people would come and visit. But I obviously made it quite clear that's not what I wanted, so those visits became less and less. My going out became less and less. And I find that keeping my own company is what I -- I don't think "prefer" is the right word, but that's my default method of operation. So I very much wanted to share 10 my home and my life with both Jan and her son, but 11 found I was incapable of tolerating them in my space.

- 12 Q. Your dad has also provided us with a statement, and he 13 has spoken about the fear and the anxiety that he and 14 particularly your mum had over you through the years 15 and the effect on their mental health. Do you want to 16 say anything particularly about your mum and the 17 effect it had on her?
  - A. So my attitude on this is, I was adopted, they had the opportunity to give me back, they chose not to do so. When I started counselling, we touched upon this and I was asked how I felt as an adopted child, and I felt cherished, and that hasn't changed.

My parents, John and Pat, have given me every encouragement and every support, and it -- this is going to become quite emotional -- in some respects

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1 out of curiosity to see what the process was, but 2 I did find it very useful. 3

- Q. Had you ever been offered counselling by the NHS?
  - A. No.
- Q. We spoke earlier about your earlier retirement due to ill-health and you were then reliant on benefits.
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  - Q. You applied for Disability Living Allowance, and that was rejected initially.
- 10 A. Yes. Obviously my wife and I married, we were both 11 working for the bank in separate -- she was in branch 12 banking, I was in the head office department, and we 13 embarked upon our married lives with the assumption we 14 would both be earning for a period of time and we 15 would look forward to a future together that should've 16 been within remunerated. I was on a successful career 17 path. So it came quite devastating really that 18 suddenly there was I not earning any money, career 19 over. And it was a struggle.

The bank were very good, so I did draw down my pension early, but it was -- a lump sum had been commuted to settle the liabilities that any young person would have at that time.

And, yes, we were struggling financially, and my mother took umbrage at this, as anybody who met her

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might imagine, and she had made enquiries as to whether there was any support available, because she saw what had happened to both myself and other haemophiliacs was unjust.

I do recall that Frank Dobson, the then health minister, stood up in the Houses of Commons and said, "These people are suffering, we have a system available, that's the benefit system, so they should apply for benefits". So that's what we did, and it was rejected out of hand, without so much as a by your leave.

Again, my mother waded in and wrote to my local MP, Nicholas Soames, and got a very nice letter from Nicholas Soames saying he would look into the matter and wished me all the best. Within a very short period of time -- I can't remember how long it was --I received a letter saying, "Oh, we have reviewed the situation and you are going to receive benefits in full for life". So the higher rate of disability for life.

- Q. We'll come to the for life point in just a moment, but in between you being rejected for the Disability Living Allowance and it then being accepted, as you say, your mum had written to the MP.
- 25 A. Yes.

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issues involved, ministers decided that they could not make an exception to that general policy in the case of haemophiliacs infected with hepatitis C. The government is funding a project, developed by the Haemophilia Society, which aims to meet the advice and information needs of young people with haemophilia who have been infected with hepatitis C.

"I hope that Mrs Rankin and her son will accept that the issues were very difficult in this case and that the most careful consideration was given to them."

Then it notes you had been awarded the Disability Living Allowance.

What were your mum's thoughts about that response?

- A. Inadequate I think would be an understatement. She wasn't satisfied that that was the right decision to have been made. She was adamant that a mistake had been made and, furthermore, that once that mistake had been realised, that the wrong approach had been taken and the wrong conclusions had been reached, some form of restitution was due.
- 23 Q. You said a moment ago that you were awarded the 24 Disability Living Allowance for life.

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A. Yes.

Q. You also received a letter back from your MP enclosing a letter from Frank Dobson.

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Q. We're just going to have a look at that now. 0357003, please, Henry.

It says this -- we are not entirely sure of the date. We can see it in the top right-hand corner, but it's not entirely clear what it is. But the response is this:

"I am sorry to hear that Mrs Rankin's son has haemophilia and has been infected with hepatitis C. On 28 July last year, I announced the decision not to introduce a special payment scheme for people infected in this way. Ministers do appreciate that they and their families felt deep disappointment at the decision. I wrote to the Haemophilia Society explaining the reasons for this decision and stressing the particularly careful consideration which had been given to all the issues.

"The government's general policy is that compensation or other financial help to patients is only given to patients when the NHS or individuals working in it have been at fault. After looking at a number of different approaches to the question of special payments and thinking long and hard about the

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1 Q. What happened when the DLA changed to a PIP? 2 A. When the decision was made to switch from DLA to PIP. 3 I was invited to attend an assessment for PIP.

I decided that that's not what I want to do. I did not wish to go through the embarrassment and ignominy of jumping through yet more hoops for something which I didn't think was right in the first place. So

7 8 I decided no, I was not going to do that.

9 Q. You've said you decided for your own self-esteem that 10 you needed to do something.

11 A. Yes.

Q. And what do you now do?

13 A. I very fortunately -- if I take a step back for 14 a moment, the original prognosis post-transplant was 15 that I could expect hopefully between five and 16 seven years of life, possibly as little as three, 17 depending on how virulently the virus returned.

> About five years ago, my clinical team said, "Look, there's still no sign of hepatitis C, so as things stand at the moment, we see no reason why you shouldn't see 75". So the prognosis changed greatly and I thought, well, although I could sit on a sofa for the rest of my life watching daytime TV, that probably wouldn't be particularly healthy medically -mentally. So I thought I best find something to do.

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My skill set was far too out of date to return to banking, and not that I wanted to anyway, bit of a poison challis these days, so I thought: what can I do? I'm afraid to say my confidence was nonexistent. I thought: what can I offer? I did think, well, perhaps driving examiner. Nice civil service job with a pension at the end of it, can't be too difficult. But that would have been a full-time job, which is something I wasn't capable

of doing at the time.

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A. Yes.

I had a discussion with my next door neighbour, who runs a small driving school, and he said, "Why don't you think about coming and working with me and teaching driving instruction?" I had been an instructor with the Army Cadet Force, so I had a skill set that was transferable there, and so, yes, I've ended up in what I like to call logistics, but, yes, it's various aspects of the logistics industry, teaching people to drive, undertaking the delivery of drivers' CPC, fork lift courses, et cetera, et cetera. So, yes, I embarked upon a different industry, and I have found it most rewarding. It has rebuilt my confidence and given me something to do. Q. That work is flexible, convenient, nearby the house.

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1 considerably less than that that I had anticipated as 2 a result of my career path.

3 Q. Those are the questions I have for you. Is there 4 anything else you would like to say?

A. No, other than to thank the chair and all of your team. This was a process I was not certain that I wanted to be part of. Like many haemophiliacs of my age, we all remember the tombstone leaflet, where suddenly it became necessary to be anonymous, and it's something that stays with you. But your team have made it, if not an easy process, a process that has not been difficult. So thank you, Sir Brian, and thank your team.

SIR BRIAN LANGSTAFF: Well, you've given us a detailed, objective, precise account of what has happened to you, concentrating, I suspect, more upon the facts than upon your intimate feelings about it, that may be a reflection of the wall that you've described, but thank you very much for that.

It is, as all witness evidence is, but yours in respects which is true of yours alone and not of others, particularly valuable to this inquiry. Thank you.

24 A. Thank you, Sir Brian.

SIR BRIAN LANGSTAFF: Well, we'll take a break until 2.50.

Q. Which makes it manageable.

2 A. It makes it manageable, it means that I can dictate 3 when I'm working, when I'm not working. And, yeah, 4 that's something that I find is necessary.

5 Q. You've also received payments from the EIBSS.

6 A. Yes.

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Q. Which helps as well.

A. Yes, it does. Are we going to talk about finances?

Q. I was about to ask you, did you have anything else you 10 wanted to say about them?

11 A. When -- the last year that I worked in full for 12 NatWest bank which was in 1996. 1997 was when I was 13 retired through ill-health. My income for that year 14 gross was approximately £25,000. So that was 1996. 15 The payments from the EIBSS is -- have only just 16 caught up with what I was earning back in 1996.

> Within the bank there was a tiering system, and I was A tiered, which means I was suitable to go on to senior management or even executive management. If I had stayed working for NatWest, albeit now it's Royal Bank of Scotland Group, assuming a natural progression through that career path, I probably would've retired as a senior manager by this age, mortgage free and on a full salary pension.

So the remuneration I currently receive is

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1 (2.30 pm)

2 (A short break)

3 (2.50 pm)

4 SIR BRIAN LANGSTAFF: Our next witness wishes to be known

5 as Mary, does she?

6 MS RICHARDS: Yes, sir.

7 SIR BRIAN LANGSTAFF: Mary, please.

MARY GRINDLEY (affirmed) Questioned by MS RICHARDS

10 MS RICHARDS: Mary, you're here to talk about your late 11 husband, John,

12 A. That's right.

13 Q. Who had severe haemophilia A.

A. That's right. 14

15 Q. We're going to put a picture of John on the screen.

Henry, it is 2336018, please.

17 Was that your wedding day?

18 A. It was, yes.

19 We're going to leave that picture on the screen apart 20 from when we have documents up.

21 So you met John first of all when you were at

22 teacher training college.

