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Wednesday, 8 May 2019

SIR BRIAN LANGSTAFF: Good morning.

SIR BRIAN LANGSTAFF: Before we begin, may I just say

a few words about what will happen today because some aspects of it will be unusual to those of you who have been following the Inquiry so far and some of you were not here last week when I made my first restriction order restraining people from saying anything which might lead to the identification of the witness on that particular day.

Today, we will hear two accounts of sons who lost their lives to infection. The first will be given by two parents who I understand wish to be known as Alan and Chris. They will be supported by their daughter. Their daughter won't be giving evidence and so won't take the oath but both Alan and Chris will be asked questions and will take the oath as a result. That explains why there are now three seats in front

There will on occasions later on in the Inquiry be as many as six seats where we have a group of six people who were infected or affected who have particular points to make about certain parts of the

witness this afternoon, it is unavoidable if we are to make sense of her testimony and allow her to give evidence as she would wish, that she will mention the names of her sons.

In her case that might lead to her identification and so nothing may be said by anyone which mentions the names of her sons or any other member of her family for that matter because they might lead to her identification.

You may ask when you hear it, well, this is being recorded, the transcript goes out from the Inquiry, why isn't the world -- why don't they have that name? The answer is that we have processes in place which make sure that where the transcript is published there will be a blank wherever the name appears. That means that if you want to look back tomorrow or the day after at what you've seen and heard, you won't see anything of the witness and you won't read all the details of what someone has said. That is part of the lengths to which we will go in a proper case to protect the anonymity of someone who wishes us to do so.

I am sure there are some details, which Ms Richards will add to in due course, but that's the broad outline of what will happen.

evidence and whose stories will be heard in that way rather than focusing just upon one or maybe two people at a time.

But today you have your first foretaste of that in there being two witnesses who will be giving evidence together about the same victim.

The next two witnesses after that, so that will be after Alan and Chris, are both witnesses who have asked us to pay particular respect to their anonymity and I consider it is right to do so. So in their cases, nothing may be published which may lead to their identification. Indeed, before each gives evidence, I shall formally make an order just to remind those of you who are here now, and anyone who might have come in between now and then, that they must not do so and, indeed, it would be a serious offence for them to do that.

One of the reasons for mentioning it is that you may ask, well, if they're sitting there why aren't they having their image live-screened across the nation? The answer is that in those cases the cameras will not be showing their faces. Instead they will have to put up with Ms Richards or me, but I think largely Ms Richards.

What they say you will hear and in one case, the

2

1 First, Ms Richards, do you want to say anything 2 more about that?

MS RICHARDS: Sir, only this: the evidence both of Alan and Chris and of our following witness, who will be referred to as Mr B, will be live-streamed as normal.

In the case of the witness, who will be referred to as Mrs C, who is giving evidence this afternoon, although as you have explained, sir, she is likely in the course of her evidence to mention her son by name (because it would not be practical or fair to expect her to do otherwise given the nature of the events that she will be relating, and so those who are sitting in this room hearing her evidence will learn her son's name), the restriction order that you have made, sir, prevents anybody in this room disclosing or publishing or repeating that name and her evidence will not be live streamed. So those watching from elsewhere will not be able to follow live this afternoon's evidence.

However, a transcript, a written transcript of her evidence, will be published on the Inquiry's website with names redacted later on, probably later this evening, possibly tomorrow, and the audio recording of her evidence will be made public after the audio technicians have removed any reference to

3

4 (1) Pages 1 - 4

1	any names in the course of her evidence, so it will be	1	from there, so within a month, fortunately, before he
2	public but her evidence will not be live streamed this	2	was 11 or 12 months, he was diagnosed as a severe
3	afternoon.	3	haemophiliac. He had less than one per cent clotting
	SIR BRIAN LANGSTAFF: Thank you very much. Shall we have	4	factor.
4			
5	Alan and Chris.	5	MS RICHARDS: For the first year or so after his diagnosis
6	ALAN PERCY FOWLE (affirmed)	6	I think he was treated at St James's Hospital in
7	CHRISTINE FOWLE (affirmed)	7	Leeds.
8	Questioned by MS RICHARDS	8	CHRIS: Yes.
9	MS RICHARDS: Alan and Chris, you are here today to tell	9	MS RICHARDS: After that, his care was transferred to the
10	us about your son, Christopher, who was born in	10	care of Harrogate General Hospital and he was under
11	June 1974, I think, and you have one other daughter,	11	the care of a doctor there called Dr McAvoy.
12	Joanne, who sits with you today to give you support?	12	CHRIS: Yes.
13	CHRIS: Yes.	13	MS RICHARDS: Pre-school, so when Christopher was very
14	ALAN: Yes.	14	young, did he have much of a problem with the
15	MS RICHARDS: Christopher was diagnosed with haemophilia	15	haemophilia?
16	when he was very young; is that right?	16	CHRIS: No, he didn't, did he.
17	CHRIS: Yes.	17	ALAN: Not too much.
18	MS RICHARDS: What can you recall, either of you, about	18	CHRIS: Not too much, not until I suppose it was school,
19	the circumstances in which he was diagnosed?	19	starting with school, when he started to have
20	CHRIS: When he was maybe six months, I was doing the	20	frequent, more frequent bleeds, yes.
21	motherly thing, changing a nappy, and he had a huge	21	MS RICHARDS: On the occasions in those first few years
	bruise on his leg here (indicated) and which, you	22	
22	•		when he did need treatment was it cryoprecipitate that
23	know, no reason for it, so I immediately took him to	23	he was given at first?
24	the doctor and fortunately the doctor immediately got	24	CHRIS: Yes, initially it was cryoprecipitate, not for
25	to a paediatrician at Harrogate Hospital who went on	25	long. The Factor VIII came in fairly quickly, didn't
	5		6
1	it.	1	treatment changed to factor products.
	ALAN: Fairly soon after we started getting regular		CHRIS: Not over and above the fact that it would be far
2		2 3	
	treatment. The problem with the cryoprecipitate was		more convenient for us, and we would be able to take
4	it was such a huge volume it used to involve massive	4	our medicine on holiday or goes visiting to take our
5	pain for him, so	5	medicine with us, et cetera. Nothing I can't
6	MS RICHARDS: So he started school and you have described	6	remember anything
7	in your statement how with the rough and tumble of	7	ALAN: Well, you did ask about the safety factor of the
8	playing on a concrete playground he would get lots of	8	Factor VIII.
9	bumps, he would get bleeds and you were having to take	9	CHRIS: That was later, wasn't it.
10	him to hospital I think pretty frequently; is that	10	MS RICHARDS: So I think there came a point when you asked
11	right?	11	about safety.
12	CHRIS: Yes. It was maybe two or these times a week it	12	CHRIS: Oh, yes.
13	could be.	13	MS RICHARDS: Was that later?
14	MS RICHARDS: You ended up moving him to a different	14	CHRIS: It was when media start breaking news about HIV
15	school without a concrete playground and I think	15	infection and it being a blood product, I went and
16	smaller numbers where you hoped he wouldn't have so	16	asked our consultant I told our consultant I was
17	many bumps and wouldn't need so much treatment.	17	concerned and he assured me that I didn't have to be
18	CHRIS: Yes.	18	because it was generally in the homosexual community.
19	MS RICHARDS: But he did continue to need treatment and	19	MS RICHARDS: I think you say in your statements you were
20	there came a point in time when Christopher's	20	pleased with the Factor VIII products because it was
21	treatment switched from cryoprecipitate to Factor VIII	21	less painful for Christopher and you understood that
22	products.	22	if the one of the objectives was that it could be
	•	23	administered at home either by you or by Christopher
23	CHRIS: Yes. MS PICHAPPS: Cap you recall anything at all about any		
24	MS RICHARDS: Can you recall anything at all about any	24	himself; is that right?
25	conversations you had with doctors at the time the	25	CHRIS: Yes.

(2) Pages 5 - 8

1	ALAN: Yes.	1	of factor products?
2	MS RICHARDS: If we just have up on screen please, Paul,	2	CHRIS: No.
3	a document, it's 1805002.	3	ALAN: No.
4	There should come up on screen a handwritten	4	MS RICHARDS: Now, you again said in your statements that
5	document. I am not going to ask you anything about	5	it didn't occur to you to question what was being
6	the detail of this but this is one of the few bits and	6	recommended for Christopher because you placed your
7	pieces of Christopher's records that you have and we	7	faith in the professional judgment of the doctors
8	can see here it shows from 1981 onwards, for a number	8	looking after him and you didn't think doctors would
9	of years up until I think 1989, Christopher receiving	9	give your child anything that was unsafe; is that
10	regular Factor VIII products, often on a weekly basis.	10	right?
11	CHRIS: Yes.	11	ALAN: That's right.
12	MS RICHARDS: Does that accord with your recollection?	12	CHRIS: (The witness nodded)
13	CHRIS: Yes.	13	MS RICHARDS: I think it goes without saying, but your
14	ALAN: Yes.	14	statement does say it, that had you been informed
15	MS RICHARDS: Thank you. That can come down.	15	about any risks your attitude to the suggestion of the
16	At the time that the factor products were first	16	change in treatment would have been very different.
17	starting to be used on Christopher, leaving aside any	17	CHRIS: I'm sure it would have been, yes.
18	later conversations you might have had with the	18	ALAN: It would have been.
19	doctors, were you given any information about there	19	MS RICHARDS: I think the doctor showed you both how you
20	being any risks of infection associated with those	20	might administer the Factor VIII, how you might mix it
21	products?	21	up I think is the phrase you use
22	ALAN: No.	22	CHRIS: Yes.
23	CHRIS: No.	23	MS RICHARDS: and administer it. What can you remember
24	MS RICHARDS: Were you ever given any information or	24	about that?
25	advice about any differences between different types	25	CHRIS: Gosh. He was injecting himself at home so we were
	9		10
	v		10
1	making up the medicine at home or if we were away	1	MS RICHARDS: rather than your normal local hospital
1	making up the medicine at home or if we were away. I can't remember the I think it was one of the	1	with the bottles and the doctors would refuse to do
2		2 3	
3	nurses actually who showed us how to make it up safely		the injections. ALAN: Yes.
4 5	and cleanly. Can you remember?	4 5	CHRIS: It did happen, yes.
	•		
6 7	ALAN: Yes, I can. With regards developing the ability to	6 7	MS RICHARDS: And you, because of the concerns the two of
8	inject Christopher, we were taken to a session at the	8	you had about you injecting Christopher for the
	hospital and we had to inject each other and find		reasons you've explained, Alan, you thought it was
9	a vein and so forth and we both did it successfully but realised how difficult it was and Christopher's	9	important that he should learn how to self-administer the treatment.
10	•	10	
11	veins were much smaller than ours and we were worried	11	CHRIS: Yes.
12	about the danger of actually cutting the vein, which	12	MS RICHARDS: For a period of time he went to a residential school where there would be those who
13	we could do with the point of the needle.	13	
14	So we adopted more the attitude that we'd take	14	could assist him to do that; is that right?
15	the medicine with us wherever we went and we'd then go	15	CHRIS: Yes.
16	along to a hospital and we would offer to mix up the	16	ALAN: It was a facility being run I understand by
17	medicine for them for a doctor to inject, and	17	Newcastle University, Welburn College, up in
18	sometimes that worked and sometimes it didn't because	18	North Yorkshire moors and the idea was that if he
19	they strangers walking in saying, "Inject this into	19	developed the ability he had so much more freedom.
20	my son", they didn't want to know.	20	MS RICHARDS: I don't think Christopher was terribly
21	MS RICHARDS: Yes, you have explained I think a couple of	21	impressed with your idea from what I gather from your
22	times you were away from home and so you would have to	22	statement. He wasn't so keen on it but did he learn
23	take him to the hospital that was local to where you	23	to self-administer?
24	were	24	CHRIS: Yes, he wasn't there very long. He did
25	ALAN: That's right.	25	self-administer, yes.

