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1 Friday, 18th October 2019 2 (10.00 am) 3 SIR BRIAN LANGSTAFF: Good morning. Our first witness 4 this morning is Tony, is it? 5 MS RICHARDS: Yes, sir. 6 SIR BRIAN LANGSTAFF: Tony, please.

> ANTHONY VICTOR FARRUGIA (sworn) **Questions by MS RICHARDS**

MS RICHARDS: Tony, we are here to talk about your dad, Barry, what happened to him and the impact it has on your family. We are going to hear after your evidence from your twin brother, David.

Your dad was one of four children. He had two brothers, Victor and David, known to you as Uncle Vickie and Uncle Dave, I think, and a sister, Angela. Your dad and his brothers all had mild haemophilia A.

A. That's correct, yes. 17

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- 18 Q. We will just put up a couple of photos. First of all, 19 we have a photo of Victor and David as young men. It 20 is 1218016. We can see them there. Can you tell us 21 which is which?
- 22 A. Yes. My Uncle Dave -- they are both ripped, as you 23 can see. My Uncle Dave is the one on the left and my 24 Uncle Victor is the one on the right with the glasses.
- 25 **Q.** That's when they were both in the merchant navy?

- 1 Q. So when he was in Wales, he would receive treatment in 2 Cardiff under the care of Professor Bloom.
- 3 A. That's correct, yes. If there was a problem when he 4 was on holiday, he always knew he could drop into 5 Cardiff and receive treatment there.
- 6 Q. Generally speaking, he didn't require much treatment.
- 7 A. No, no. Very little.
  - Q. Sometimes he had had accidents. I think he fell off his motorbike or came off his motorbike once and he didn't require any treatment for his haemophilia at
- 12 A. That's right. He broke his collarbone as well and 13 there was no haemophiliac treatment required.
- Q. When he did get treatment, it wasn't prophylactically; 14 15 it was only in response to bleeding episodes.
- 16 A. Yes, that's right, yes. If I can just say, most of 17 the bleeding episodes with my father, there were some 18 spontaneous there, but the majority of treatment was 19 for work injuries. He was a gas fitter.
- 20 Q. Now, in August 1977, the family were on holiday in 21 Wales.
- 22 A. That's correct.
- 23 Q. Your dad had a recurrence of a forearm bleed.
- 24 A. That's correct, yes.
- 25 Q. He went to the University Hospital in Cardiff.

- A. That's right, as mild haemophiliacs, yes.
- Q. They both lived a robust physical life.
- 3 A. Normal life, yes, normal life.
- 4 Q. We are going to come back to what happened to them 5 towards at the end of your evidence.

Then we have a picture of your dad. 1218015, please, Henry.

That's your dad. Can you tell us the date and the year of that photo?

- 10 A. Yes, that photo was taken on 13 July 1985. It was the 11 day of LiveAid. It is my elder brother's birthday.
- 12 Q. We will keep that photo up for a few minutes whilst we 13 talk a little about your dad, and then we are going to 14 start looking at some of your dad's medical records, 15 which I know are an important part of the story you 16 want to tell. The photo will come down then but we 17 will put it back up again at the end, okay?

Your dad worked for many years as a gas fitter.

- 19 A. That's correct, yes. He started his apprenticeship at 20 the age of 16 with North Thames Gas.
- 21 Q. He received treatment primarily at the Royal London 22 Hospital in Whitechapel.
- 23 A. That's correct, yes.
- 24 Q. But the family would go on holiday to Wales a lot.
- 25 That's correct, yes.

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- 1 A. Yes. He had previously been treated I think just 2 a few weeks before for that bleed by Dr Colvin and 3 then while we were on holiday in Wales. He was 4 adamant he was going to take us out in a dingy. 5 I think we all got in the dingy. I mean, we were very 6 little children then. We got into the dingy. As we 7 were sort of going out, one of the waves hit the boat 8 and tipped it. He put his arm down to stop the boat
- 9 going over and, yeah, recurrence of a small forearm 10 bleed, so he went off to Cardiff.
- 11 Q. Up to that point, the treatment he had received from 12 Dr Colvin in London had been cryoprecipitate when he 13
- 14 A. Yes, but he had previously been treated with fresh 15 frozen plasma before cryo was introduced in the mid 16 1960s.
- 17 Q. But no Factor VIII concentrate until that point?
- 18 A. Nothing, no, that's correct.
- 19 Q. It was that holiday in Wales when he was seen by 20 Professor Bloom in 1977 that he received Factor VIII
- 21 products for the very first time.
- 22 A. Yes.
- 23 Q. We are going to look in a moment at some documents 24 from August and September 1977. Before we do so, we 25 will see that Professor Bloom claims in correspondence