23 A. That's right, yes.

24 Q. He was the brother of a friend of yours.

25 A. That's right, yes. I was at training -- at teacher's

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- training college in north London, and I was a friendof John's sister. Do you want me to elaborate?
- Q. Well, I think it was -- you met him a few times over
   the following years, but you didn't start going out
   together until a few years later, in the mid-1970s; is
   that right?
- 7 A. Yes, I became a family friend. I originally -8 I first met John when I went to south-east London,
  9 where he lived, with John's sister. And it was
  10 actually the Romans that brought us together! Because
  11 we went to -- I went with John's sister to a lecture
- 12 about the Romans at Hornimans Museum in south-east London, and history was my main subject at college.
- Q. And you stayed in touch with the family, you becamea family friend.
- 16 A. Yes.
- 17 Q. It was a few years later, in the mid-1970s, you and18 John started going out.
- 19 A. Yes. It was mainly after John's sister got married20 and left home.
- 21 Q. The two of you got engaged in 1977.
- 22 A. That's right.
- 23 Q. On the Silver Jubilee day.
- 24 A. That's right.
- 25 Q. You married the following year in Suffolk, which is

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- Q. Now, when you'd first met John, he had been in
   a wheelchair because he had had some form of surgery
   to his legs.
- 4 A. No, he was in -- he was in his wheelchair because of 5 his haemophilia, the deterioration of the joints. But 6 I don't know much about -- but he had some kind of 7 operation, which I considered quite a miracle, really. 8 He was able to walk much more than he had done. He 9 could not bend his knees. When we got married, he 10 couldn't kneel down at the altar. But he could walk 11 much better than he had been previously.
- Q. You say in your statement you were drawn to him inparticular because of his strength of character.
- 14 **A.** Yes.
- Q. And you observed many haemophiliacs that you've metover the years have tremendous strength.
- 17 A. Yes, I would like to pay tribute to each and every one
   18 of you here, because, yes, I think it is -- they've 19 because they've had to fight for all that they 20 their treatment and financial things.
- Q. Up until the mid-1970s, John was receivingcryoprecipitate as his main treatment.
- 23 A. Sorry, could you repeat?
- Q. Up until about 1976, as we'll see from somecorrespondence --

- 1 where you were from.
- 2 A. Yes.
  - Q. I just want to ask you a little about John's life before the two of you met.

He had spent a lot of his childhood in EvelinaChildren's Hospital in London.

- 7 A. He had, yes, yes. He lost a lot of schooling because 8 of his haemophilia, and I think his education suffered 9 quite a bit.
- 10 Q. But there then came a time when he went to Treloar's11 College.
- 12 A. That's right, yes.
- 13 Q. And he became head boy.
- A. He became head boy. I think it was because he was the oldest. I think that was in 1971/1972.
- 16 Q. He recalled that as a happy time.
- A. He did. He enjoyed it very much, yes. I was talking
   recently to some old boys from Treloar's and they were
   talking about the camaraderie that they had there,
   despite their difficulties.
- Q. He was able to do some City & Guilds qualifications in
   electronics engineering, despite the amount of school
   he'd missed.
- A. Yes. He passed his City & Guilds in electronicsengineering.

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1 A. Yes.

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- Q. -- John had been receiving cryoprecipitate, but he was
   one of the first then to move on at St Thomas' to
   Factor VIII concentrate and home treatment.
  - A. Yes, he was very eager to get on to home treatment.
- Q. We'll just have look at a letter from early 1976.
   Henry, it's 2336021, please.

We can see it's dated 21 January 1976. It's addressed to John's GP, and it says this:

"We are at last receiving sufficient supplies offreeze ..."

12 I'm sorry, are you able to follow it?

- 13 A. I'm fine, thank you.
- "We are at last receiving sufficient supplies of 14 15 freeze dried Factor VIII concentrate to be able to 16 offer to suitable haemophiliacs the material and 17 equipment to treat their own bleeding episodes at 18 home. This has come to be widely regarded as 19 an improvement in the management of the ordinary run 20 of episodes of haemophiliac bleeding. I have been 21 reviewing the haemophiliacs who attend here and I 22 think that Mr Grindley would be suitable for this form 23 of management."

The "here" was the Haemophilia Centre at St Thomas' Hospital by this time.

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1 A. That's right. we go to page 9, please. 2 Q. The letter continues: 2 We can see here this is an extract from the 3 3 "We would see that Mr Grindley had sufficient National Haemophilia Database records, and we see from 4 4 1969 -- there is a reference to 1969 John receiving understanding of his disorder to know when he should 5 give himself a treatment and how much he should give. 5 Factor VIII BPL, but then it's fresh frozen plasma or 6 6 We will teach him to perform his own venipunctures and cryoprecipitate until we get to 1970. Then there's 7 to administer his doses. We would see that he 7 again some references to Factor VIII BPL. 8 8 understood the possible risks of intravenous therapy Then we can see that John received a range of 9 9 and that he made appropriate plans for the storage and different products, including Koate, Factor VIII, disposal of his equipment. We would of course supply 10 10 Profilate and cryobulin. the treatment materials and the necessary syringes, 11 11 Then, please, Henry, could we have page 16. 12 needles and so forth." 12 The last page took us up to 1980, and we see on Then it talks about and the possibility of 13 this page, from 1980 onwards, again we can see him 13 14 allergic reactions. 14 receiving cryobulin, BPL Factor VIII, haemophil, 15 Do you know what information was given to John 15 Profilate -- so a full range of different commercial 16 about any risks of going on to this course of 16 products as well as the NHS product. treatment? 17 (Nodded) 17 18 Q. John was keen to use home treatment. 18 A. Well, I wasn't actually married to him then and I was 19 teaching in Suffolk. I only saw him during, you know, 19 A. Yes. 20 holidays, school holidays. Not that I know of. 20 Q. He found it liberating. 21 Q. Don't worry. 21 Yes, he did, and he did improve. He was able to go 22 22 Then we're going to just look at the records and out more and do more things, yes, definitely. 23 see the wide range of Factor VIII products that John 23 Q. He was working by this time in a small electronics 24 received over the years. 24 firm in south-east London. 25 Henry, could we have 2336009, please, and could 25 A. That's right, yes. 117 118 Q. After you married, you moved to London to join him. 1 English haemophiliac to die from AIDS. 1 2 2 A. Yes, I possibly had the better job, but we wanted John A. That's right, yes. 3 to stay under St Thomas', and Suffolk wouldn't have 3 Q. You recount in your statement you stood up at the 4 provided the -- such good treatment. 4 meeting and you asked what the implications might be 5 Q. You became pregnant and you had your son. 5 in terms of being able to have other children, because 6 A. Yes. 6 you desperately wanted a second child. 7 7 Q. You talk about the relationship between John and your A. Yes, that's right. 8 8 son in this way in your statement. You say: Q. And was there any response? 9 9 "There were things John couldn't do, like play A. Yes, it was Dr Macfarlane who was speaking, and he 10 football with him, but he did what he could and was 10 said basically, "We don't know how AIDS is a really good father to his son." 11 11 transmitted, put everything on hold as far as having 12 A. He was, yes. 12 a second child." 13 Q. Indeed, your son in his witness statement has said: 13 Q. You and John went home and you discussed it and you "He was as good a dad as anybody could ask for. 14 decided you couldn't take the risk of having a second 14 15 I have nothing but fond memories." 15 child. A. Good. 16 16 A. No, that's right. 17 Q. I wanted to ask you about a Haemophilia Society 17 Q. You decided not to have a physical relationship from 18 meeting that you and John attended. 18 that point onwards. 19 A. Mm-hm. 19 A. That's right, yes. 20 Q. Henry, if we could have the photo back up on the 20 Q. You say in your statement the thought of no more

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screen, please.

A. Yes April 1983.

You say in your statement you think it was 1983

and it was an AGM of the Haemophilia Society.

Q. You remember it because news had broken of the first sell it because there would be no more children, and 119 120 (30) Pages 117 - 120

children nearly broke you.