(3) Pages 9 - 12

1	MS RICHARDS: Now, there came a time in when Christopher	1	CHRIS: We were but, I mean, that was just a point of
2	was about nine years old I think when Dr McAvoy called	2	reference that the doctor told us. We were never
3	you both to see him at the hospital.	3	given a name or any details. We didn't particularly
4	What can you recall of that discussion that then	4	want to. They couldn't do that, but they did say they
5	took place?	5	had traced it. We know no more than that.
6	CHRIS: Amazingly little. I don't even I can't even	6	MS RICHARDS: Were you given any other advice or
7	remember whether I was called especially or whether	7	information about the condition at that time or
	I was just going because Christopher but yes, we	8	
8			prognosis?
9	were called to the hospital anyway and were told that	9	ALAN: No.
10	Christopher had been infected and he was now HIV	10	CHRIS: Amazingly, well none really.
11	positive. Really, that was it.	11	MS RICHARDS: Were you given any advice or information
12	ALAN: And that was it, really.	12	about how to manage any risks of infecting others?
13	CHRIS: Really, that was it.	13	ALAN: No.
14	MS RICHARDS: He was nine years old.	14	MS RICHARDS: I think you had a particular concern given
15	CHRIS: Nine/ten years, yes.	15	Christopher's age and he used to play with his friends
16	MS RICHARDS: You said in your statement, but I do not	16	and do all sorts of activities, you had a concern
17	know if this was something you were told at the time	17	about the risk of him infecting other children.
18	or later, that Dr McAvoy said that Christopher might	18	ALAN: That's right.
19	expect to live for another 12 years.	19	CHRIS: Yes, because we didn't know what was dangerous and
20	CHRIS: Yes.	20	what wasn't, you know. We just had to glean what we
21	ALAN: Yes, that's correct.	21	could, really. But the information that came through
22	MS RICHARDS: I think one of you has a recollection that	22	from the hospital was
23	at some point, you're not I think sure whether it was	23	ALAN: Was minimal. We didn't get any.
24	then or later, you were told that doctors had been		CHRIS: very inadequate. It was inadequate, yes.
	able to trace the infected blood to an infected donor.	24	
25		25	MS RICHARDS: Your reaction on being given that
	13		14
1	information you put in your statement very powerfully,	1	CHRIS: no contact sports which he couldn't do and for
2	you say:	2	maybe four or five years it became his passion and it
3	"We were devastated because our son was an	3	took up a lot of your time, didn't it, on weekends
4	innocent nine-year old. His life was going to be cut	4	and
5	short because he had been treated with blood products	5	ALAN: Well, my background being engineering I spent
6	that were not safe."	6	a long time developing the models for him.
7	ALAN: That's right.	7	CHRIS: So that's where we found something that he
8	CHRIS: Yes.	8	could be passionate about and that's what we wanted
9	MS RICHARDS: You decided, given Christopher's very young	9	for him.
10	age, not to tell him at that point about his illness.	10	MS RICHARDS: He did pretty well in competitions?
11	CHRIS: Yes.	11	CHRIS: He was sitting high, second and third in the
12	MS RICHARDS: You decided you wanted to do everything you	12	country.
13	could to make the years he had happy.	13	ALAN: Top 20 in two groups.
14	CHRIS: Yes.	14	CHRIS: Top 20 in two groups, yes.
15	MS RICHARDS: There was a particular activity that	15	MS RICHARDS: Now, Christopher of course had to did
			keep receiving factor products because of his
16 47	Christopher loved and that you encouraged.	16	
17	Can you tell us about that.	17	underlying condition but this I think was the point in
18	ALAN: Remote control car racing, 10th scale. We	18	time at which you were told that the products were now
19	travelled all over the country.	19	heat-treated and you were told that they would be
20	CHRIS: I'll take over. We travelled all Alan and	20	safe.
21	Chris travelled all up and down the country and abroad	21	What ongoing care or support, if any, did the
22	with this remote control because it was something that	22	hospital provide after you were informed of that
23	he could get really excited and passionate about, but	23	diagnosis other than the routine haemophilia care?
24	it was it wasn't football or, you know	24	ALAN: None that I'm aware of.
25	ALAN: Non-contact	25	CHRIS: No

(4) Pages 13 - 16

1	MS RICHARDS: There came a point when you decided that you	1	I think he understood. He understood enough and we
2	needed to tell Christopher. When was that?	2	were quite adamant of trying to tell him how safe he
3	CHRIS: When he was 15. He was becoming a young man and	3	must be.
4	you had the obvious dangers of becoming a young man,	4	MS RICHARDS: You've explained in your statements that, in
5	and it was time for him to realise his	5	addition to the HIV, Christopher was also infected
6	responsibilities, really, you know, and how dangerous	6	with hepatitis C.
7	things were, so I told him the situation.	7	CHRIS: Mm-hm.
8	He seemed to take it very well. Probably at 15	8	MS RICHARDS: Just dealing, first of all, with the HIV,
9	you don't understand the full consequences but he did	9	had you been asked for your consent for him to be
10	come home. He went out that night with some friends	10	tested or even told that he was going to be tested for
11	and he did come home and said, "You know, Mum, I was	11	the condition?
12	looking round and thinking I'm different, I'm not like	12	ALAN: No.
13	these people", and immediately separated himself out	13	CHRIS: No.
14	in here (indicated). I'm quite convinced of that, you	14	MS RICHARDS: The hepatitis C, how did you find out
15	know. We took life from there.	15	Christopher was infected with hepatitis C?
16	MS RICHARDS: You again said in your statements, both of	16	CHRIS: Do you want me to tell them?
17	you, that you weren't sure at that stage at least	17	ALAN: Yes.
18	whether he fully understood the implications. He was	18	CHRIS: Alan was in
19	only 15.	19	ALAN: In an evening.
20	CHRIS: 15, you know, it's	20	CHRIS: Pardon?
21	ALAN: He was a bright lad.	21	ALAN: An evening once, you know. A young doctor.
22	CHRIS: You know, he was a clever he was a bright lad	22	CHRIS: We'd gone you know, if he got a head knock,
23	and I think he understood to a point but	23	which sometimes it was an evening one anyway, and
24	ALAN: Maybe not the acceptance.	24	Alan said something about you must be worried about
25	CHRIS: Yes, you know, you can't be absolutely sure.	25	the HIV dangers and the doctor turned round and said,
20		20	
	17		18
1	"I'm more worried about the hepatitis C", and we	1	can be up to six months, I understand, and yet I was
2	went we didn't know, did we?	2	never, ever retested.
3	ALAN: No, not until that point.	3	MS RICHARDS: Now, in terms of Christopher's physical
4	CHRIS: Then it was almost in passing conversation.	4	condition, he seemed reasonably well, I think, for
5	MS RICHARDS: Was any advice or information ever given to	5	a while whilst doing the kind of activities that
6	the two of you about being tested yourselves for HIV	6	you've described but there came a point at which he
7	or hepatitis C?	7	started to become physically unwell.
8	CHRIS: No. Well, I was tested the one time I told you	8	CHRIS: Yes.
9	about.	9	MS RICHARDS: What can you tell us about that?
10	MS RICHARDS: Can you tell us about that, how you came to	10	CHRIS: He coped very well for a few years and then he
11	be tested.	11	started to lose weight. Then for a year he actually
12	CHRIS: Alan was away and he had banged his head during	12	picked up. Do you remember, Alan, when you were
13	the day and it was still when I was going to the	13	playing golf with him every night, do you remember
14	hospital I was still at the hospital then, and he	14	that, Jo?
	had a head knock and I took him up to the hospital and	15	
15	·	16	It was one year, and then the last would you
16	the doctor refused to take the needle (because usually		say it was the last six months or the last year of his
17	you just put it in a sharps box) and she refused to	17	life when he really started going downhill?
18	have it in the hospital and wrapped it up in tissue	18	JO: 18 months, I'd say.
19	and gave it to me. This is early hours of the	19	CHRIS: 18 months would you say? The last 18 months of
20	morning.	20	his life he started to go down, started to lose
21	I put it in my pocket, got home and I was	21	weight, and he never carried a lot of weight anyway,
22	pricked. I phoned the hospital the next day and they	22	and he just got worse and
23	had me up there for a test and it was clear. But it	23	ALAN: You gave up work.
24	was dreadful at the hospital, you can imagine. They	24	CHRIS: Mmm?
25	never, ever retested me because I think, you know, it	25	ALAN: You gave up work and looked after him.

(5) Pages 17 - 20

1 CHRIS: Yes, I stopped working because I needed to nurse 2 him and we turned part of our house, a little snug 3 room, into his bedroom. JO: He had the -- hospital with pneumonia, do you 4 5 remember? He has two bouts of pneumonia, didn't he, 6 when he was in hospital --7 **ALAN:** He had two bouts of pneumonia when he was in 8 9 CHRIS: Yes, he did. Do you know, I'd forgotten about that. I'd forgotten about that, you know. He had two 10 bouts of pneumonia and he went into hospital. I had 11 12 district nurses every day coming in and then -- the ulcers, horrible ulcers, infected ulcers in his legs, 13 14 and a lot of pain, a lot of pain, and this went on for 15 the last 18 months until --16 JO: It got progressively worse, didn't it, progressively

17 worse the last six months.

CHRIS: Progressively worse and that last six months the 18 19 district nurses were coming in every day, re-dressing 20 his ulcers and his infections and --

21 ALAN: The main problem was hygiene. We didn't have 22 a downstairs --

23 CHRIS: We didn't have a downstairs cloakroom and I was 24 getting, I have to say, I have to admit, that I was 25 getting tired, you know, and the district nurse tried

21

CHRIS: Yes, as he got older he was angry. He lost 1 2 interest in, not in living as such but in doing 3 anything constructive with his life; is this right, 4 yes? JO: Lost a bit of purpose. 5 CHRIS: Sorry? 7 JO: Lost his purpose. 8 CHRIS: Yes, that's good. Yes, he did. He lost his 9 purpose. He didn't have a purpose, you know. 10 MS RICHARDS: You said in your statements he began not to care what was happening around him and to understand 11 that his life wouldn't be normal, his life would end 12 13 prematurely. CHRIS: Absolutely. 14 MS RICHARDS: You left it to him, I think, if he would 15 16 tell any of his friends.

17 CHRIS: As he got older, once we were told I advised him

18 not to, I have to say that, I did advise him not to. 19 The main reason for that is just the whole media thing 20 was just horrendous and it still was. Even then, it 21 still was not good.

MS RICHARDS: About AIDS? 22

CHRIS: Yes. I found out -- when he was poorly, actually, 23 24 right at the end when he was very poorly -- that he 25 told one girl friend, a friend that was a girl, Heidi.

23

to persuade him to go into our local hospice, which he 2 absolutely refused to do.

3 ALAN: Respite for you, really.

CHRIS: Yes, as part of respite for me and, anyway, she 4 5 said, "Look, just come for the two weeks. You need a bath. You really do need a bath", two days, sorry, 6 7 a long weekend, not two weeks, and he did. He agreed

8 to and said it was really lovely so he thought he'd

9 stay for a fortnight, and in that fortnight he passed

10 away. It's not pleasant. He was very, very thin --

11 ALAN: Jaundiced.

12 CHRIS: -- very thin, jaundiced, and he did go blind, and that was -- that was the last thing I remember really 13 14 of him not being able to see.

MS RICHARDS: I think he died the day after his 22nd 15 16 birthday.

CHRIS: Yes, he did. 17

MS RICHARDS: In the years before that, before the end, 18

19 how had his emotional state been? I think he left

20 school at 15 in the end; is that right?