A. It did. I remember an incident -- we lived in a small

flat, and my mother-in-law had brought a pram for my

son, and we asked her if she could take it away and

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1 it nearly broke me. Q. You have said this -- sorry, we'll see the response, 2 Q. You say from that day onwards, you and John changed 2 actually. 2336007, please, Henry. 3 3 your lifestyle in other respects. He would use his We can see it's a letter of 16 March 1981 from 4 4 the Department of Health and Social Security to you: own towel, crockery --5 A. Yes. 5 "Dear Mrs Grindley, 6 Q. -- cutlery and the like. 6 "Thank you for your letter of 12 February 7 A. Yes. 7 addressed to the Prime Minister about Factor VIII. I 8 8 Q. You think that was the first you'd heard of AIDS or have been asked to reply. I am sorry I have not been 9 9 HTLV III, but you say in your statement you had been able to do so earlier. 10 10 "The National Blood Transfusion Service, aware, and John had been aware, of problems of including the Blood Products Laboratory, was the 11 infections with hepatitis prior to that. 11 12 A. You're talking about non-A, non-B? 12 subject of an adjournment debate on 15 December. In 13 13 his reply, a copy of which I enclose, Sir George Young 14 A. Yes, I think John was well aware before we got married 14 spoke about the need to redevelop the Blood Products 15 that he had non-A, non-B. 15 Laboratory, which manufactures a range of blood 16 Q. You remember, your statement says, writing indeed to 16 products for the NHS, including Factor VIII for the Ronald Reagan in 1980 about that. 17 17 treatment of haemophiliacs. 18 18 A. That's right, yes. "However, Sir George emphasised that it is not 19 Q. Because you were concerned about American blood --19 possible to redevelop overnight a facility as complex 20 A. Yes. 20 as that laboratory. A number of issues are involved, 21 Q. -- as long ago as 1980. 21 for example funding, technology and plasma supply, and 22 22 A. That's right. it will necessarily be several years before 23 Q. You wrote to Margaret Thatcher, who was Prime 23 redevelopment can be completed. Planning has already 24 Minister, in 1981. 24 begun, however, and although I cannot yet say how soon A. Yes 25 25 it will be possible to start building, I can assure 121 122 1 you that ministers are very much aware of the need for 1 of the letter. 2 2 the new laboratory. A. Yes, I've lost the rest of it. I don't know where it 3 "You have asked Mrs Thatcher to stop the impact 3 4 of Factor VIII from abroad. May I say that I can 4 Q. That's your handwriting at the bottom. 5 understand your feelings, but I am afraid that this is 5 A. Yes, scribbled, yes. 6 simply not possible at present. However, the 6 Q. It's very legible, but this ending is important. The 7 7 upgrading programme described by Sir George will ending of the letter from Lord Skelmersdale was this: 8 8 enable the Blood Products Laboratory to double its "We have fully financed the new 60 million BPL 9 9 output of Factor VIII by the end of next year, though at Elstree to ensure the earliest possible completion 10 it will still be necessary for health authorities to 10 date. The new factory was opened on 29 April 1987. 11 purchase some Factor VIII commercially." 11 Production is expected within the next few months, So we can see from that that in early 1981, you 12 leading to very substantial products next year and 12 13 were sufficiently knowledgeable about and concerned 13 self-sufficiency in all products by 1989." about the risks of American products to write to 14 14 So we can see, although we don't know the date 15 15 central government. of this letter, it obviously postdates April 1987, and 16 16 it's the same issue that you'd picked up on back in A. Mm. 17 Q. That was the response that you received. 17 1981. 18 A. Yes. 18 A. That's right. 19 Q. You continued to write on this particular issue to 19 Q. You and John read what you could about AIDS and tried 20 politicians over the years. 20 to inform yourself about the situation. 21 A. Yes. 21 A. That's right, yes. 22 22 Q. There is a letter we'll pick up in 1987. Q. We can see that John raised concerns with your MP in 23 23 Henry, it's the same exhibit number, 2336007, late 1983. We'll have a look at two letters, Mary. 24 but it's page 7, please. 24 A. Uh-huh. 25 We can see from this -- it's just the last page 25 Q. Henry, it's page 3 of this exhibit, please. 123 124

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1 So this is a letter from your MP written at action the DHSS is taking to make sure that AIDS is 2 John's behest to Kenneth Clarke, then Minister of 2 not imported into the United Kingdom with foreign 3 3 State and the Department of Health and Social blood products. Is there any way of synthesising 4 Security. It is dated 2 November 1983. 4 these products, and is there any programme to ensure 5 5 that the United Kingdom is self-sufficient in blood It says: 6 6 "Dear Kenneth, products at some foreseeable time in the future?" 7 "Mr Grindley is a constituent of mine who came 7 Then he refers to enclosing some copies of 8 8 to see me. He suffers from haemophilia and, as newspaper articles which John had passed on to your 9 9 a result, has to have regular blood transfusions. He 10 10 is very concerned about the spread of AIDS, A. Mm. 11 particularly as apparently the United Kingdom imports 11 Q. We'll see the response to this letter. It's the next 12 most of its blood products from the United States. 12 page, please, Henry. The particular ingredient which he requires, 13 It's dated 16 December 1983, and it's from the 13 14 Factor VIII, the clotting factor, is I understand 14 Joint Parliamentary Undersecretary of State and the 15 imported mainly from Alpha Therapeutic Corporation in 15 Department of Health, and it says this: 16 California. As you know, there has been a serious 16 "Thank you for your letter of 2 November 17 17 spread of the AIDS problem in the United States and it addressed to Kenneth Clarke about acquired immune 18 deficiency syndrome (AIDS) and the supply of blood 18 can be passed on by blood transfusions. 19 "Mr Grindley tells me that another haemophiliac 19 products in this country. 20 recently died of AIDS, which he acquired from a 20 "I can well appreciate the anxiety, particularly 21 foreign ..." 21 amongst haemophiliacs and their families, which recent SIR BRIAN LANGSTAFF: Must be "blood". 22 22 press reports on AIDS may have caused, and would first 23 MS RICHARDS: Should be "blood product": 23 of all like to put matters into perspective. The 24 24 cause of AIDS is as yet unknown and there is no "This seems to me to be a very serious, and 25 I should be grateful if you could let me know what 25 conclusive proof that the disease has been transmitted 125 126 1 by American blood products. 1 these regulations, there is still a quantity of stock 2 2 "Nevertheless, I would like to assure your which has been made from pre-March plasma. The FDA 3 constituent that the government is committed to making 3 has recently decided not to ban the use of such stocks 4 4 this country self-sufficient in blood products. Over because to do so would cause a crisis of supply. The 5 £2 million has already been spent on improving the 5 same considerations apply here. 6 production facilities of the Blood Products Laboratory 6 "We are of course anxious to minimise the 7 7 possible risk of the transmission of AIDS by blood at Elstree, Herts, and a major redevelopment programme 8 8 is underway. When this is complete, the Central Blood donation in this country. My department, in 9 9 Laboratories Authority will have a new laboratory of conjunction with regional transfusion directors, has 10 a size capable of meeting the demands of England and 10 issued a leaflet, 'AIDS and how it concerns blood 11 Wales for blood products. 11 donors', which asks people from high risk groups to 12 "Meanwhile, in the absence of a satisfactory 12 refrain from giving blood. A copy is enclosed. 13 alternative, we shall be dependent upon imports from 13 I hope you find this useful." That was the response that you and John received 14 the USA for an adequate supply of Factor VIII. While 14 15 there is as yet no test for AIDS, such imports 15 to the concerns you'd raised about the spread of AIDS 16 16 prepared from plasma collected after March this year from blood products. 17 will be subject to new regulations initiated by the US 17 A. Yes. 18 Food and Drug Administration designed to exclude 18 Q. That we can see was late 1983. 19 donors from high risk groups, eg persons with symptoms 19 You recall John having some kind of skin or 20 and signs suggestive of AIDS, sexually active 20 patch test in November 1983. 21 homosexual or bisexual men with multiple partners, 21 A. Yes. 22 22 Q. We'll look at what happened to John's arm as a result, intravenous drug abusers. 23 23 "Although future supplies of Factor VIII, both but before we do that, can you remember what the test 24 for export and for use in America, will be 24 comprised at all? 25 manufactured from plasma collected in accordance with 25 A. Well, I didn't actually go with John at the time. As

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- far as I remember, it was like a prick test that you
  would have for allergies. As you know, at this time
  there was no actual blood test for AIDS as far as
  I know, and as far as I remember, it's a prick test on
  the arm like you would -- it was about, you know, four
  or five different pricks on the arm.
  - Q. We can see a photo of how John's arm responded. It is 2336028, please, Henry.

So we can see there what happened to John's arm, and then could we go to the next page, please, and see what was written on the back of the photo. There's a difference between the black and the blue ink here.

13 A. Yes.

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- 14 Q. That has some significance in terms of when it was15 written.
- A. Yes, in the blue was what I wrote on the back of thephotograph when I took it in November 1983.

The rest of it, in black, is what I've put on the photo for the Inquiry.

- Q. So we can see the date that it was was November 1983,
   and your understanding, yours and John's, was this
   some form of AIDS reaction test.
- A. Yes. In his notes it doesn't say AIDS, but that -- wecalled it an AIDS test.
- 25 Q. Yours and John's understanding of the way in which

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1 this extract from his notes.

- A. Yes.
- 3 **SIR BRIAN LANGSTAFF**: Well, it must follow that if there 4 was no test at the time, and this is referring to one, 5 it must be looking at a sample retrospectively.
- A. This test, when it says negative, it refers to theprick test.
- 8 MS RICHARDS: The skin test.
- 9 A. The skin test.
- 10 SIR BRIAN LANGSTAFF: I see.
- MS RICHARDS: That was Mary and John's understanding at
   the time, that the skin test was the available test at
- 13 the time, not a blood test.
- 14 **A.** Yes.
- MS RICHARDS: And this is the information that they wereprovided with, as I understand from Mary.
- 17 SIR BRIAN LANGSTAFF: Thank you.
- MS RICHARDS: Your recollection in your witness statement,
   Mary, was that John was given a diagnosis of HIV in
   1986.
- 21 A. Yes.
- Q. The records and diary entries that we've been able to
   look at subsequently suggest that it was probably
   1985.
- 25 A. Yes. It's a bit confusing as to what happened.

1 John's skin reacted was that he was negative.

- A. Yes. John explained it to me as -- that because the arm blew up, it meant he had good immunity at that time.
- Q. We'll look at his clinical notes. 2336026, please,
   Henry. It's the entry at the very top of the page, if
   you could highlight the first three lines in yellow
   please, Henry.

9 We can see the words, "HTLV test neg 22/11/8310 sample."

- 11 A. That's right.
- Q. So John's understanding that this was a negative and
   therefore a good result was shared by the clinicians
   or clinician who made the entries in the record.
- A. Yes. And can I make the point that I think the first
   sentence possibly refers to him giving blood, because
   he used to give blood for research. But what that
   research was, I don't know.
- 19 **SIR BRIAN LANGSTAFF:** If the test for HTLV, HIV as it became, was not in operation in 1983, to your 21 understanding, this must have been something written 22 in afterwards, referring to a sample taken on 22 November.
- 24 A. I really can't say.
- 25 MS RICHARDS: This is the form in which you've received

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Q. Well, again, we'll just look at two or three documents
 to see what information there is in the records about
 dates.

Henry, could we have -- in fact, it's further down that page. Could you highlight the entry for 1 April 1985, please.

## (Pause)

So we can see the date is 1 April 1985.

- A. Thank you.
- Q. It refers to John being given Profilate, and then it
   says, "HTLV III positive. Serocon. To discuss implications with patient."
- 13 A. Yes.

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- 14 Q. That appears to be the positive HTLV result.
- 15 A. Yes.
- Q. But there is an entry in John's diary to suggest that
   what he was told in July of 1985 was that the test was
   negative, and we'll just look at that. 2336027.

We can see the date. If we could just zoom in, please, on the 16 July entry. Thank you. The date is July 1985. We can see a meticulous record here.

Is this your writing or John's writing?

- A. This is John's writing.
- Q. We can see a record there of a bleed, and thetreatment that he received.

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1		Then the very bottom entry is, "Got results from	1		has gone. I've tried to put things in the back of my
2		AIDS test. Neg."	2		mind for many years, and the years this a long time
3	A.	Yes.	3		ago.
4	Q.	So	4		John always said that he converted from negative
5	A.	Two months later.	5		to positive on heat-treated blood, but I don't
6	Q.	John's understanding there we don't have any	6		I don't know. I
7		clinical records that show him being told of his	7	Q.	Don't worry about the precise dates, Mary, because the
8		diagnosis, but his understanding there was that it was	8		records themselves do not paint a clear or consistent
9		negative.	9		picture.
10	A.	Yes. I don't think he would lie we had a very good	10	Α.	Yes. But I can't remember, when I went to have my
11		relationship. I don't think he would have lied to me	11		tests, whether we actually knew at that time or not.
12		and put that in the diary if it wasn't true.	12	Q.	Whatever the precise date, can you recall what
13	Q.	We can see a later blood test in October 1985.	13		information was provided to John about prognosis or
14		Henry, that's 2336023, please.	14		treatment?
15		We see this is a test for John. The serum date	15	Δ	There again my memory has gone. I mean, I think the
16		is 21 October 1985, "Antibodies to HTLV III detected."	16	۸.	general prognosis was only a few years, but I don't
17		Indeed, it was after that the records show you	17		know what specific things were said to John. We
18		yourself went to be tested too.	18		certainly thought it you know, he wouldn't live
19	۸	Yes.	19		very long.
				0	, -
20 21	u.	And had an anxious wait until the negative result came	20 21	Q.	, , , , , , , , , , , , , , , , , , , ,
		back.			diagnosis initially, you kept it to yourselves. Yes. Yes.
22		So whether it was April, July or October, in the	22		
23		course of that year, John and you learnt that he had	23	Q.	
24		been infected with HIV.	24		a number of years show signs of physical
25	A.	I'm not clear. I'm still not clear. My memory is	25		deterioration, so you tried to carry on as normal as
		133			134
1		best you could.	1		him.
2	A.	Well, yes, for the sake of our young son, we did,	2	A.	Well, yes, yes, it was, yes. But he that was the
3		really.	3		way he was that was what he was like. He
4	Q.	It was in the early 1990s that John started to become	4		I don't know whether you're coming to it, but he, two
5		seriously unwell.	5		years before he died, when he more or less he was
6	A.	That right, yes.	6		technically in work for the last two years of his life
7	Q.	We have a couple of photos that show you and John	7		because they very kindly paid him, but he gave up
8		together in the early 1990s. Henry, could we have,	8		about two weeks two years before he died. And he
9		first of all, please, 2336020.	9		actually went into the undertakers and he paid for his
10		We can see that's a picture of the two of you.	10		funeral plan, and subsequently he went in two or three
11		Was that in your garden?	11		times and actually told them what was wrong with him
12	Α.	No, it was in a relative's no, a friend's garden.	12		so that I wouldn't have to deal with that when the
13		That was the summer before John died.	13		time came. And also he thought of the undertakers
14	Q.	So that would've been 1993?	14		themselves, that they knew what they were dealing
15		That's right, yes.	15		with, and how they could handle him.
16		And then we have 2336019, please.	16	O	Indeed, he planned the music and the poetry he wanted
17		And that's I think more or less the last picture I've	17		to have at his funeral.
18	,	got of John. That was about it's possibly about	18	Δ	That's right. We planned it all together.
19		four months before he died.	19	Q.	He went to see the Reverend Tanner to ask him to
20	0	When John became ill, he decided he would tell people,	20	w.	conduct his funeral, which he agreed to do.
21	w.	and he made a list of the people he needed to tell.	21	Δ	That's right.
22	٨	That's right.	22		It was at that point you say this in your statement:
		And he just phoned them up and told them.	23	w.	"It was when we were planning John's funeral
23			23 24		• •
24	Α.	That's right, yes.	24 25		that I remember him lying down on the couch and crying
25	Q.	You said that must have been incredibly difficult for	25		for the very first time."
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1	A.	Yes.	1		"This is a copy of a notice put up on the wall
2	Q.	"John was an incredibly strong person and I never knew	2		at the electronics firm where he worked."
3		him to cry. It was totally out of character. He	3		Then if we have, please, the following page,
4		said, 'I don't want to die.""	4		page 3:
5	A.	What do you say to somebody? What do you say?	5		"Danger, government health warning, Mr Grindley
6	Q.	You said, "I know you don't."	6		can seriously damage your health. Congratulation,
7	A.	When your partner is dying like that, you don't know	7		you've just meet HF head-hunters [sic]."
8		what to say, do you?	8	A.	HF is high frequency. It's an electronics term.
9	Q.	Before John had to give up work in 1992, he was	9	Q.	Again, that's a copy of a notice put up on the wall of
10		starting to have to take time off work and was	10		the firm where John worked.
11		starting to look unwell.	11	A.	Yes. Yes, I think this was a prank. I don't think it
12	Α.	Yes.	12		was actually malicious, because John was well liked,
13	Q.	So he took the decision to tell the managing director	13		but I really don't quite know the motivation.
14		of the firm of his illness.	14		I think the management got to know about it, it
15	A.	That's right.	15		was a small family firm, and it was soon taken down,
16	Q.	And word got around.	16		and the firm were very good about it.
17	A.	Excuse me, I think he I think they already knew	17		But I do have another document, which you
18		because there had been incidents at work, which you	18		probably haven't got, where John actually had to sign
19		may refer to.	19		to say that he was it was some kind of pass to get
20	Q.	Yes, we'll look at a couple of the examples you've	20		into the store where the electronics parts were that
21		given in your statement, Mary.	21		he needed for his work. So he had to sign this pass
22		Henry, could we have 2336006, please.	22		to say he was it was okay for him to come in.
23		We can see on the left-hand side:	23		So but I must say, the firm, John's firm,
24		"Danger, watch out, it's a Mr Grindley!"	24		were very, very good to him. Very, very good to him.
25		You've written on there:	25	Q.	Now, you talk in your statement more generally about
		137			138
1		the stigma associated with HIV and AIDS.	1		didn't have trouble.
2	A.	Yes.	2	A.	Yes, and that was through the police, actually.
3	Q.	You said that you and John had to lie to people.	3	Q.	In 1987, early 1987, you saw the press reported some
4		Sometimes they became suspicious and you felt like	4		comments made by Edwina Currie, then a junior health
5		second class citizens.	5		minister, when she had said at a meeting:
6	A.	That's right, yes.	6		"Good Christian people who wouldn't dream of
7	Q.	You've given a couple of examples in your statement of	7		misbehaving will not catch AIDS."
8		experiences you had with neighbours.	8	A.	That's right.
9	A.	Yes.	9	Q.	You wrote to her about this.
10	Q.	One was where you were living in a house with two	10	A.	I did, yes.
11		flats and there was a young couple who had somehow	11	Q.	We can see the reply that you got at 2336002, page 2,
12		found out of John's condition. The young woman	12		please.
13		upstairs came down the stairs with her child in the	13		It's dated 23 March 1987 and it says this:
14		pushchair, you opened the doors at the same time and	14		"Dear Mrs Grindley,
15		she suddenly shouted something to the effect, "Your	15		"Mrs Currie has asked me to thank you for your
16		husband's got AIDS, your husband's got AIDS."	16		letter of 13 February about her remarks on 12 February
17	A.	John wasn't even positive then, so I don't know	17		about AIDS. She has asked me to reply.
18		yes, she backed off and I think that was the last	18		"I am sorry that you do not agree with what she
19		I saw of her. She got a transfer.	19		said. We are very concerned about the dangers of
20	Q.	You've also described another time where you had	20		AIDS. There is no cure or vaccine and no prospect
21		a neighbour who was harassing you. You say she must	21		that either will be developed for some years. The
22		have found out about John. Amongst other things, you	22		government is supporting research and funding
23		saw her smash John's car window.	23		a wide-ranging public education campaign to bring home
24	A.	Yes.	24		the threat that AIDS poses to us all. It is essential
25	Q.	Eventually you were moved to a new house where you	25		that the message is put across clearly, at every
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		***			(30) rages 137 - 140

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opportunity, that the only way to stop AIDS spreading is for all our people to behave responsibly.

"I understand that you take particular exception to Mrs Currie's reminder about good Christian people not catching the disease. She had in mind merely that, for most people, a responsible and caring way of life should protect them and their loved ones from the threat of AIDS in future.