21 CHRIS: Yes, he did. He -- help me here, Jo, because you

22 being his sister you also probably spoke to him more

23 than we did at times. He sort of lost interest,

24 didn't he?

JO: Yes, angry.

22

1 Heidi knew and she gave him a big cuddle, you know.

2 That was the only person, in his wisdom, he decided to

3 tell, yes, yes.

MS RICHARDS: You've shared with us a photograph of 4 5 Christopher before he became physically very unwell.

6 CHRIS: Yes.

7 MS RICHARDS: I am going to ask for that photograph to be 8 displayed please, Paul. It's 1805003.

9 How old was Christopher there?

10 **CHRIS**: 19?

ALAN: Yes. That was in his good year. 11

JO: 19? Was he 19? 12

ALAN: 18.

JO: 18, yes -- late teens. 14

MS RICHARDS: And he didn't want photos taken after that, 15

16 he said.

17 CHRIS: Oh, he never had all his life. He hated his 18 photograph being taken. And that was the last good

19 photograph we got of him, yes.

ALAN: Under duress from his sister.

MS RICHARDS: Because you were trying to give him a sense 21

22 of purpose as he got a little older, having left

23 school I think you arranged for him to come and work

in your firm with you, running the business you were

25 running?

24

24

(6) Pages 21 - 24

1	ALAN: Yes. I had a very technically capable university	1	grandparents. That was all, that's all we told.
2	student who was running the CAD system, the computer	2	MS RICHARDS: After Christopher died I think the doctor's
3	aided design, and we put Christopher with him and he	3	certificate had put the cause of his death down as HIV
4	taught him how to use the CAD drawing system, so he	4	or AIDS and you asked for that to be changed because
5	had a small purpose in his life and we used to	5	you didn't want that to be how his death was
6	pressure him to get drawings out on time to send to	6	remembered. Is that right?
7	clients and sometimes it worked, sometimes we had to	7	ALAN: I did because we were protecting Christopher's
8	get them done by the student.	8	memory really. That was all.
9	MS RICHARDS: Then as he got worse I think emotionally	9	MS RICHARDS: Were any of you, Christopher, either of you,
10	also he would become very upset. You've described you	10	your daughter, were you ever offered any form of
11	might have a quiet family evening sitting around	11	counselling or any kind of emotional support?
12	watching TV and then suddenly he would break down and	12	CHRIS: Yes, by the hospice.
13	start sobbing uncontrollably.	13	MS RICHARDS: So in the last two weeks?
14	CHRIS: Mmm.	14	CHRIS: Not from the NHS, but by the hospice.
15	MS RICHARDS: In the course of those last few weeks and	15	ALAN: After Christopher died.
			·
16	months when you had the district nurses visiting,	16	CHRIS: After he died, this was after he passed away, yes.
17	I think one of the district nurses told you at some	17	But I didn't do it.
18	point something Christopher had said about you both.	18	MS RICHARDS: You have said in your witness statement that
19	CHRIS: Do I have to repeat that?	19	you feel that Christopher's death was avoidable, and
20	MS RICHARDS: Shall I repeat it?	20	you've said that for a very specific reason based upon
21	CHRIS: Please.	21	things you think could have happened at the time. Do
22	MS RICHARDS: He said, "I have the most brilliant	22	you want to just tell us what those are.
23	parents". You had borne the brunt of this largely in	23	CHRIS: It was avoidable because I believe or we all
24	secret, I think. You didn't tell family and friends.	24	believe, don't we, that the Government or Health
25	CHRIS: We told close family, obviously, his sister,	25	Service knew of the risks of buying blood from, say,
	25		26
1	America. Knew the risk. I honestly do believe that	1	JO: Because of the outlay.
2	and the fact that they knew also that if these	2	CHRIS: Yes, because of the outlay, yes.
3	products are heated to a certain level you can kill	3	MS RICHARDS: I am just going to read one last bit from
4	any carry-over from them, you know, and that didn't	4	your statement because I think it is probably easier
5		5	for me to read it than ask you to say it. You've both
6	happen.	6	
	There's another part of this answer, you know,	7	said this in your statements:
7	and it's gone out of my head now.		"Christopher should never have lost his life.
8	MS RICHARDS: Your statement, let me prompt you in	8	He was our only son. We have been denied seeing him
9	relation to your statement. You have talked about how	9	get married, have children, travel and most of all
10	the two of you attended a seminar run by the	10	sharing our lives with him as we get older. We do not
11	Haemophilia Society and I think you learnt something	11	think time will heal our pain because we forever think
12	there that you thought was relevant.	12	about what might have been."
13	CHRIS: Yes, we did. We attended a seminar run by the	13	Is there anything else you will like to add?
14	Haemophilia Society and there was a doctor there who	14	CHRIS: I think that just about sums it up for me.
15	had come, did	15	MS RICHARDS: Alan?
16	ALAN : She developed a system of centrifuging blood from	16	ALAN: No.
17	donors so you separate the white cells from the red	17	MS RICHARDS: I am going to turn and ask Steven Snowden
18	cells, which meant that registered donors could donate	18	who, as you know, represents you if there's anything
19	twice as often and we could have become	19	further.
20	self-sufficient in the country. She needed six of	20	Nothing further, sir.
21	these machines, I think.	21	SIR BRIAN LANGSTAFF: There is just one thing which I want
22	CHRIS: She run up and down the country and Government	22	to ask you about. It's something which Ms Richards
23	wouldn't	23	did mention but the transcript doesn't show that you
24	ALAN: Entertain it.	24	replied and I can't remember you having replied.
25	CHRIS: entertain it because of the	25	It was about what you were told some time in the
	27		28 (7) Pages 25 - 28
			(.)

1	middle of the 1980s about heat-treated blood.	1	ALAN: Yes, I would say so.
2	CHRIS: There was a concentrate that we made up and we	2	SIR BRIAN LANGSTAFF: Do you remember who told you that?
3	were told in this was with hindsight, in	3	ALAN: I wasn't privy to this one.
4	retrospect, that if that Factor VIII that was infected	4	CHRIS: No, I can't. It would have been
5	with HIV had been heat-treated initially when	5	ALAN: It must have been Dr McAvoy.
6	Factor VIII first came on to the market, then this	6	CHRIS: It would probably have been a conversation with
7	disaster would not have happened.	7	Dr McAvoy.
8	SIR BRIAN LANGSTAFF: Did he go on receiving Factor VIII	8	SIR BRIAN LANGSTAFF: That would be Dr McAvoy at Leeds?
9	after you knew that he was HIV positive?	9	CHRIS: The consultant haematologist.
10	CHRIS: We had to do that because he	10	MS RICHARDS: At Harrogate.
11	JO: Then it was heat-treated after a certain time.	11	CHRIS: At Harrogate Hospital, yes.
12	CHRIS: It was heat-treated after a certain point anyway.	12	SIR BRIAN LANGSTAFF: Thank you. That's all I have to
13	ALAN: We were told then it was safe.	13	ask.
14	SIR BRIAN LANGSTAFF: You were told then it was safe?	14	Thank you very much indeed, all of you, for your
		15	
15 16	CHRIS: Yes, but Christopher was already	16	evidence, Alan and Christine, helped I think by your
16 47	SIR BRIAN LANGSTAFF: Do you remember roughly when that		daughter. So thank you all.
17	was?	17	We shall take a break now as usual. We will
18	CHRIS: '80s.	18	take a break until, let us say, 11.45/11.50, let us
19	ALAN: After, obviously after he was 9 years old because	19	say 11.50.
20	the thing is he already had HIV then.	20	MS RICHARDS: 11.50, sir. Thank you.
21	JO: It would have been after 1984, post 1984.	21	(11.11 am)
22	CHRIS: Post 1984.	22	(A short break)
23	ALAN: Which, yes, that would make him ten years old,	23	(11.55 am)
24	thereabouts.	24	SIR BRIAN LANGSTAFF: Ms Fraser Butlin, before Mr B gives
25	SIR BRIAN LANGSTAFF: So is around 1985 about right?	25	evidence, let me remind people of the order which
	29		30
1	I told you earlier this morning, those of you who were	1	A. Yes.
2	here, I would make.	2	Q. Please can you tell us what that is.
3	This is an order designed to protect the	3	A. It's a genetic blood disorder, chronic anaemia. My
4	anonymity of the witness. The order is that the name	4	body doesn't produce red blood cells and, yeah, it's
5	and address of witness W1943 (we shall know him as	5	not a good thing. Without red cells, we can't
6	Mr B) and any other identifying information such as	6	breathe, we can't function and we would die.
7	the witness's image or a description of their	7	So the treatment for that will be is regular
8	appearance cannot be disclosed or published in any	8	blood transfusions.
9	form unless express permission is given by me or by	9	Q. How frequently do you have those transfusions?
10	the solicitor to the Inquiry acting on my behalf.	10	A. So currently, at this age, it's every four weeks I have three units of blood. As a child, you didn't
11	Witness W1943 must be referred to only as	11	• •
12	"Mr B". The order remains in force for the duration	12	need as much blood and it might be two units every six
13	of the Inquiry and at all times thereafter unless	13	weeks and as you're getting older, they step it up.
14	otherwise ordered, although I may vary or revoke it by	14	Q. Are there any side effects of having regular
15	making a further order during the course of the	15	transfusions?
16	Inquiry. I would of course only do so if a proper	16	A. Yes, absolutely. So with the constant infusion of
17	reason arose.	17	blood, what happens is iron starts to build up in your
18	Can I remind those of you who are tweeting by	18	body, and the iron will build up in your vital organs,
19	all means tweet but don't in it say anything which	19	mainly your heart, your pancreas, your thyroid and
20	could lead to the identification of this witness,	20	various different parts of the body, and if it gets
21	Mr B. If anyone does, they are in serious trouble.	21	too much those organs will fail, so we need
22	Mr B.	22	a treatment for that.
23	MR B, affirmed	23	Q. How is that treatment administered?
24	Questioned by MS FRASER BUTLIN	24	A. So the treatment has evolved over the years. As
25	Q. Mr B, you have beta thalassaemia?	25	a child, from about the age of five it was an
	31		32 (8) Pages 29 - 32

(8) Pages 29 - 32

injection in the backside administered by the nurse and then my parents.

Now, it evolved to a more effective treatment but a much harder regime where you had to inject put a butterfly into your stomach, a butterfly needle with a little pump. We used to do it in the evenings and it had to stay for ten hours, slowly pumping in the

Now, at first, my parents used to do it but then, from about the age of probably 11/12, I was doing that myself.

- Q. And now how is it dealt with? 12
- A. Now it's evolved into tablets. There's different 13 14 forms of tablets on the market but some patients are 15 not tolerant to those tablets and still have to go via 16 the old regime of long injections.
- Q. You were having, you still have and you were having 17 very regular blood transfusions. Were you ever warned 18 19 of any risks involved in those transfusions apart from 20 the iron issue?
- 21 A. No, it was only the iron.
- You contracted hepatitis C from one of those 22 23 transfusions.
- A. Yes. 24

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But understandably you don't know which transfusion 25

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- 1 then to be told this, it really hit them hard, and
- 2 they were aware of AIDS at the time and they thought
- 3 it was kind of the same thing, you know. But, yeah,
- 4 they reacted badly.
- 5 Q. You said there were no leaflets, no handouts, there 6 really was no available information.
- 7 A. No.
- 8 Q. How did you react to the news?
- 9 A. I thought, okay, here we go, another problem to deal 10 with but then it manifested in my mind a lot more and 11 it started to make me think why am I bothering with, 12 at the time, the painful treatment, why bother with 13 all of that if you've now got this virus that's attacking your liver. And I wasn't great at biology 14
- 15 but I know you need a liver. So, yeah, it started to 16
 - manifest itself as very negative thoughts.
- 17 Q. At that stage you told your partner that you couldn't 18 carry on taking your iron chelation therapy for
- 19 thalassaemia because, "What's the point? Even if I'm
- 20 treating the thalassaemia, the hepatitis C is going to
- 21 kill me".
- 22 A. That's exactly what I said to her. It just felt like
- 23 all of the suffering from the years before, this was
- 24 just -- it just felt too big for me to overcome at the
- 25 time, you know, I was young and I told my girlfriend

- infected you.
- 2 A. No.