"Thank you for taking the trouble to write about this important matter."

- 11 A. Can I just say --
- 12 Q. Yes.

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- A. -- how angry I was at the time, and how angry I stillam at her remark.
- Q. Now, you'd started to try and explain things to yourson.
- 17 A. Yes.
- 18 Q. The time came when you had to tell him that his daddy19 was seriously ill and that he might die.
- 20 A. Yes.
- Q. Unsurprisingly, you describe him as becoming quiteanxious and not wanting to be parted from his father
- 23 at the time.
- 24 A. That's right.
- 25 Q. John also learnt around 1992, your statement says,

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- Q. It was a relatively short period of time between John
   becoming seriously ill and his death.
- A. He was losing weight and getting very tired, but
   I don't think he had major symptoms until he had two
- 5 opportunist infections.
- Q. He had pneumonia.A. Yes, the one that's peculiar
- 7 A. Yes, the one that's peculiar to AIDS.
  8 Q. Yes, that was February 1994, and he was admitted to
- 9 St Thomas'.
- 10 A. That's right.
- Q. Then at Easter of 1994 he had serious diarrhoea andsickness.
- 13 A. Yes.
- 14 Q. And was admitted again.
- 15 A. It was -- I can never say it, crypto --
- 16 Q. Cryptosporidiosis.
- 17 A. Yes.
- 18 Q. We'll come back to that in a moment.
- 19 A. Yes.
- 20 Q. But around this time your father was also very ill.
- 21 A. Yes, he was, he -- I think -- in April 1993 the --
- 22 about a year before, he'd had a major stroke and was
- 23 in Ipswich Hospital, and then he was -- I think he was
- 24 transferred to a hospital in the north of Suffolk,
- 25 right in the wilds of Suffolk, and to a geriatric

- 1 that he had been infected with hepatitis C.
- A. Yes.
  - Q. But he had been aware of non-A, non-B hepatitis and having that for some years.
- 5 A. He had, but I think at that time there was -- the
- 6 hep C test had just come in.
- 7 Q. So the formal diagnosis was made and he was told.
- 8 A. Yes.
- Q. You and he regarded it really as just one more thingbecause he was so ill with HIV by that stage.
- 11 A. He was, yes.
- Q. But for the sake of completeness, we will put up
   a letter that was sent to you subsequently by the
   UKHCDO. It is 2336008, page 2, please.
- 15 It's a letter in response, I think, to a request 16 from you for records about batch numbers.
- 17 A. Yes.
- 18 Q. It's May 2003. It's from Dr Hay. But it says this:
- 19 "Much later epidemiological evidence suggests 20 that patients developed hepatitis C following their 21 first exposure to concentrate, which in your husband's 22 case was BPL concentrate in 1969."
- 23 So your understanding is that John had been 24 infected with non-A, non-B hepatitis C for many years.
- 25 A. Yes.

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- 1 hospital, and he had another stroke there.
  - 2 Q. Your father died about eight months before John.
  - 3 A. Yes.
  - Q. In the period prior to your father's death you weretravelling to Suffolk to visit him.
  - 6 A. Yes, yes.
  - 7 Q. And then coming back to London.
  - 8 A. Yes
- Q. And you had a particular fear in your mind at thattime.
- 11 A. Yes.
- 11 A. 165.
- 12 Q. Because John had spoken of suicide.
- 13 A. That's right, yes. He -- well, he said in the past
- 14 that if things got too bad he would inject himself
- 15 with air. And I -- because he wasn't -- he was off
- work by then, but he wasn't too bad, he could just
- 17 about fend for himself for a day or so, you know,
- and -- but I sometimes would have to stay overnight in
- 19 my -- in my father's house when visiting him in
- 20 [redacted] or further up in Suffolk, and I didn't
- 21 know, when I came back, what I might find.
- Q. Your fear was you might come home from visiting yourdying father to find your husband had taken his own
- 24 life.
- 25 A. I don't think John would've done it, but --

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- Q. But you had that extra worry.
- A. Yes.

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And also can I just mention, that in between my father dying and John dying, John's father died, and we went to see -- John was just about able to walk then. We went to see John's father in hospital as he was dying, and John said to his father, "See you soon, Dad. See you soon, Dad."

- Q. Was that the last time he saw his father?
- A. Yes. They are actually -- they are buried together orscattered together, the ashes are scattered together.
- Q. So after -- when John was in hospital for the second
   time around Easter 1994, you had to go and help nurse
   him in hospital because there weren't sufficient
   nursing staff to --
- A. Well, there were nurses around, but they were busy.
  He needed so much attention that, you know, he wasn't getting it, you know. I had to help him onto the
  toilet and things like that and try and feed him. He
  wasn't eating much because -- and it was coming out of
- Q. You had to leave your son, who was now a teenager, to
   fend for himself, you said, which you still feel
   guilty about.

different orifices, yes.

25 A. Yes.

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- A. Pads, that's right, for him, and that was about all.
  - So it was a very -- and we were sleeping in the same bed because we didn't have any more room. It was -- it was hell, actually.
- Q. Eventually nurses from the local hospice helped younurse him for a few days at home.
- 7 A. Yes, that's right.
- Q. Then John was transferred to St Christopher's Hospice,which is where he had wanted to --
- A. Yes, before he was discharged from St Thomas', he said
   he wanted to die in St Thomas', but prior to that we
   had -- when he was well, we had looked at a hospice.
- 13 Q. You visited him every day whilst he was there.
- 14 A. That's right, yes.
- 15 Q. And you've said the staff there were very good.
- 16 A. They were wonderful.
- 17 Q. And you were allowed to sleep there for the last four18 days.
- 19 A. Yes, in a bed in the same room, yes. I didn't wash,20 I didn't take my clothes off. I didn't eat. I just
- 20 I didn't take my clothes off, I didn't eat, I just 21 paid attention to him.
- Q. On the last day of John's life, you say his mother wasthere.
- 24 A. Yes.
- 25 Q. There was a nurse from St Thomas' there

- Q. John was sent home from St Thomas' with little
   warning.
- 3 A. That's right.
- Q. And you describe he was sent home in an ambulance with
  other patients and he was the last to be dropped off
  because you lived furthest away, so it was a long
  journey.
- 8 A. I was with him when he was actually discharged, but they wouldn't allow me to go home in the ambulance
- with him, and so I managed to get home. It was a long
  way from St Thomas' to where we lived, and he was the
  last one to be dropped off. They discharged him, and
- when the ambulance dropped him off, he almost fell into my arms.
- 15 **Q.** You had difficulty getting him upstairs.
- 16 A. Yes, that's right, yes.
- 17 Q. And for the following six weeks, you looked after him18 on your own.
- 19 A. Yes, the doctor was supposed to -- my local GP was
   20 supposed to come. He didn't come and he didn't come
   21 and he never did come.

22 They did eventually send a nurse, but basically 23 she just brought -- oh, I can't think what you call 24 them -- well, sort of nappies -- not nappies, but --

25 Q. Pads.

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- 1 A. Yes, she had recently left her job at St Thomas', but 2 she'd had some experience of palliative care and she'd 3 come along, so she was there, yes.
- Q. You were there, and you say in your statement:"We willed him to go and he died peacefully."
- A. That's right. Apparently that's what you do, going on
   the advice of the nurse there. She said that was what
   we should do, and that's what we did.
- 9 Q. And so John died June of 1994.
- 10 A. That's right, yes.
- 11 Q. And he was just 41 years old.
- 12 A. That's right.
- Q. You've said in your statement that your initial
   emotion was a sense of relief for him that his pain
   was over.
- 16 A. That's right, yes.
- 17 Q. But it was over the following months that things18 really hit you.
- 19 A. That's right, yes.
- Q. And you've struggled really ever since then to copewith the loss of John.
- 22 A. I have, yes.
- Q. You've explained in your statement you got to a stagewhere you tried to do lots of things, lots of classes,
- 25 lots of courses to try and keep yourself occupied.

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- A. Yes.
- 2 Q. But you became stressed, anxious and depressed.
- 3 A. Yes. I did try to go back to teaching after
- 4 18 months. I had about two terms, it was just
- 5 a temporary post, in a nursery. It all became too
- 6 much. I -- it was the day after the ... Dunblane --
- 7 Dunblane incident, and I had a breakdown in the
- 8 classroom in front of 25 small children, nursery
- 9 children, and I never went back to teaching after
- 10 that
- 11 Q. You did begin to see a psychologist regularly.
- 12 A. Yes.
- 13 Q. You found --
- 14 A. She's very kindly here today to support me.
- Q. And you've said that you found a psychologist who wasone of few who had specialist knowledge of AIDS.
- 17 A. Yes.
- 18 Q. And that she was a great help to you.
- 19 **A.** She was, yes, both -- I saw her before John died and 20 after.
- 21 Q. But you've described in your statement the impact of
- 22 losing John on your life, and if I may, I'm just going
- 23 to read out a passage from your statement where you
- 24 describe it very powerfully. You say this:
- 25 "I feel I have lost so many things in my life

- Q. As we've heard, John was only 41 when he died and he
   had to give up work two years before, and you were
   unable to return to work.
- 4 A. Yes.

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- Q. So financially, things have not been easy for you inthe years that followed.
- A. It hasn't been as bad for me as a lot of other widows.
  I did have a pension from John because he was in work
  until the end of his life. Although he hadn't worked
  for two years, the firm kindly paid him. He was just
  about to go on half pay when he died.
  - I had a teacher's pension, and I now have state pension, you know, old age pension. Somehow we've managed. And I've had the ex gratia payments.
- 15 Q. You use those to help with housing costs.
- A. That's right. Yes, I still have a mortgage, but it's
  an interest-free mortgage and it's very small now.
  I think -- you know, as I say, I'm -- I manage.
- 19 **Q.** You've observed in your statement that for the first 20 four or so years after John died, and your son was 21 still under the age of 18, you received regular 22 payments from the Macfarlane Trust, but after that, 23 nothing.
- A. That's right. At that time they -- the Macfarlane
   Trust only gave payments to widows with children or

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- and the whole situation has affected me beyond
   measure. I have lost the love of my life and been
- left to bring up my son alone. I lost my career as
   a teacher and have not been able to work since because
- 5 of bad depression. I am still devastated by not
- 6 having a second child. Since my son left home, now
- 7 married with two small children, I have lived alone.
- 8 It is very lonely with only the four walls to talk to.
- 9 There is nobody to confide in, to make me a cup of tea 10 or care for me when I'm ill, although my family help
- as much as they can and have been a great comfort,
- 12 which is much appreciated.

"I think people must think that maybe after all these years have gone by I would somehow forget what had happened. In fact, John's death has permeated every area of my life and affected every area of my life. I lost the love of my life and he is not here anymore."

19 I am going to ask you about two further matters,

20 Mary.

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- 21 **A.** Mm-hm.
- 22 Q. Financial implications of what happened to John.
- 23 A. Yes.
- 24 Q. Then some of your campaigning activities.
- 25 A. Okay.

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- 1 disabled widows.
- Q. Since that time, and since there have been means
   tested schemes, you've refused to apply because you
   strongly disagree with the principle of means testing.
  - A. Yes, and I think most people here would agree with that
  - Q. You have received some funding from the English Infected Blood Scheme that have assisted you to recently receive counselling from the same psychologist.
- A. That's right, and I did -- last year I did receive one
  winter payment, but neither of those were means
  tested.
- Q. In terms of the Skipton Fund, you said you had to fight hard for those two payments. You were turned down two or three times, but you were eventually accepted with the help of one of the doctors from St Thomas'.
- A. That's right, Dr Bevan from St Thomas' helped me get stage 1 and stage 2. Stage 2 I got on the probability that John had hep C and -- well, we knew from the test that he had hep C, and that he would possibly go on, if the AIDS didn't get him -- well, the AIDS did get him first, but, you know, the hep C could have been a problem for him.

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vidows with children or 25 a pro

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Q. You've recorded in your statement that you once went to see Martin Harvey when he first became chief executive of the Macfarlane Trust --A. That's right. Q. -- to ask for regular help for all widows not just yourself. A. Yes. Q. How did that conversation go? A. Well, I went to see him when he first became chief executive of the Macfarlane Trust. As you say, it wasn't really for me, I -- as much as some widows that I knew were struggling, and I thought he's a new broom, he'll be sympathetic. Boy, was I wrong. 

He said to me, "What did your husband do?" And I said, "He was an electronics engineer." And he said, "Well, don't they have some organisation or a scheme where they can help you?" And he never said anything about, you know, the Macfarlane Trust helping me, and I was disgusted. I couldn't -- I couldn't believe he was saying that to me.

Q. We can see that John had been concerned about issues of financial stability and financial impact during his life. In particular, life insurance and costs of treatment. We'll look at a letter in that regard. Henry, it's 2336007, please. It's page 6.

A. That's right. Yes. He had been with I think the Prudential, and had some kind of -- I can't remember the exact policy, but just as some kind of savings policy, and he had a payout, and then he decided to try for life insurance, but he was turned down.

I think there were questions about AIDS, I can't -- I think that's why we must have written.

**Q.** Then the letter goes on to say this:

"The provision of health services for haemophiliacs is well established and rests with individual health authorities, who have detailed knowledge of local circumstances and are therefore best placed to determine local needs and priorities."

Now, as I understand it from your statement, and it may have been what prompted John's approach to the MP, John was being charged for one particular kind of drug.

A. Yes, he was being charged -- because he was still in work, he was charged for his antiviral drugs, AZT, Retrovir. He had to pay for a payment card, you know, for prescriptions, which we were absolutely disgusted about.

- Q. Now, you've continued campaigning and letter writingin the years since John has died.
- 25 A. Yes.

It's a letter of 19 April 1988, and it's from the Department of Health and Social Security, the Parliamentary Undersecretary of State for Health addressed to Colin Moynihan MP.

- A. Mm-hm.
- Q. "Thank you for your letter of 1 March about your
   constituent, Mr J Grindley, and his concern over
   availability of life assurance for haemophiliacs
   infected with the human immunodeficiency virus and the
   funding of treatment for haemophiliacs. I am sorry
   for the delay in replying."

Then the first paragraph deals with the issue of insurance and says this:

"Decisions as to the risks undertaken by insurance companies are a matter for the commercial judgment of individual insurance companies. The government does not intervene in these decisions and recognises that insurance companies must take account of the commercial implications AIDS and HIV infection present. However, the government is in touch with the Association of British Insurers to ensure that each new application for cover is judged solely on the individual circumstances of the proposer."

Pausing there, John had obviously been concerned about a difficulty or inability to get life insurance.

Q. We've looked already at some of the letters sent by or in respect of matters that you raised or John raised, but we're just going to look at three more.

Henry, could we have 2336007, page 11, please.

We can see that the issue that was being raised here -- it's 18 April 1995:

"Dear Mrs Grindley,

"Thank you for your letter about the hepatitis C campaign being run by the Haemophilia Society."

So this is the year following John's death.

- A. Yes.
- Q. "I have much sympathy with your comments and with the points which the Society make. As you may know, the issue has already been ventilated in the House of Lords, where the minister explained that the government does not accept liability for those infected by contaminated blood products on the grounds that such patients received the best treatment available, given the medical knowledge at that time.

"Whilst a parallel can be drawn with those who contracted HIV, the minister claims that this was a special case, that the consequences are not comparable and that agreeing to what would be in effect no-fault compensation could involve substantial expenditure, not only for those cases, but for others

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			The intested blood in	. de	in y
1		of a similar nature for which a precedent would have	1		letter says this:
2		been created.	2		"I was sorry to read of the death of your
3		"However, having explained the government's	3		husband and that you have been affected by the issue
4		stance, I do accept that there is an argument for	4		of contaminated blood. I appreciate that this must be
5		consideration being given to ex gratia payments in	5		a difficult time for you.
6		certain cases and I shall seek opportunities to raise	6		"This government deeply regrets that patients
7		this in the House of Commons or informally with	7		acquired serious infections as a result of NHS
8		ministers."	8		treatment some two or more decades ago, and extends
9		So you were involved in trying to support	9		every sympathy to the patients and their families who
10		a campaign for payments for those who had been	10		have suffered as a result of the very treatments which
11		infected with hepatitis C.	11		should have transformed their lives for the better.
12	A.	Yes, yes.	12		"The department understands the sense of
13	Q.	Could we have, please, Henry, within the same exhibit,	13		grievance that some people may feel as a result of
14		page 25.	14		what has happened, and that there are deeply held
15	A.	Can I just say that	15		opinions on the appropriateness and timeliness of
16	Q.	Yes, of course.	16		decisions and actions taken many years ago. In his
17	A.	this is off my own bat individually. I wasn't	17		report, Lord Archer did not find the government of the
18		involved in any particular group at that time.	18		day to have been at fault and did not apportion blame.
19	Q.	So page 25, please.	19		"The government is committed to ensuring that
20		We can see this is a more recent letter, it's	20		people with haemophilia and others who have been
21		19 June 2009, and this is after Lord Archer had	21		infected with hepatitis C and/or HIV from blood and
22		reported. You gave evidence to the Archer Inquiry.	22		blood products are well cared for, supported in their
23	A.	That's right, yes.	23		communities and fully informed about how best to look
24	Q.	Again, you have written to Dawn Primarolo about the	24		after their health. The government gave very careful
25		government's response to Lord Archer's report, and the	25		consideration to Lord Archer's recommendations and
		157			158
1		believes its final response is as positive as	1		death. The government is deeply sorry about the
2		possible. The government has published the final	2		events that led to the infection of so many people
3		response on the Department of Health website."	3		with HIV and hepatitis C and has the utmost sympathy
4		Then we have a link to it:	4		for all of those who were affected.
5		"This includes details of the steps taken in	5		"I can assure you that the department
6		response to each recommendation.	6		sympathises with the distress and deep sense of
7		"Owing to diary commitments, it is not possible	7		injustice felt by the families of haemophilia patients
8		to meet with the minister. However, I hope this reply	8		infected with blood-borne viruses through their
9		is helpful."	9		treatment. It is tragic that people were harmed
10		You had been involved with the Archer Inquiry,	10		because of the very treatments that were supposed to
11		you gave your evidence.	11		help them."
12	Α.	Yes.	12		Pausing there, although we don't have your
13	Q.	And this letter was prompted by your view that the	13		letter, Mary, it seems from what follows you were
14		government's response was inadequate.	14		asking for a public inquiry.
15	Α.	Yes, that's right.	15	A.	Yes, possibly, yes, I was.
16		Then, finally, Mary, 2336007 so same exhibit,	16	Q.	It says this:
17		Henry, but page 28, please.	17		"It has been the view of successive governments
18		We can see this is more recent	18		that there is no justification for a public inquiry
19		still, November 2012. Again, you've written to the	19		into these matters in England after all this time.
20		Department of Health or in fact you've written to	20		The relevant facts are already in the public domain.
21		David Cameron and the letter has been passed to the	21		All relevant documents held by the Department of
22		Department of Health.	22		Health on blood safety covering the period 1970 to
23	A.	Yes.	23		1985, when the heat treatment of clotting factor
24		It says this:	24		products was introduced, have now been published in
25		"I was very sorry to read of your husband's	25		line with the Freedom of Information Act. If any
		159			160 (40) Pages 157 - 160
					(40) rages 107 - 100