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- 3 Q. You were told that you'd contracted hepatitis C in 1988 or 1989, somewhere around that time? 4
- 5 A. That's what we believe, yes.
- 6 How were you told?
- 7 A. I was called in to my -- my consultant called my
- 8 parents -- well, me, my parents went to the
- 9 haematology department and our consultant just came
- 10 out with it, "You've got hep c".

Now, our consultant had looked after us since we were little kids, babies, and she never put sugar coating on anything. She just told us the way it was.

14 We -- my parents had no idea what it was but, as 15 parents who or immigrants I guess, their understanding 16 is limited and they started to fear the worst, you've 17 got a virus, et cetera, et cetera, and that was it 18 really. The consultant turned around and said to us 19 don't worry are we're going to beat this and that's 20 how -- that was the whole content of the meeting.

- 21 Q. You were in your early 20s at that point.
- 22 Yeah, yeah.
- Q. You have said that your parents were in pieces. 23
- Oh absolutely, because having to, one, accept they've 24 got two kids with thalassaemia major, beta major, and 25

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- 1 exactly how you put it. There's no point.
- 2 You've said in your statement that all the
- 3 thalassaemia patients were told at about the same
- 4 time?
- 5 A. Yeah. All of those who tested positive for HCV and
- 6 HIV at the time, it was like one in one out. You
- 7 know, there was a special clinic that they held, the
- 8 one I went to, and we were just told.
- 9 Q. Were you aware that you were being tested?
- 10 A. No. I mean, I have every month -- before having
- blood, you have to have a cross-match and multiple 11
- 12 other blood tests. So, no, it was just either another
- 13 tick in the box or write off forms but we never used
- 14 to see the forms back then.
- Q. When you go in for transfusions you often see the same 15
- 16 people, don't you?
- 17 Absolutely. Α.
- 18 Q. You say there's a thalassaemia community?
- 19 A.
- 20 Q. And that going in for blood used to be a bit of 21 a social event.
- A. Absolutely. 22
- 23 Q. Especially when you had to stay in overnight?
- 24 A. Yeah, back in the day, it was -- for us that worked or
- 25 who couldn't come during the day we'd stay overnight,

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- 1 normally on a Friday night, and yeah it was a party
- 2 atmosphere. We'd take crisps and food and our little
- 3 ghetto blasters, you know. It was great. But we were
- 4 all friends, kind of we're called like blood brothers
- 5 and sisters because we're linked by this blood
- 6 disorder and we started, you know, that's when you
- 7 started to hear, like, "Psst, did you get any
- 8 results", or, you know, and that's how it started, you
- 9 know, people talking to each other, you know.
- 10 Q. But within that community you said that people didn't11 really say whether they were infected or not.
- 12 A. No. There were some people that, you know, it's only
- 13 like now 30 years later that you're hearing, "Oh, did
- 14 you know ..." People were very, very secretive about
- 15 it. I only ever openly talked about it with one other
- 16 patient.
- 17 Q. You called the virus something particular?
- 18 A. Yeah, we -- so when we were talking we would refer to
- 19 the virus as the plague, yeah. That's what it felt
- 20 like to us, something that was destroying us and we
- 21 would, you know, we'd get our plague updates from one
- 22 another and so on and so forth.
- 23 Q. Why do you think that within the thalassaemia
- 24 community people weren't saying that they were
- 25 infected? What was it?

- 1 A. I think one would say that's when the real depression
- 2 started, yes. So it was just with all of the other
- 3 side effects that I think we all know about, the
- 4 fevers, the insomnia, the inability to sleep, came
- 5 a depression and it wasn't good for me in the sense
- 6 that I was taking it out on my treatment of the
- 7 thalassaemia. So, yes, around that time is where
- 8 I started to feel generally low and I just felt like,
- 9 you know, I kept saying to myself, my girlfriend,
- 10 "What's the point, what's the point", you know.
- So, yeah, we went through the treatment.
- 12 Q. You thought it would kill you, was what you were
- 13 thinking?
- 14 A. Yeah, it was hard on the body, even worse on the mind.
- That's the thing, because the physical symptoms come
- and go, you know, but it's I guess the mental impact
- it had on me that, yeah, it was -- I thought it was
- 18 going to kill me or I was going to kill me, yeah.
- 19 Q. When you started treatment you will still working.
- 20 A. Yes.
- 21 Q. What were you doing?
- 22 A. I was a computer engineer, qualified Olivetti
- 23 engineer, and also I was studying C programming and

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- 24 I was also had the ability to do assembly language
- 25 programming at the time, which --

- 1 A. Well, it was, in its simplest terms, it was a virus
- 2 transmitted via blood which immediately kind of people
- 3 start looking at you and stigmatising you and then
- 4 thinking, well, is it like HIV? Are you -- you know,
- 5 there was a lot of stuff on the news about HIV and all
- 6 that. So we felt that we were contaminated or
- 7 infected by blood, so we didn't want to kind of talk
- 8 about it or put it out there because as you go through
- 9 the statement you'll see later on there was stigma
- 10 from medical professionals.
- 11 Q. You describe it as:
- 12 "All I knew about it back then was AIDS, but
- then as time progressed and there were a few clinics
- where we found out they would treat hepatitis C [you]
- 15 started to see a few people that were attending those
- 16 clinics with [you] and it was a nod. Many chose to be
- 17 secretive about it because of the stigma associated
- 18 with being infected."
- 19 A. That's right.
- 20 Q. In about 1990, you started treatment for the
- 21 hepatitis C.
- 22 A. Yes.
- 23 Q. That was interferon?
- 24 A. Yes, just interferon.
- 25 Q. You became even more depressed at that point?

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- 1 Q. During the treatment you stopped?
- 2 A. Yeah, I couldn't. The physical toll and the mental,
- 3 you know -- my capacity to work was gone completely.
- 4 Q. After six months of the treatment, you hadn't
- 5 responded so the treatment was stopped.
- 6 A. That's correct, yeah.
- 7 Q. But a few years later you were treated again, this
- 8 time with peginterferon and ribavirin?
- 9 A. Yes.

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- 10 Q. What can you recall how you felt during that second
 - round of treatment?
- 12 A. What I would say it was worse, much worse than the
- first round. In terms of physical impact, you know,
- 14 pretty similar to the first round but the mental
- 15 impact, you know, there were some very dark thoughts
- 16 going through my mind, dark, and I -- and I went
- through a phase of just closing people out rather than
- having to face anyone, just closed the doors on
- 19 everyone and I would be in my own little world with my
- 20 thoughts, yeah.
- 21 Q. You've said you started worrying about things you'd
- 22 never worry about before?
- 23 A. Yes
- 24 $\,$ Q. While you were on treatment you had no positive
- 25 thinking?

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(10) Pages 37 - 40

- 1 A. No.
- 2 Q. You kept thinking that you were going to beat the
- 3 thalassaemia but that you were going to die of liver 4 failure?
- 5 A. Yes, that's exactly how I felt and also it's this
- 6 irrational worrying about everything, a kind of
- 7 paranoia, anxiety, you know.
- 8 I would, as I think it's on my statement,
- 9 I would get in my car and I'd start panicking,
- thinking what if I crash, what if something happens to
- me on the way? Just completely irrational thoughts,
- 12 you know. I could find something to worry about on
- 13 anything, on any event, you know.
- 14 Q. That second round of treatment also failed?
- 15 A. Yes, that failed.
- 16 Q. And in 2002 you had a third round of treatment.
- 17 A. That's correct.
- 18 Q. This time again with ribavirin and interferon.
- 19 A. Yes.
- 20 Q. This time you suffered with a loss of appetite, the
- 21 fevers again --
- 22 A. Yes.
- 23 Q. -- and your lymph glands became swollen --
- 24 A. Yes.
- 25 Q. -- and you became very emotional?

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- 1 preparation for this treatment was I downgraded jobs.
- 2 I found the job that I could do, so I worked in a shop
- 3 selling mobile phones, and I would go -- I would
- 4 actually get home, I was so tired, I would eat, go to
- 5 bed, I would not be able to sleep but it was the
- 6 thoughts and the fears and that darkness in my head
- 7 again that just kept going and the worry, just random
- 8 things to worry about, and I really -- I'd be lucky if
- 9 I got, say, two hours, maybe three at best, worth of
- 10 sleep before having to get back to work.
- 11 $\,$ Q. That meant that when you went back to work the next
- 12 day ...?
- 13 A. It meant I weren't in great shape. I was very tired.
- 14 The treatment was harsh enough, the physical effects
- 15 of the treatment. Luckily at the time my manager in
- the store was an old friend so he would put me on back
- office duties. When I used to say to him, "It's a bad
- day for me today", he put me in the back to just do --
- so I wouldn't have to deal with the public and be on
- 20 my feet all day, but it was hard focusing, you know,
- 21 doing the simple tasks I struggled.
- 22 Q. You underwent that treatment for about 18 months?
- 23 A. Yes.
- 24 Q. And this time you successfully cleared the virus?
- 25 A. Yes, 2004, around November I was told it's been clear

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- A. Yes, very emotional. I -- it's also I think the first
- 2 time I noticed that I've lost my sharp responses to
- 3 questions and my wit and all those wonderful things
- 4 that I was proud of as a younger man. Things were
- 5 slowing down up here in the head because it was
 - a brutal 18 months of treatment, you know. There's
- 7 a picture of me, you don't have it, but I was at
- 8 a party, a thalassaemia event, and I look back at that
- 9 picture now and I just see a skeleton, a skeletal, you
- 10 know. It's frightening.
- 11 Q. You've described that again you suffered from very
- 12 severe anxiety.
- 13 A. Yes
- 14 Q. You felt completely sad and empty inside?
- 15 A. Yes.
- 16 Q. You started worrying about how you would get anywhere.
- 17 If you were travelling on a train you would be worried
- that the train was crashing. What if you got robbed
- 19 or mugged?
- 20 A. Yes, I would worry about everything.
- 21 Q. But the hardest thing, I think, in this stage of
- 22 treatment was the insomnia?
- 23 A. Yes.
- 24 Q. What can you tell us about that?
- 25 A. I was working at the time and what I had to do in

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- 1 for quite a while now so, yeah, that was good news.
- 2 Q. But unfortunately you continue to feel quite unwell?
- 3 A. Yes. Once the dust had settled and the treatment
- 4 stopped, the anxiety and the slowness didn't go away,
- 5 so from 2004 to today there's been a decline in my
- 6 ability to think clearly, to be focused, and my
- 7 anxiety levels are always high. I mean, I'm anxious
- 8 right now but ... it's the silly things, the
- 9 irrational things that cause me the most amount of
- 10 anxiety and, you know, I'd been lucky enough from
- working in a mobile phone shop to getting a good job
- as a business analyst, project manager, but there's
- 13 been a decline and I notice.

14 I left work last year in March but four years

- prior to that there was a decline. I'd go to meetings
- with my clients, I'd forget what we spoke about, you know. When I was writing down notes, I would miss
- Tr know. When I was writing down notes, I would mis
- things out and, you know, luckily for me or unluckily
- 19 maybe, I was made -- the role was made redundant last
- 20 year but it worked out quite well for me because I'd
- been with the company for 15 years almost so I got my redundancy and my fears are now all about the future.
- The past is done, a lot of questions about the past but I'm more concerned of what lies ahead. What
 - if I can't get a job that I want? What if this gets

- 1 worse, you know?
- 2 Q. You had rebuilt your career after that final round of
- 3 treatment up to a much more senior position?
- 4 A. Yes.
- ${\bf 5}$ $\,$ $\,$ $\,$ $\,$ $\,$ $\,$ $\,$ $\,$ $\,$ And then chose after your redundancy not to look for
- 6 a job at this stage?
- 7 A. Yes.
- 8 Q. Because you didn't feel you were capable of dealing
- 9 with it?
- 10 A. Yes and I'm not capable of doing what I was doing
- 11 I can never be a project manager or a business analyst
- 12 again, not while my head is in the shape it is and,
- 13 you know, what I'm going to do I have no idea at this
- 14 stage.
- 15 Q. You had several liver biopsies?
- 16 A. Yes.
- 17 Q. It's been confirmed that you have cirrhosis of the
- 18 liver.
- 19 A. Yes, that was confirmed not long after I was
- 20 diagnosed. The first liver biopsy pretty much
- 21 confirmed that. They wanted to do a couple more for
- 22 some reason, so yeah.
- 23 Q. You've said, "I'm no wimp when it comes to pain from
- 24 procedures but the impact of the pain from the
- 25 biopsies was terrible".

- 1 Q. Can you tell us what that's meant for you.
- 2 A. Well, there's different facets of it. First, I'm of
- 3 Cypriot origin and if the Cypriot community, so what
- 4 my parents' community as I call them, have no -- you
- 5 know, they always look down at a thalassaemic. If you
- 6 had a son that wanted to marry a girl with
- 7 thalassaemia, no, and vice versa.
- 8 To add to that mix you say you've got an
 - infection, it doesn't matter, you could be cured or
- 10 whatever, in that -- that's one level of stigma.
 - The other stigma I had very bad treatment, or
- the way I was handled, by the dental profession.
- 13 Q. Can we come to that in a moment?
- 14 A. Yes.

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- 15 Q. Just staying with the stigma within the community, you
- 16 have said that you didn't speak about your infection
- 17 with your friends?
- 18 A. No.
- 19 Q. Your parents knew but it became a dirty secret.
- 20 A. Absolutely, yes.
- 21 Q. It's also impacted on your personal relationships.
- 22 A. Yes.
- 23 Q. In the 1990s you split up with a long-term girlfriend?
- 24 A. Yes, in 1999 I split up with a woman I was with for
- 25 13 years and we were happy, we were in love but she

- 1 A. Yeah, it was. The first one set the impression. When
- 2 they first -- because you're awake. They use local.
- 3 They plunge you, but he missed the liver so he had to
- 4 go twice, so after that the agreement, the only way
- 5 I would agree to have a liver biopsy is to be put
- 6 under general and that's ... it was painful. I can't
- 7 tell you.
- 8 Q. You've also had some heart problems?
- 9 A. Yes. I've got heart problems, diabetes, you know.
- 10 Q. Pancreatic enzyme deficiency --
- 11 A. Deficiency, yes.
- 12 Q. -- which means you have to take tablets before you
- 13 eat?
- 14 A. Yes. So my food can be broken down and the nutrients
- taken in by the body otherwise the nutrients just all
- 16 leave the body.
- 17 Q. You are not sure whether that's because of the
- 18 treatment for hepatitis C or something related to the
- 19 thalassaemia?
- 20 A. Yeah. It's one of those things where with the
- 21 diabetes, the heart and this enzyme deficiency, it's
- 22 more than likely thalassaemia, yes, but we don't know.
- 23 Q. You say in your statement that the stigma in society
- 24 has had a profound impact on you?
- 25 A. Yes.

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- 1 wanted a family or a commitment from me and because
- 2 I never cleared, I was still HCV positive, I said, "No
- 3 way. There's no way I'm going to commit to you, start
- 4 a family and die of liver failure".
- 5 Looking back with hindsight now, maybe
- 6 I shouldn't have done that but that's what we done,
- 7 what I done at the time and in 1999 she just had
- 8 enough and went her own way.
- 9 $\,$ Q. Your fear at that time wasn't dying of the
- 10 thalassaemia?
- 11 A. No.
- 12 Q. It was dying of liver failure?
- 13 A. Yes, because the thalassaemia is in control. It has
- 14 been for many years now.
- 15 Q. You've spoken a couple of times about stigma that you
 - have faced from the medical and dental profession.
- 17 A. Yes

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- 18 Q. In 2011 you decided to have your sperm frozen.
- 19 **A.** Yes
- 20 Q. Can you tell us what happened?
- 21 A. So for safe-keeping I thought I'd have it
- 22 cryogenically frozen and if I met the right person,
- 23 you know -- because thalassaemia also impacts your
- 24 reproductive systems and whatever. So I was -- it was
- 25 the day of my surgery and the -- basically, the

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1 cryogenics lab in London calls up to say, "I'm sorry 2 but we can't store your sperm". 3

"Why?"

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"Because you're HCV positive."

"But I'm not, I've cleared."

"No, we've done your bloods and you've got the antibodies."

So we all know that you will have the antibodies pretty much forever but it took several phone calls, faxes from my thalassaemic haematology team to the cryogenics lab, yes, to get them to agree and I felt quite small. I felt -- I don't know. I didn't feel right. It didn't feel right.

- Q. You also had issues with dental treatment. 14
- Yes. 15 A.
- 16 Q. What can you recall about those issues?
- A. I was in severe dental pain, so I thought go out and 17 find a dentist, you'd go into the dentist, because 18 19 I wasn't registered with one, and fill in a form, 20 there's a couple of questions on there, "Have you been 21 diagnosed with HIV?" or "Have you been diagnosed with

22 hep c?" So, keep it honest, I ticked the hep c. They

23 refused to take me on.

> This was a couple more dentists after and then I had to -- it got to a point where it was an

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1 Luckily, there was one guy that said he'd treat 2 me and he's been my dentist ever since.

- 3 Q. But even on that second occasion, several years later, again you went in to dentists and they wouldn't treat 4 5 you?
- 6 A. Absolutely, yeah.
- 7 Q. Moving on to financial assistance, you've received 8 payments from The Skipton Fund.
- 9 A. Yes.
- Q. But you weren't even aware that the Caxton Foundation 10 11
- 12 Α

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- 13 Q. How did you find out about it in the end?
- A. A lot of what I've learnt over the years, the past few 14 years, is due to social media, yeah. There's various 15 16 groups, support groups, out there and they're talking 17 about these things, Caxton and this and that and 18 I thought ... but I've never pursued it. As far as 19 I knew I'm getting what I'm getting and that's it.

I was working as well; so, you know, I was happy with my life. But it's the social media groups that highlighted to me to other people who are going having the same symptoms I'm having now, you know. It's like, "Oh, that's exactly what I'm going through", so a lot of my knowledge was sparked off by social media

emergency now.

2 Q. So before it became an emergency, how many dentists do 3 you think you had been to?

4 A. If I remember it was three or maybe four. Because I'd 5 walk down the high street where there was three or 6 four dentists and I tried them all.

7 Q. And they all declined to treat you?

8 Yeah, yeah, for the same reason, and I went to King's 9 Cross Dental Hospital. I got a referral and they said 10 to me, "All right, we'll look after you but you have to be the last patient of the day because we need to 11 12 decontaminate everything", and that hurt, you know. 13 For someone who spent an entire -- whose entire life 14 in and out of hospitals to now be treated so 15 differently, that was ... that was painful, really.

> But it carried on. I mean, eventually there used to be a hospital off Tottenham Court Road, a dental hospital, which specialised in HIV patients, so I managed to get myself into that dental hospital and they were looking after me until one day they said that the funding for hep c has been cut. It's only going to be HIV. I thought fine, my teeth were all right, you know, you don't worry about it. Maybe a few years went past and I had another problem with my teeth. Same thing: I could not find a dentist.

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1 and then Google and away you go.

- 2 But initially all you were aware of through your 3 treating doctors was Skipton?
- 4 A. Yes.
- 5 Q. Those are the questions I have for you. Is there 6 anything else you would like to say?
- 7 Not a great deal. I mean, I think a question I have 8 is there's what I need cleared up for my own head.
- 9 I was, say, diagnosed in the late '80s/maybe '90s,
- 10 early '90s. At what point did we, you know, were all
 - the HCV victims diagnosed around the same time or were
- 12 there earlier because if I was told earlier,
- 13 potentially, you know, I might not have had or got the
- cirrhosis of my liver and that's important for me to 14
- 15 know because if I could have been told, for instance,
- 16 in '82/83, it would have given me a few more years to
- 17 try some treatment. It may not have worked
- 18 but ... that's what I want to know.
- 19 Q. I am just going to turn my back and ask Mr Lock who, 20 as you know, represents you whether he has anything 21 further.

22 He doesn't have any further questions.

23 A. Okay.

24 SIR BRIAN LANGSTAFF: Nor do I. It remains for me to say 25 thank you very much indeed, Mr B, for coming to give

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1 us evidence. You are the first witness to give 2 evidence orally who suffered from thalassaemia and 3 that perhaps demonstrates how particularly brave you 4 have been to come and give evidence. Thank you very 5 much.

A. Thank you.

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SIR BRIAN LANGSTAFF: There is something generally I'd like to say and it is to the press.

Anything that the press can do to alert those who suffer from thalassaemia to the fact that they can participate if they wish to in this Inquiry and they can do so in a way which protects their desire for secrecy, which Mr B spoke of so eloquently, would be very much appreciated.

We think it inconceivable that because those who suffer from thalassaemia have regularly to have transfusions and did so during the 1970s, 1980s, into the 1990s that they will not have suffered from hepatitis C in great numbers and if they do and have not been tested, they may wish to know that and know that they can be treated.

So leaving aside even the Inquiry, the knowledge that they might have been infected by regular transfusions during those years would be potentially of assistance, maybe even life-saving assistance for

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Witness W2687 must be referred to only as "Mrs C". The order remains in force for the duration of the Inquiry and at all times thereafter unless otherwise ordered. I may vary or revoke the order by making a further order during the course of the Inquiry.

Mrs C.

MRS C, affirmed Questioned by MS RICHARDS

10 Q. You're here to give evidence with the support of your husband about your son, S? 11

12 Α.

13 Q. You're going to use his name in your evidence because

it would be very hard for you to talk about him

without naming him but the effect of the restriction 15

16 order is that nobody can publish or disclose or pass

17 on or report that name.

18 A. Yes.

Q. This I know is the first time you have spoken outside 19 20 of your immediate family about what's happened?

21 A.

22 Q. If you need a break at any time please don't hesitate 23 to tell us.

A. Thank you. 24

25 So S was born in 1978?

2 That's all I want to say and I leave that in the 3 good sense of the press as to whether they can do 4 anything to assist.

With those words, let me then say we'll take a break, shall we, until 2 o'clock.

MS FRASER BUTLIN: At 2 o'clock we will hear from Mrs C and of course the live stream will be turned off this afternoon.

SIR BRIAN LANGSTAFF: Yes. 10

(12.35 pm) 11

12 (Luncheon Adjournment)

13 (2.00 pm)

14 SIR BRIAN LANGSTAFF: Our next witness is to be known as

15 Mrs C. I make an individual restriction order in the 16 same terms as I made earlier. Let me just set them 17 out.

It is ordered that the name and address of witness W2687 (we shall know her as Mrs C), the name of her son who died, the name of any other member of her family, and any other identifying information such as the witness's image or a description of her appearance, cannot be disclosed or published in any form unless express permission is given by me or by

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the solicitor to the Inquiry acting on my behalf.

A. Yes. 1

2 He was diagnosed almost immediately I understand with 3 haemophilia A?

4 A. He was, yes.

5 Q. His haemophilia was classed as severe?

6 A. It was, yes.

7 One of your older children had also very recently at

8 that point been diagnosed haemophilia whilst you were

9 pregnant with S?