1 further documents from that period come to light, the touched on some of them --2 department will also publish them in line with the 2 A. Yes. 3 3 Freedom of Information Act. The issue now is how best Q. -- how important it's been to you to try and raise 4 4 these issues, as you and John did during John's life to support those affected. 5 5 "Successive governments have recognised the and subsequently. 6 6 plight of all those affected by NHS supplied A. Yes. 7 contaminated blood or blood products, and a number of 7 Q. I just wanted to read one further bit from your 8 8 ex gratia payment schemes have been put in place to statement where you address this. 9 9 provide financial support. To date, these schemes You say this: 10 10 "I felt all along that I never failed John in have paid out over £264 million." life, and I tried to be the best wife I could under 11 If we can go over the page. 11 12 "In January 2011, the then Secretary of State 12 the circumstances. I know he loved me and he told me for Health, Andrew Lansley, made a statement to the 13 13 near the end what I good wife I had been. However. 14 House of Commons in which he said he viewed the events 14 I failed him in death, because I haven't been able to 15 that led to thousands of patients contracting 15 get justice for him and the thousands of others who 16 hepatitis C and HIV from NHS supplied blood and blood 16 have died or are still alive, many of whom I know products as one of the great tragedies of modern 17 17 personally, or the widows who I know or don't know. 18 18 healthcare. He also said how sorry he was that it had "I know that John would want me to try and be 19 happened and expressed his deep regret for the pain 19 happy. He didn't want me to cry after his funeral, 20 and misery that many have suffered as a result." 20 and I didn't, but I've cried buckets since and still 21 Did you regard that as an adequate answer to 21 do. He said when he was ill that he wanted me to 22 22 your concerns? grieve for him for a year and then forget him, perhaps 23 A. Not at all, no. No. 23 remarry with his blessing. Well, I have learnt that 24 Q. Mary, it's clear from your statement and from some of 24 is impossible. We still have no closure, no admission 25 the many letters you've written -- and we've only 25 of wrongdoing. Everything has been swept under the 161 162 1 carpet and no one listened." 1 British Government have said, you know, it was up to 2 2 That's one of the reasons why you have continued the European Parliament. 3 over these years to write these letters, raise these 3 So -- but anyway, eventually it did come in 4 issues. 4 via -- or first of all with Frank Dobson, I think he 5 A. Yes. 5 brought it in for children, and then subsequent years 6 Q. Because you believe that's the right way for you to 6 it's come in. 7 7 Q. Mary, those are the questions I have for you. I'm honour John's memory. 8 8 A. Yes. Can I also say, I did campaign over recombinant going to ask Mr Williams if there's anything further 9 9 Factor VIII. he'd like me to ask. 10 Q. You did. We have a number of those letters in the 10 (Pause) materials you've provided to the Inquiry. 11 11 Mary, there's just one further point which 12 A. Yes. 12 Mr Williams asks me to raise with you. 13 Q. That was a very important part of --13 Q. We don't have the letters to display on screen, but 14 A. That was important to me, because I wanted --14 15 15 I certainly have seen them and they've been provided I wanted, you know, people to be free of viruses and 16 16 things. So that's why I campaigned, and I had by you, it's correspondence in February 1984. 17 a question put by my MEP to the European Parliament. 17 A. Uh-huh. 18 At the time recombinant Factor VIII had VAT on it. 18 Q. This is after John had undertaken that form of skin 19 I don't know whether it still has, but -- and this is 19 testing. 20 what was stopping the haemophilia centres from 20 A. Right. 21 purchasing it. So they were -- they were still, you 21 It's correspondence in which John was asked by 22 22 St Thomas' to donate blood and the letter reads: know, having human Factor VIII in their centres 23 23 because of the cost. "Dear Mr Grindley, 24 And -- but the European Parliament said it was 24 "We are desperately short of haemophiliac blood 25 up to the British Government about VAT, and the 25 at the hospital, which means we have difficulty in

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monitoring operations on patients with a problem similar to yours. We would be very grateful if you could donate some of your blood to us, assuming that you have not treated yourself within the last week."

I think, from memory, there were two such requests for John to donate blood.

- A. Could you just tell me the dates again please?
- Q. The first letter is 17 February 1984. The second letter I think follows fairly shortly thereafter. October of 1984.

Do you recall John being asked to donate blood?

- A. Well, I don't know specific dates, but, yes, he did, because he was interested in medical research. He frequently gave blood for research at St Thomas'. But what it was for, I don't know.
- Q. Thank you.

Mary, those are the questions, but is there something further that you would like to say?

A. Could I just raise, before I read my -- what I've got to say, the incident with Dr Savidge at St Thomas'. This was in 2003. I had requested from the National Haemophilia Database John's medical records, treatment records, for the American litigation, and the notes actually didn't come to me, I had to pick them up via St Thomas', from Dr Savidge. And Dr Savidge had a big

About a year after my husband died, I went to the GP because I was very depressed, and this was before my breakdown. He was very unhelpful, and more or less told me to get over what happened and move on in a cold -- very cold manner. A few friends and relatives have told me since to my face that this happened all long ago, and I should move on.

But how can I? I live with it every day. On the surface I may appear that I've moved on. I'm known for my smile, but underneath I haven't, and I don't think I ever will. I have many activities, feel I'm very popular and well liked, I enjoy socialising and I have plenty of friends, both ones who know my situation and those who don't. But I also have had deep periods of deep depression and loneliness, and even at times I've had suicidal thoughts.

There have been and still are days when I have had to force myself out of bed, where I don't wash all day. I sit around in my underwear and my nightwear with the curtains closed. I have been under a wonderful clinical psychologist who is here today for the past 18 months, who I was seeing before John died, and she is currently seeing me through this very difficult time and I'm sure beyond, and I thank her

row with me in the reception room -- reception at the Haemophilia Centre. He didn't want me to have the notes. And eventually he did give them to me, but when he gave them to me, he said, "These are possibly not accurate anyway". What he meant by that, I'm not quite sure, whether he was hiding something from me, or -- he possibly thought I was going to sue him, which I wasn't.

But I did get the notes eventually, and it really did have a very strong effect on me. I ran into the toilets at St Thomas' and cried.

- Q. And those were treatment records from the National Haemophilia Database, as you've explained.
- 14 A. Yes.
- Q. Previously you'd actually approached St Thomas' andasked for copies of John's records.
- 17 A. Yes
- 18 Q. You were told it was all too long ago and they'd been19 destroyed.
- A. That's right. I did get his ordinary medical records,but not the treatment records.
- Q. Mary, there was something further I think you want tosay.
- A. Yes, if you wouldn't mind. Some of this has beenrepeated.

for all her support.

My son has also suffered greatly, going into denial and not knowing how to deal with what happened with no father, and a mother who was stricken with grief. He has only just started to open up to me this week by allowing me to read his witness statement. I hope now, after more than 25 years, we can begin to talk about what has happened more openly.

I am just one of thousands of people who have suffered from this dreadful tragedy. Indeed, as we know, thousands have died, and those left and their families have been left to endure horrendous physical and mental pain and suffering. What is more, they have been left without help, or no help, having to be means tested and begging for money.

The widows, some of whom I know, have been -- and some of whom have been tragically infected themselves, have been made to feel like second class citizens, scroungers, and treated worse than dogs and left to survive themselves.

Yet, all this should never have happened, and what has happened until now has been swept under the carpet and truths denied. I have in a small way been a little voice battling against the odds through nearly 40 years by my individual campaigning, trying