10 A. Yes, we found out when I was six months' pregnant with 11

But that was only after a prolonged period of time, 12

13 a distressing period of time, in which your other son

had bruising and swelling and you were being accused 14

15 or suspected of having injured him?

A. I was, yes. 16

17 Q. But after some 11 months or so, your eldest son was

18 diagnosed with severe haemophilia?

19 A.

20 Q. And so S's diagnosis was picked up at birth?

21 A. Straight away, yes.

22 Q. I think when he was little, you were very conscious of

23 his condition?

24 A. Yes.

Q. You used to wrap him in cotton wool?

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- 1 A. I was always frightened for anything to happen because
- of my other son, I'd seen what had happened. So he
- 3 didn't learn to walk until he was two and that was
- 4 when he was in the hospital having treatment and the
- 5 physiotherapist got him walking, but that was purely
- 6 because I didn't really let him go about very much
- 7 because I was frightened. In them days they used to
- 8 say they padded a play pen for him and my other son
- 9 and that's like all cotton wool so they couldn't get
- 10 hurt. So I think I restricted him from walking,
- 11 actually.
- 12 Q. But he did learn to walk.
- 13 A. He did.
- 14 Q. You've described him as a very easy child, a lovely
- 15 chubby boy?
- 16 A. He was, yes.
- 17 Q. Did he as a baby need any treatment for his
- 18 haemophilia?
- 19 A. Not for the first, I would say he had his first
- 20 treatment when he was about 18 months.
- 21 Q. That was when you were on a trip somewhere to visit
- 22 a relative?
- 23 A. Yes, we was on the trip to go and see my sister and he
- 24 was sitting on my knee and it was an all-night coach
- journey but by the time we got off the coach he didn't

- 1 Q. Who would administer the Factor VIII to him?
- 2 A. At first before I learnt how to do it, we used to go
- 3 to the hospital and they would do it, but then
- 4 I practised with one of the doctors used to let me
- 5 practice on him. First, it was with an orange and
- 6 then it was him until I learnt, and we were told it
- 7 was a brilliant thing because we could take the
 - treatment home and keep it in the fridge, so because
- 9 the boys used to have quite a lot of bleeds, they used
- 10 to say that we could give them the Factor VIII
- 11 immediately so it didn't get as bad, so that's what we
- 12 did

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- 13 Q. So you welcomed it as something that would make life
- 14 easier in terms of your ability to treat your boys?
- 15 A. Exactly.
- 16 Q. Were you given any warnings about the Factor VIII
- 17 products?
- 18 A. No, I was just told it was an amazing thing and, in my
- 19 head, it did seem that way because when we used to go
- 20 to the hospital and it was cryo, you would go and
- 21 you'd wait to see the doctor, then the doctor would
- 22 bring the stuff down, then you had to wait again and
- 23 the cryo used to take quite a long time to go in as
- 24 well, so this was a lot better.
- 25 Q. Was there ever any discussion with you about the

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- 1 want to move his arm. It wasn't swollen or anything
- 2 but you could see he just didn't want you to touch it
- 3 or anything. So we had to -- I took him to the
- 4 hospital in Burnley and they then, I don't think they
- 5 knew much about haemophilia, but they contacted the
- 6 hospital in Charing Cross where we used to attend and
- 7 they told them what to do and to give him his
- 8 Factor VIII.
- 9 Q. Was it cryoprecipitate he was given at that stage?
- 10 A. At that stage, yes, it was.
- 11 Q. After that he ended up having to go to the hospital
- 12 fairly regularly to receive, at that stage,
- 13 cryoprecipitate?
- 14 A. That's right yes.
- 15 Q. And he didn't like it did he?
- 16 A. No, he didn't.
- 17 Q. You'd have to wrap him up and hold him down, the
- 18 family.
- 19 A. Yes, and it used to take quite a long while for it to
- 20 go in as well, so it was quite difficult with him.
- 21 Q. So the point in time came, I think you recalled in
- 22 your statement, around 1983 when his treatment changed
- 23 from cryoprecipitate to what you were told were
- 24 Factor VIII products.
- 25 A. Factor VIII, yes.

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- 1 particular Factor VIII products that were being used
- 2 or any differences between different kinds of
- 3 Factor VIII products?
- 4 A. No.

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- 5 Q. A year or two, I think, after he'd started on the
 - Factor VIIIs he developed a problem with a milk tooth.

Can you recall what happened?

- 8 A. It got very wobbly and it was bleeding but his gum
- 9 swelled round it so it wouldn't fall out. So I phoned
- 10 up the hospital. We used to have to go to the
- 11 haematology unit because they never had a haemophilia
- 12 clinic there and she told me to come up and what she
- 13 would do is see if the dentist could take it out. We
- 14 got to the hospital and they called the dentist down.
- 15 When she did come down, she come in a space-suit and
- 16 it's like she didn't want to touch the ...
- 17 She said that it would fall out eventually. So
- 18 I said to her it wouldn't because this had been going
- on for a couple of weeks. I said his gums is too --
- 20 I was trying to show it to her but she didn't want to
- come close and she certainly didn't want to put her
- 22 hands by his mouth, so then the doctor said to her
- 23 that they needed to take it out. It wouldn't take -
 - because it was so loose so that she took him away, and
- 25 I said to the doctor what is going on because I didn't

understand and she took me in a room. That is when she give me blue plastic bottle and a box of gloves and she told me that the boys had been tested for HIV. I didn't know what she was talking about and she said that they'd tested positive and in future when I give them their Factor VIII I had to wear gloves and use the blue plastic bottle to put them in.

I said to her, because I'd seen how the dentist was reacting, "but what about my other children", and she just said to me she didn't know and then sent me home and that's how it was.

- Q. So you'd gone for what you thought was routine dental
 treatment essentially to deal with the swelling that
- 14 had arisen around S's tooth?
- 15 A. Yes.

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- 16 Q. The dentist had come and you understood that there was
- 17 something strange, something odd going on because of
- 18 the way the dentist was clothed, you described it as
- 19 a space suit, the dentist had a mask on, and the
- 20 dentist was you thought very obviously reluctant even
- 21 to touch S.
- 22 A. Yes.
- 23 Q. That's how you were told by the doctor who was there
- that your two boys, including S, were HIV positive.
- 25 A. Yes.

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- 1 reasons but you had a baby at home.
- 2 A. Yes.
- 3 Q. And you asked about the risks of infection and what
- 4 you should do in relation to any of your other
- 5 children and the only answer you got was that --
- 6 A. That she didn't know.
- 7 Q. Did you know that your boys were going to be tested
- 8 for HIV?
- 9 A. No.
- 10 Q. Did you ever receive anything in writing about the11 diagnosis of HIV from the hospital after that?
- 12 A. No
- 13 Q. So it was a bottle, gloves and "I don't know".
- 14 A. Yes, and then later, I think about a week later, my GP
- 15 turned up at my door. He had a lady with him.
- 16 I think she must have been something to do with
- 17 education because it was about, they would come and
- they said to me they had to go to the boys' school to
- 19 let them know that they had been tested HIV and that
- 20 was all I heard after that.
- 21 Q. You didn't understand why the school needed to be
- 22 informed but, in fact, the school treated the boys and
- 23 you okay?
- 24 A. They didn't treat us any different, no.
- Q. I think your immediate reaction on being told the news

- Q. You've described being given the blue plastic bottle
 and plastic gloves.
- 3 A. Yes
- 4 Q. You were told that that was how you should administer
- 5 Factor VIII in future to the boys?
- 6 A. Yes
- 7 Q. Did the doctor tell you what HIV was?
- 8 A. No
- 9 **Q.** Did the doctor tell you anything about the connection
- 10 between HIV and AIDS?
- 11 A. No, she didn't but then later on in them days there
- was a lot coming on on the news but then they were
- saying it was drug takers, gay people that were
- 14 getting it, and it was horrible actually at that time.
- 15 It was really horrible. But to be honest, I don't
- 16 know, I think I shut it out of my mind. I just
- 17 didn't -- these two little boys, I just didn't accept
- 18 what they were saying.
- 19 Q. S was at the time we're describing seven years old?
- 20 A. He was six going on seven.
- 21 Q. And you weren't I think given any information about
- 22 what the longer term prognosis would be for either of
- 23 them?
- 24 A. No.
- 25 Q. You were particularly concerned for a whole range of

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- 1 at the hospital in the way you've described, you went
- 2 to see your sister in a state of shock and you called
- 3 your husband?
- 4 A. I did because I didn't know what to do, so I run to my
- 5 sister -- she is the only one I actually told, to be
- 6 honest, and then we phoned my husband and he come
- 7 home. My sister she was shocked but even she didn't
- 8 actually know what this meant.
- 9 Q. What you said in your statement at that point is you
- just didn't understand what was meant by the diagnosis
- 11 that you had been given.
- 12 **A**. No
- 13 Q. You've described how you became aware from stuff that
- 14 was on TV or in the newspapers about AIDS but you
- 15 didn't really associate that with what was happening
- 16 to your children.
- 17 A. No, I didn't.
- 18 Q. Your children were children with haemophilia who had
- 19 been treated by the National Health Service and you
- 20 couldn't make the correlation.
- 21 A. No
- 22 Q. I think you were told by your sister or a friend about
- 23 an article in the newspaper?
- $\,$ 24 $\,$ $\,$ A. $\,$ My sister phoned me up and she said that her neighbour
- 25 had bought a paper, the Daily Star, and that in it it

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- 1 was saying that there was three boys, two brothers 2 have got AIDS in the hospital that my children attend 3 to. I knew that there was only three haemophiliacs in 4 that hospital. It might seem silly but it was true, 5 there was only three boys there, my two and another 6 little boy, so I knew they were talking about my sons 7 so I went to the hospital to ask them what was it 8 about and the doctor said to me that she wasn't sure 9 who had leaked the news out but they were trying to 10 find out, but it wasn't AIDS, it was HIV that my sons 11
- 12 Q. I am going to ask to be put up on the screen in front of you a newspaper article from around that time, 13 14 2687006, please, Paul. Are you able to highlight the 15 top left-hand article. Thank you.

So this is from a newspaper, The Gazette, we've also got the Daily Star article that you referred to but they say the same thing. If we just look at this briefly together, please, Mrs C.

So it talks about three boys with a deadly virus in hospital. It says the children do not necessarily have the killer disease AIDS but experts say that about 1 in 10 people found with the virus later develop the disease and that because of their low resistance to infections haemophiliacs stand a higher

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- 1 treatment done there so we was at the hospital a lot, 2 but I don't know if they was being monitored closely 3 for this.
- 4 Q. You can take that down, thanks, Paul.
- 5 In 1986, the boys' care was transferred to 6 St Thomas' Hospital?
- 7 A. Yes.

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- 8 Q. The haemophilia care was under the care of Dr Savidge 9 there?
- 10 A. Yes.
- 11 Q. Then in terms of the HIV infection under the care of Dr O'Doherty? 12
- 13 A. Yes.
- Q. Around this time it was suggested to you by the 14 hospital, I don't know if it was Charing Cross or 15 St Thomas' hospital, that you should tell the boys --16
- 17 Α. Yes.
- 18 Q. -- that they had HIV.
- A. Yes, they were very keen for us to tell them, but my 19 20 two children was only seven and eight. I just didn't 21 think that I could tell them that, so we didn't. We 22 eventually told them when I think S was 12 or 13 --23
- Q. That's all right, no, no. You can say S's name. 24
- A. My other son was 14 and that's when we told them.

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than average chance of catching the disease.

Had you been told any of that by the hospital?

3 A. No.

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- Q. The higher chance of HIV turning to AIDS because of --4
- A. I've only just -- when they sent me this paper, 5
- I think it was last week, I only saw it then. So 6
- 7 I wasn't aware of it, no.
- 8 Q. The hospital hadn't told you that?
- 9
- Q. Then if we just read on down it says: 10

11 "The parents of the children know of the risks 12 to their children."

Had the risks ever been explained to you? 13

14 A. No.

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15 Then a spokesman for the Northwest Thames Regional 16 Health Authority says:

"They have been informed about the positive 18 tests. They are being counselled by senior doctors 19 and the three boys are being monitored very closely."

20 Were you counselled by senior doctors?

- 21 A. No, I was not.
- Do you recall whether the boys were being closely 22 23 monitored at the hospital?
- 24 Well, we used to go to -- we actually did go to the Α.
- 25 hospital a lot because we used to go and have their

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- Q. I think what you said in your statement is the 1
- hospital kept telling you from day 1 you should tell 2
- 3 them but you couldn't see, given their young age, why
- 4 they should and, again, when they got to 11 or 12 the
- 5 hospital were saying you should tell them but again
- 6 you thought that was too young?
- 7 A. I did, yes.
- 8 Q. Eventually you told them, and focusing for present
- 9 purposes on S, he was 13 or 14 years old?
- 10 A. He was about 13 and we told them; we told them both 11 together, actually.
- What can you recall about that discussion? 12
- 13 We explained what was the matter with them. First of all, they just went very quiet and then we explained 14 that when they cut theirself they had to be careful 15

16 and to keep it covered.

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17 Maybe I didn't speak about it too much because, 18 to be honest with you, it was bad enough me knowing 19 without telling them. At that point they seemed quite 20 healthy and maybe in my head I thought this isn't 21 really happening anyway, so we didn't go in any big

22 detail about it. 23 Later on, when I looked at S's diaries, he does 24 make a thing that he knew there was something because

I used to treat them different. When they went out,

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- 1 I'd make sure they had scarves and stuff on, whereas 2 with my other children I didn't used to; so,
- obviously, they were all aware but they never actuallysaid anything about it.
- Q. You have described in your statement how theyreally -- they were quiet on receiving the news?
- 7 A. Yes.
- 8 Q. You weren't sure how much they understood?
- 9 A. No.
- 10 Q. Were you ever given any help or support or advice11 about how to tell them or how to support them?
- 12 A. No.
- Q. When S was about 11 years old, he was prescribed at
 St Thomas' Hospital treatment in relation to the HIV,
- 15 AZT.

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A. Yes. Up until then, up until the day we went to the
hospital, S was still fine, he was still quite chubby,
he had energy, he used to play cricket, but we went up
for one of our normal appointments.

They took S to do his bloods because each time we went up there they had blood tests done, and the doctor took me to another room and he said there was a problem with S's white T cell count and there was something wrong with it. So he was going to start him on something they called AZT to help it, which they

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Eventually somebody from Guy's said just give him a bit -- he was absolutely fantastic. He said he would find something to be able to put on S's mouth so that he could eat and he brought a thick paste that S could put on his mouth so he could manage to eat.

By this time S was getting quite paranoid. He used to love his food and he was documenting everything down, when he could drink, he was so proud when he could drink or he could eat anything.

They took a part of his tongue away for a biopsy to find out why but we didn't get any answers back for that one. I think at that point it got too late.

About two weeks before S died, he was watching something on the TV and it was a lady and her husband had been having AZT and she said that before he started having AZT he had been fine but once he started having AZT all these problems come.

When I went up to the hospital, S gave me a letter and he said to me don't read it there, wait until I go home. So I went home and read the letter, and he was terrified. He said he'd seen this on the news and he knew that he was having AZT.

So I went back to the hospital and then asked to speak to the doctor. When he come, he -- well, what he said was in the beginning when they give S the AZT

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- Q. Just pausing there, Mrs C, were you told anything
 about any side effects or risks or disadvantages to
 the AZT treatment?
- 5 A. No, I was just told this will help his T cell count.
- Q. What actually did happen in terms of S's physicalcondition after that?
- A. Not long after, I would say about a month to six
 weeks, you noticed there was a difference in S. He
 seemed to stop growing. He lost a lot of weight. He
 got thrush. Then he started getting ulcers in his
 mouth. We used to go to Guy's Hospital there and the
 dentist there used to try and -- his gums used to
 bleed. He was like a different person, to be honest.

The ulcers in his mouth got really bad and eventually they went down in his stomach and his bottom. In the end they started giving him steroids. They said that would help the ulcers. S apparently had a TB, which we were told it wasn't the sort of TB we would get, it was a TB that people with HIV got. He -- everything, actually, that happened to S, it was always the same thing: it wasn't what we would get; it was what people with HIV got.

But the ulcers were a big problem. They gave him steroids. It then started that he couldn't eat.

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it was working but it wasn't working now, so they'dstop him taking it.

I went along with it because to be honest it

gave S a little bit of relief because he was so

frightened. In my head, I didn't believe it because

from when S started taking the AZT, that was when all

his problems started. They stopped his AZT then but

that was just two weeks before he died.

- 9 Q. When you say you didn't believe it, you didn't believe10 that the AZT had been working and had now stopped.
- 11 You didn't think it had ever been working?
- 12 A. I don't think it had. I don't know. I think it just
- hurried it along because previous to that he had beenfine.
- 15 Q. You said in your statement that you feel that S wasused as a guinea pig by the hospital for AZT?
- 17 A. Ido.

25

- 18 Q. Why is that?
- A. I think it was because it was -- S, it happened in
 early days. I don't think actually they knew -- don't
- get me wrong, I'm not blaming the doctor at all for
- 22 that. Dr O'Doherty was brilliant. I don't think
- 23 actually at that point they knew what to do. So
- 24 I think that was just given to S.
 - I later found out that AZT actually isn't very

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72 (18) Pages 69 - 72

- 1 good on its own. It needs to go with a combination of 2 things. S wasn't given that. He was just given AZT.
- 3 Q. Your other son wasn't given AZT at all?
- 4 A. No.
- 5 Q. And didn't develop any of these problems?
- 6 A. No.
- 7 So in January of 1994, S's condition worsened?
- 8 Α.
- 9 Q. He became very ill indeed. You described his paranoia. His weight went down to about 5 stone? 10
- A. It was, yes. 11
- 12 Q. As well as the ulcers he started getting bad chest,
- coughing and stomach pains? 13
- 14 A. He was. He was in a lot of pain. He was having a lot
- 15 of morphine. At one point, because the morphine used
- 16 to make him sleep, they tried to bring it down a bit.
- He was so frightened of that because he used to argue 17
- with them because he was, I think the pain was too 18
- 19 much. It was awful.
- 20 He was just -- I don't know. The days when he 21 could even just eat one thing made him so happy and
- 22 that's all he used to wish for, that when -- he used
- 23 to love actually Kentucky chicken and chips and he
- 24 used to say that when he was better he would go and --
- 25 that's the first thing he's going to have. He used to

73

- A. No. 1
- So he was taking, even without the AZT, 12 to 13 2
- 3 tablets daily at that point.
- 4 A. Yes.
- Q. The ulcers had spread down from the mouth to his 5
- 6 stomach --
- 7 Stomach, yes.
- 8 Q. -- you were told and the doctors wanted to start
- 9 radiation therapy on the ulcers?
- 10 A. Yes.
- 11 Q. S came home from the hospital for a weekend on
- 16 February? 12
- A. That's right, yes, and he had to go back on the 17th. 13
- Q. I think he was quite chatty? 14
- A. He was. 15
- Q. That visit home? 16
- 17 A. That visit home he was very chatty. I've never heard
- 18 him chat so much.
- Q. He was talking about the new baby? 19
- A. Yes, and that when the baby got bigger and he's got 20
- his job he was going to get everything for him. 21
- Q. And then you took him back to hospital on 17 February 22
- 23 for the radiation to begin?
- 24 A. Yes. We left him in the evening time. He was fine.
- 25 My baby was three weeks old at the time and we'd gone

like cappuccinos. We used to take him down to the canteen but he couldn't ever drink them.

3 They used to give him in the end some -- it 4 was -- I think, it was called Ensure. They used to 5 freeze it for him because then he could just hold it 6 in his mouth a bit, because his mouth was so sore. 7 Even to the extent of -- he couldn't go to the toilet 8

a lot and they'd give him an enema. My poor boy used 9 to like having that done because it gave him some

10 relief

Q. You found -- we will talk about his diaries in 11 12 a little while but one of the things he recorded in

his diaries was that he would be happy on the days he 13 14

could go to the toilet because it would stop the pain

15 and discomfort?

16 A. Yes. He used to feel so bunged up, that was his words 17 that he used to use.

Even once the AZT was stopped a few weeks before he 18 Q. 19 died he was still being prescribed the steroids?

20 A.

- 21 He had to take iron tablets because of his anaemia?
- 22 A.

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- 23 Q. And morphine for the pain, and you described how he
- 24 was frightened of that being reduced because he didn't
- 25 want the pain.

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1 up to bed, and then in the early hours of the morning

2 we got a phone call and my husband answered it and the

nurse said that S wanted us to go up there. So he

4 just said to him, we'll be there at 9 o'clock in the

morning and she said, "Oh, okay", and he put the phone down.

7 Half-an-hour later the phone rung again. When 8 my husband answered it she said I think you'd better 9 come up now. So he went up to the hospital and I got 10 a phone call. It was my husband. When he got there S

12 So I had to wake one of my elder sons up to look 13 after the children and I got a minicab up to the

hospital. When I got there, as I said, it just looked 14

15 like S was sleeping with a sheet over him. I didn't

16 know what my husband saw at that time. And even then, it's stupid --

18 Q. It's not stupid.

had just died.

- 19 -- but I thought it was a mistake. I sat there with
- 20 him and I was holding his hand and I thought in
- 21 a minute he'll wake up and that's how he was. But
- 22 then I felt the nurse kept coming in and then she said
- 23 that she had to do the room ready for the day staff to
- 24 start, but even in my head I'm thinking why is she
- 25 saying that for? I didn't want to go but then my

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(19) Pages 73 - 76

husband said to me we'd better go because they -- and when I come out, I saw Chris. She was one of the ladies that was with Dr O'Doherty and all I could say to her was why? She said to me she didn't know. And we went home.

We were told that we could go to the haemophilia centre on the Monday and then I could go and see S in the chapel of rest. So we got up and we went there in the morning but when we went in the door, Dr Savidge met us and his words to us was we didn't really need to keep coming up the hospital now.

To me, that was telling me S had gone. They didn't have to worry anymore. So I said that we could go and see S but we needed somebody to take us down to the chapel of rest because you can't just go down there yourself, so somebody took us down there and we went and saw S down there.

They did say to me about the funeral parlour to go to, because they said there'd been a few families, that some funeral parlours won't let you view them, so sent me to somewhere where they'd said he's quite nice. In a way, we was lucky because when I got there, I didn't know but when we did get there, the man that run it was the headmaster from my children's school from before so he knew us and he was -- he used

77

- Q. He liked to put pictures on and you've said he was 1 meticulous in the way in which he wrote and drew? 2
- 3 A. Very, very.

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- Q. Your statement talks about some of the things he put 4 5 in his diary. Do you want to share any of them or 6 would you like me to or we can just leave that?
- 7 A. I'd like you to.
- Q. Okay. So you've told us in your witness statement some of the things that S put in his diary. He wrote about how he was feeling, his views about the treatment he was receiving, the pain he was in, his 12 aspirations for the future, about how he'd look after 13 your new baby when he was older and better and how the baby would want for nothing. You've described how the 14 diaries were very neatly and carefully written. He 15 16 was very tidy. He wrapped everything in tissue. He recorded his thoughts and feelings about his illness.

That's where he wrote he'd noticed how he was treated different because you were very protective of him.