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1	to halt unsuccessfully the use of unsuitable donors	1	justice for him and all the others who so tragically
2	from American prisons and homeless. Still, the	2	died or have been infected or affected.
3	pharmaceutical companies continued to send out	3	l will fight on.
4	untreated blood products, even when they knew heat	4	I'm extremely grateful for this opportunity to
5	treated blood was available, for their profit, and the	5	give my evidence. We all hope Sir Brian and his
6	American government still allowed them to do it.	6	wonderful team will finally uncover the truth by this
7	I tried to halt the importation of those blood	7	public inquiry, and I thank them for all their hard
8	products. I wrote to Margaret Thatcher,	8	work.
9	Kenneth Clarke and others who deliberately ignored	9	I just hope, as we all do, that the government
10	what was happening and to successive governments who	10	will be listening to these findings and act
11	ignored pleas for help and never accepted	11	accordingly, to give all those infected and affected
12	responsibility, which was really their duty of care to	12	some closure and that we might finally get some
13	the haemophilia community. But those letters fell on	13	closure that we have been denied.
14	deaf ears.	14	I would like to thank my wonderful
15	I battled with the Macfarlane Trust to try to	15	daughter-in-law here for all her help with my witness
16	get regular payments for all widows, but to no avail.	16	statement and for being here at my side. For my
17	I also campaigned for recombinant Factor VIII,	17	wonderful son, who has supported me through many
18	but initially it was too expensive for haemophilia	18	difficult years. My friends and family here today.
19	centres because of the VAT, and then only given	19	Lynne Kelly from Haemophilia Wales, who has supported
20	eventually to children.	20	me both before the public inquiry and since, and who
21	I promised my husband, when he was very ill,	21	has worked tirelessly to help bring this public
22	that I would seek justice for him. Until now, my	22	inquiry, together with others.
23	efforts have been in vain. Although I feel I did all	23	I would like to thank the staff at Watkins &
24	I could while he was alive, I feel I have failed him	24	Gunn particularly Michael Imperato, Lucy O'Brien and
25	in death, because I have not been able to get the	25	Megan Rogers, and my barristers, Lloyd and Christian,
	169		170
	100		110
1	for their tireless work on my behalf.	1	SIR BRIAN LANGSTAFF: You're fighting on.
1 2	for their tireless work on my behalf.  Very lastly. I would like to pay tribute to all	1 2	SIR BRIAN LANGSTAFF: You're fighting on.  A. Yes, I am, I am fighting on. Sir Brian.
2	Very lastly, I would like to pay tribute to all	2	A. Yes, I am. I am fighting on, Sir Brian.
2 3	Very lastly, I would like to pay tribute to all those infected and affected who have given their	2 3	<ul><li>A. Yes, I am. I am fighting on, Sir Brian.</li><li>SIR BRIAN LANGSTAFF: Thank you very much.</li></ul>
2 3 4	Very lastly, I would like to pay tribute to all those infected and affected who have given their evidence and all their witness statements to this	2 3 4	<ul><li>A. Yes, I am. I am fighting on, Sir Brian.</li><li>SIR BRIAN LANGSTAFF: Thank you very much.</li><li>A. Thank you very much, thank you.</li></ul>
2 3 4 5	Very lastly, I would like to pay tribute to all those infected and affected who have given their evidence and all their witness statements to this inquiry. They have shown great courage to do so.	2 3 4 5	<ul> <li>A. Yes, I am. I am fighting on, Sir Brian.</li> <li>SIR BRIAN LANGSTAFF: Thank you very much.</li> <li>A. Thank you very much, thank you.</li> <li>SIR BRIAN LANGSTAFF: Mary's evidence has brought this</li> </ul>
2 3 4	Very lastly, I would like to pay tribute to all those infected and affected who have given their evidence and all their witness statements to this inquiry. They have shown great courage to do so. I have met some amazing people, both before and during	2 3 4	<ul> <li>A. Yes, I am. I am fighting on, Sir Brian.</li> <li>SIR BRIAN LANGSTAFF: Thank you very much.</li> <li>A. Thank you very much, thank you.</li> <li>SIR BRIAN LANGSTAFF: Mary's evidence has brought this phase of the Inquiry to an end, and it's time to</li> </ul>
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Both individually and often as a family after 2 the death of someone we valued above all others, it is 3 to me remarkable that so many, despite their mixed 4 emotions, have wanted to give evidence, and that 5 others whose story deserved to be heard orally have 6 allowed themselves to be persuaded to tell it in that 7 way, despite the personal cost that it might involve. 8 In my view, true courage is shown when people 9 have a choice between an easy option and a risky one, 10 and they opt for the risky choice because that is the 11 one which is most likely to help others, or allow them 12 to do their duty by someone who is no longer here to 13 do it for themselves. 14 So I'd like to pay tribute to every one of those 15 who have chosen to give evidence when asked, for they 16 have shown that sort of courage, and each in their own 17 way, despite the risks of adding to their personal 18 pain, has helped paint a composite picture which will

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shone a light onto what has happened, and the everyday consequences and ripple effects of living with it, often for 30 years or more. The Inquiry is particularly interested in the overall picture. Each individual account given may be

subtly different, one from another, but each is 173

help in trying to establish the truth. They have

steps taken by the government so far as result of that letter, increasing payments in England, have helped, but many more witnesses have repeatedly drawn attention to the continuing variations between the home nations, although at the time of their infection

the wording. The wording is not "We will consider", it is not "We wish", it is not "We want"; it is "We commit, "our commitment to guarantee equal support". Those are the words which the government has issued

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of value not just for its own sake, though it certainly is of value for that, but because taken together, they've painted the same themes from different perspectives. They've done that so clearly that you don't need me to recite those themes. Any observer can see them for themselves. They shape the context for what must follow.

But let me just mention a couple of the emerging themes.

First, it's clear that the impact of decisions made in the 1960s, 1970s and 1980s, or the consequences of not making decisions which might have been made, continue to this day.

Second, the evidence we heard only this week of a widow who became homeless after her husband's death, having had to spend the time caring for him when she might have spent it working for a wage had he not been infected, is just part of an overall picture of relentless hardship for many.

It's now just over a year ago since I wrote to the minister for the Cabinet Office calling for decisive action to be taken to alleviate this before any fundamental review which might follow from the Inquiry's conclusions.

Some evidence we've heard suggests that the

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today.

We are independent of the government. We note those words. We wait to see what happens in consequence.

As to the outcomes of the Inquiry, may I make it clear that if wrong was done, I have the power under the Inquiries Act to say so. And, if it was, I will. If there is criticism to be made, I shall make it, and I shall not hesitate to name names where it is appropriate. If there was fault, I intend to say so.

Now, where actions should be taken in remedy, I expect to make robust recommendations. This is not the same as determining liability in a civil or criminal case. I have no power to do that. That is a matter for the courts. Whether my findings at the end of the day lead others to take matters before those courts is for them, not for me, to determine.

Another repeated theme has been the often unanswered call for help and psychological support for those suddenly facing what has seemed an unfair death sentence, with all its side-effects on partners, friends and family, or the gruelling courses of treatment they've undergone with their own side-effects.

It is appropriate, therefore, that when we begin

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there was no such thing as a devolved health administration. The grinding hardship of many is not put on hold while the inquiry continues. If, as a number of witnesses have argued, there is in truth no proper justification for the significant variations in financial support as between the nations of the UK, then there can be no proper reason for those variations to be perpetuated to await the outcome of the inquiry. I've learnt today that this morning a government spokesman told the BBC this, and I quote: "We are working with devolved administrations so that we can meet our commitment to guarantee equal support for all those infected and affected across the UK." Now, perhaps it's the lawyer in me, but I note

our next set of hearings, which will begin on February 24 next year, we shall hear in particular from experts on social and psychological impact -- one was here earlier today -- as well as from experts on hepatitis, HIV, blood and bleeding this orders. That evidence is intended to place what we have already heard in a wider context and prepare for the hearings with the decision-makers which will follow. They will follow in early June. The exact date depends on timetabling the first witnesses, but we shall begin by exploring what those clinicians and, for that matter, those other witnesses who can shed lights on the policies and practices of centres from across the UK who are most closely involved at the time, can tell us about what happened and why. Well, you may ask: why wait until next June? Time is precious, aren't you wasting it? The answer

Well, you may ask: why wait until next June? Time is precious, aren't you wasting it? The answer is that we are taking time for good reason and wasting none of it.

This inquiry is not a small undertaking. The hearings are the visible part of the inquiry's work, but the majority of the inquiry team have been beavering away throughout on the investigation, and this will intensify to enable Ms Richards and her counsel team to be fully prepared to examine what the

archives.

All this and evidence of around 3,000 witnesses is to be considered, along with expert evidence. We shall also be arranging for further evidence from people who are infected or affected to be heard at the end of our evidence sessions, as I promised at the outset, people first and last. We may find space, too, for some to be heard during our exploration of specific terms of reference.

Having mentioned that, forgive me for repeating a theme which I've touched on at the end of each set of hearings so far.

You've seen -- you've seen today, you've seen throughout this week, you've seen over the last 12 weeks of hearings -- how the evidence of each witness adds something, something new, something different, to the overall picture. Just when you may think you've heard it all, another aspect is revealed. Written statements are the same. Each has real value, each sheds a slightly different light.

Each time I've asked for anyone who has been infected or has been affected by the suffering of someone close to them, or themselves, to pluck up the courage, it takes courage, I acknowledge, to make a statement, there has been a response. Well, I'm

decision-makers have to say from June onwards.

More than 11.5 million pages have been reviewed, and around 2.5 million pages already placed on the Inquiry's documents system, a figure which grows at an average of 40,000 pages per week.

These come from almost 600 organisations, repositories, archives, including international archives, trusts, haemophilia centres and government bodies. I have to confess that more documents have come to light than I had at first anticipated, and each page of each document has to be looked at. They have to be set in the right place. It feels at times like solving a million-piece jigsaw.

We've had extensive co-operation from most of those bodies, individuals, companies and organisations which hold documents, and I thank them for that. So I hope that I'm not going to be misinterpreted when I gently remind all of the expectation expressed at the highest levels of government that there will be full co-operation with this inquiry, and that having regard to the public interest in establishing the truth, that extends to waiving legal privilege, ensuring retention notices are in place, so that potentially relevant information is not destroyed, and ensuring or facilitating thorough searches of

asking again, and I'm especially interested in what those with a blood disorder such as thalassaemia or sickle cell anaemia may have to add.

Well, it's late in the day, but then I did promise we'd sit until we finished.

It remains for me just to mention two further things.

First, I feel sure that the witnesses who have been dealing with the most uncomfortable of issues have been able to do so much better because so many of you have been here supporting them, here and online.

Finally, it remains for me to wish you all, all here, a safe journey home.

Thank you.

SIR BRIAN LANGSTAFF: 24 February.

(4.30 pm)

(The Inquiry adjourned until Monday, 24 February 2020)

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