- 21 Yes. A.
- 22 Q. He also wrote that he used to lock himself in the 23 toilets at the hospital when he was in pain because he 24 didn't want anyone to know. He wrote on the cover of 25 one book that he'd carry on writing in his book until

- to let us go up everyday to see S. Actually, I think
- 2 it was him that got us through that time.
- 3 Q. At the point when S died he was 15 years old.
- 4 A. He was 15, yes.
- 5 Q. You provided the Inquiry with a copy of S's death certificate. 6
- 7 Paul. it's 2687005.
- 8 If we see in cause of death this doesn't mention 9 anything about HIV or AIDS.
- 10 A. No.
- 11 Q. Was that at your request?
- 12 No, it wasn't. I did wonder why it wasn't but, no, it
- 13 wasn't.
- 14 Q. That can go down, thanks.
- 15 After S died you discovered he had been keeping
- 16 a diary?
- 17 A. Yes.
- Q. You've shared with us some of the front pages of the 18
- 19 diary.
- 20 A. Yes.
- 21 We're going to put that up. If you need it taken
- 22 down, we will.
- 23 2687002, please, Paul.
- 24 That's one of the diaries S kept.
- 25 A. Yes.

78

- 1 the pages ran out?
- 2 A. Yes.
- 3 Q. He wrote about a future event he was hoping to go to
- in Planet Hollywood and his future ambitions and he 4
- 5 wrote down events such as your wedding anniversary?
- 6 A. Yes.
- 7 We'll just have one more document, please, on screen,
- 8 Paul. It is 2687003.
- 9 We can see S's meticulous handwriting, as you 10 describe it:
- 11 "My feelings and my life. This book is
- 12 basically all about me. Inside you'll see a lot of my
- 13 likes and dislikes, my wishes and dreams."
- 14 Also it says:
- 15 "How I feel on certain days and any worries
- 16 I had."
- 17 We see the date on which it is started.
- 18 8 February 1994, "finish when all the pages run out."
- 19 A.
- 20 He wasn't able to finish it.
- No, he wasn't. 21
- Q. Because he died very soon after that. 22
- 23 A.
- 24 Q. Thank you for sharing that with us.
- 25 A. Thank you.

80

(20) Pages 77 - 80

- 1 Q. Can I just ask you a little bit about S the boy, the 2 things he loved?
- 3 A. He was a very strong Liverpool supporter.
- 4 Q. Yes.

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A. He loved playing on his games. He was a very chatty 5 boy. He wasn't shy or anything like that. I think 6 7 him and his sister used to have arguments a bit but, 8 other than that, no, he was beautiful.

> Coming to the end before he died he started getting quite angry, which I can understand. It was mainly aimed at me. I was very confused about that. His aunties used to go up and he was totally different but with me he got very angry but when I asked Dr O'Doherty what was the matter, he said that's probably when these things happen they tend to get angry with the ones they loved the most, but he was just lovely.

- 18 Q. He loved Christmas you said?
- A. He loved Christmas. He loved Christmas and he loved 19 20 going on holidays.
- 21 Q. And he loved school. He was a very hard worker at 22 school you described.
- A. He loved school. We only found this out after he'd 23 died. He was in hospital quite a lot in the last year 24
- 25 and he was due to do his exams and he was very keen on

81

- 1 took advantage of him and we heard -- what he said was
- 2 he just wanted to be left alone so he could do his
- 3 schoolwork but we didn't find any of this out because
- 4 he never told us. We didn't find this out until after
- 5 he'd died and we looked through his diary.
- 6 Q. You discovered only years after S had died that he'd 7 also been diagnosed with hepatitis C.
- 8 A. I didn't find that out until 2009.
- 9 Q. How did you find that out?
- 10 A. We used to have the Macfarlane Trust but after S died, 11 all that, we didn't get any more correspondence from 12 them

Then 2009 apparently The Skipton Trust had taken over from the Macfarlane Trust at some point. They just sent -- it was just a normal letter thing saying that the people that had got hepatitis C and the ones that had died there was I think they called it a something payment. So I contacted them and I said that actually I wasn't aware that S had got hepatitis C because I'd never been told that. So I had to phone up the hospital and the nurse said she was going to go and try and find his records to have a look, and then when I phoned back the next day that is when she said that he had had hepatitis C but then she said she wasn't surprised because the two brothers they had the

doing his exams. I'm not just saying it because he

- 2 was my son but he was very bright. We found it hard
- 3 because we wanted to get some work to the hospital so
- 4 he could keep up because he was getting ready for his
- 5 exams but the school wasn't sending them. In the end
- 6 the hospital had to intervene and they started sending
- 7 him some stuff. But it was later, after he died, he
- 8 used to keep all his papers, his Dad had given him
- 9 a Glenfiddich tin. It was like a tube and he used to
- 10 keep all his papers in there, but apparently -- S had
- 11 gone very small. He actually was quite tiny compared
- 12 to the other children of his age then and we found out
- 13 he was being bullied, that somebody used to meet him
- 14 at the gate and take his money off him and if he
- 15 had -- S had a certain pen, apparently a teacher had
- 16 told him it was really good to help with his
- 17 handwriting, so S had got this pen and the boy took it

18 away from him. 19 As he said, it wasn't just because it was a pen

21 would help him, he wanted it and he just used to want

but it was because the teacher had said to him it

- 22 to -- he said he wouldn't even have minded if they
- 23 took him into a room and let him be on his own. He
- 24 just wanted to do his work. He used to set everything 25
 - out, but this boy, obviously because S was smaller, he

82

- 1 same, but I hadn't -- previous to that I wasn't made
- 2 aware of that.
- 3 Q. So you had never been told that he was being tested
- 4 for hepatitis C?
- 5 A.

20

- 6 Or given your consent to that?
- 7
- 8 Q. And you had never been told the outcome of any tests?
- g A. No.
- 10 Q. It was years after he died when you got this letter
- out of the blue from The Skipton Fund that you found 11
- 12 out?
- 13 Yes. Α.
- You'd kept what had happened to S from anyone other 14
- than the very close members of your family. 15
- 16 A. I didn't even tell my younger children. When S died
- 17 I told them that he had a rare form of cancer because
- 18 that's what I was told his ulcers were. It wasn't
- 19 a cancer that we could get, once again it was just
- 20 something that somebody with HIV got, so that is what
- 21 I told my children. My older children were aware but
- 22 not my younger ones.
- 23 Q. One of the reasons you'd not wanted to talk about it
- 24 more widely was because of the stigma associated with
- 25 HIV and AIDS and one of the phrases you have used in

- 1 your witness statement is not wanting to feel like
- 2 a leper?

- 3 A. That's right. When S -- when I first heard about S's
 - HIV, a few weeks later I was reading a paper and it
- 5 always sticks in my mind. There was a reporter for
- the paper and what he said was everybody with HIV they 6
- 7 should be put on an island and left there, and
- 8 I remember sitting there thinking how can they say
- 9 something like that. My children have got HIV and
- 10 they're just little children. How can you say
- 11 something like that? So actually I didn't feel like
- 12 I wanted to tell my younger children that. I didn't
- want to put them through that. 13
- 14 Q. In fact, subsequently, one of your other children was
- told at St Thomas', by a doctor treating him that S 15
- had had HIV and AIDS and had died as a result? 16
- Yes. 17 A.
- Q. That was without your knowledge and consent? 18
- A. No, I didn't know until my son come home and he said 19
- to me he didn't -- what was this about, he didn't 20
- 21 know.
- Q. And your daughter? 22
- A. My daughter was told first. She had gone for an 23
- appointment to my GP and the GP had told her. So she 24
- come told and me the same thing up but until then they 25

85

- 1 19th. They sent and they told me that they were sorry 2 to hear about S dying and they put in a cheque for 3 £1,000 to help with his funeral costs.
 - I did not actually get how they knew but then when I said to Chris, she said that she has to inform them when this happens and that was the last time I heard from them after that.
- 8 Q. You've said in your statement how none of this has 9
- ever gone away from your mind?
- 10 A. No.

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- 11 Q. You tried to push it away. You have said the Inquiry
- has brought it back but you wanted to give your 12
- 13 statement and give your evidence for S.
- A. Yes. This is the first time I've ever been able to 14
- say to somebody, it was like when S died everything 15
- 16 was -- it wasn't mentioned any more and it was like he
- 17 didn't exist in my head. He did exist. He had every
- 18 right to be here now. That was taken away from him,
- 19 but I've never been able to talk to anybody, and then
- 20 when I found out, and that was just purely by
- 21 coincidence that I found out there was going to be an
- 22 inquiry, I got quite angry because I felt S should be
- 23 there as well and that's when I contacted the people.
- 24 We even got S's picture put up, even though we were
- 25 late.

- didn't know.
- 2 Q. Has anyone ever offered you or any of your family
- 3 members testing for HIV or HCV over the years? Did
- 4 they ever offer that?
- 5 A. No.
- Did they ever offer you any support or counselling? 6 Q.
- 7
- 8 You have mentioned the Macfarlane Trust?
- 9 A.
- Q. You received some money from the Macfarlane Trust 10
- 11 while S was alive which you accepted in particular
- 12 because you wanted to take him on holiday?
- 13 A. In the beginning, I think it must have been round
- 14 about 1988, we received a letter and it was, I think,
- 15 like a solicitor's letter and it was saying that they
- 16 were going to be given this money but we had to sign
- 17 a form.

22

- 18 We were advised to sign it because they told us
- 19 we couldn't fight the Government; so it would be best
- 20 just to take it, which we did. Then the
- 21 Macfarlane Trust was set up and they used to give
 - I think it was £230 a month for S and that went on
- 23 until S died. He died on 18 February in the early
- 24 hours of the morning and I got a letter, the last
- 25 letter I ever got from the Macfarlane Trust was on the

86

- Q. One of the things you've said in your statement is 1
- 2 that, I think that's important to you, is that nobody
- 3 has ever said that they are sorry.
- A. No. Nobody's ever told me how this happened, why it 4
- 5 happened or just said to me we're sorry. I've never
- 6 heard nothing like that.
- 7 Q. I haven't got any further questions for you but is
- 8 there anything else you want to add?
- 9 A. I just want now -- I just wanted to get S's story out
- 10 there because he did exist and actually I think people
- 11 should know what happened to him because it shouldn't
- 12 have.
- 13 Q. Thank you.
- 14 A. Thank you.
- SIR BRIAN LANGSTAFF: I think you have indeed got S's 15
- 16 story out there.
- A. Thank you. 17
- 18 SIR BRIAN LANGSTAFF: Well done.
- A. Thank you. 19

24

- 20 SIR BRIAN LANGSTAFF: Thank you very much indeed for
- 21 giving your evidence.
- A. Thank you for listening to me. 22
- 23 SIR BRIAN LANGSTAFF: And thank you for supporting.
 - You can stay there as long as you like or you
- 25 may prefer to sit over there. It's entirely up to

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1	you.	1	INDEX	
2	A. Thank you.	2	ALAN PERCY FOWLE (affirmed)	5
3	SIR BRIAN LANGSTAFF: Well, Ms Richards, Mrs C was the	3	CHRISTINE FOWLE (affirmed)	5
4	last witness for today.	4	Questioned by MS RICHARDS	5
5	MS RICHARDS: That's right, sir.	5	MR B, affirmed	31
6	SIR BRIAN LANGSTAFF: Tomorrow we start at 10.00 not at	6	Questioned by MS FRASER BUTLIN	31
7	10.30, so 10 o'clock start tomorrow. Who are we	7	MRS C, affirmed	55
8	hearing from then?	8	Questioned by MS RICHARDS	55
9	MS RICHARDS: Tomorrow, sir, there are three witness:	9		
10	Della Ryness-Hirsch, Steven Carroll and Robert	10		
11	Worsley.	11		
12	SIR BRIAN LANGSTAFF: 10 o'clock.	12		
13	(2.49 pm)	13		
14	(Adjourned until 10.00 am the following day)	14		
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