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(1) Pages 1 - 4

1 and in a telephone call to Dr Colvin that your father Q. We will have a look at those records. 2 developed an inhibitor in consequence of being given 2 Henry, can we have, please, 1218002. 3 3 cryoprecipitate, and it was for that reason he was So we can see these are the inpatient treatment 4 given what's referred to in the notes as high doses of 4 sheets and outpatient treatment sheets from 1973 to 5 Factor VIII concentrate. 5 1981, it is said, for your dad, Barry Farrugia. 6 6 A. That's what I believe, yes, from the notes. A. Yes. 7 Q. But you don't think that's correct, based on the 7 Q. If we go, first of all, to page 5, please, Henry, we 8 8 can see here these are records from 1973. records. You don't think that Professor Bloom gave 9 9 A. Yes. him cryoprecipitate at all. Is that right? 10 10 **Q.** They are recording there in 1973 cryoprecipitate. A. All my dad's medical records are there, as in the 11 treatment that he received, and I approached Heath 11 A. Yes. 12 Park around about 2012 for my father's medical notes. 12 Q. If we go, please, to page 6, Henry, again we can see 13 I had already received the London Whitechapel records. 13 in 1974 they record cryoprecipitate. 14 There seemed to be a document missing, so I approached 14 A. That's correct, yes. 15 15 Wales, at which point they told me that all my Q. If we then go to page 3, please, Henry, we then get 16 16 father's records were destroyed in 1989, eight years the records for this holiday in August 1977. We can after his last treatment. But what they did send me 17 see the dates there, 11th August 1977, and then over 17 18 the following days up until 15th August 1977, I think 18 was all his treatment cards of what he had actually 19 received. As you can see, I mean, they are in your --19 the last one, and we can see that what your dad has 20 you have copies of them. All the treatment he ever 20 been given there is dried VIII concentrate, type: 21 received has all been noted down, but in 1977, where 21 22 22 A. Yes. There is no cryo there. There is no cryo there. Professor Bloom has said, "We have given him 23 cryoprecipitate and he has developed an inhibitor and 23 The thing that I picked up on this is the medical 24 we put him on Factor VIII", the Factor VIII is listed 24 records for the batches have been very good, and what 25 but the cryo is not there. 25 has alarmed me is that it's been reported he has been 5 6 1 given cryo. Everything he has been given has been 1 So could we have up on screen, please, Henry, 2 2 listed except that cryo. 1218011, page 16. If we look towards the bottom of 3 Q. I won't take the time showing the later records, but 3 the page, there's a typed entry for 12th August 1977. 4 there are records from August 1980, again a summer 4 We can see here it says: 5 holiday in Wales --5 "Telephone call from Professor Bloom." 6 A. Yes. 6 These are the London notes. These are 7 7 Dr Colvin's notes? Q. -- and then from 1981, and they are clearly recording 8 8 the Factor VIII products given then. A. That's right. 9 9 A. That's right, yes. Q. "This patient has now developed a Factor VIII 10 Q. So it is these records that are the fundamental source 10 inhibitor and is in hospital in Cardiff being treated of your belief that your dad was not given with high doses of Factor VIII concentrates." 11 11 12 cryoprecipitate in August 1977 when seen by Bloom. 12 So that was the notification from 13 A. No, it was an excuse to switch him, I believe. 13 Professor Bloom to your dad's primary treating doctor, Q. Can we have up on screen, Henry --14 Dr Colvin --14 15 15 A. That's correct. A. Sorry, can I just point out that at this time, my 16 16 father had never been exposed to any concentrate and Q. -- of the receipt of treatment with Factor VIII. 17 Arthur Bloom knew that. 17 Could we then have, please, the next page, 18 Q. And that's the source of the statement you make in 18 Henry. We see on the same day a letter from 19 your second witness statement of your belief that your 19 Professor Broom to -- I think it is to Dr Colvin. The 20 father was a "pup". 20 name has been redacted but that redaction is going to 21 A. Yes, for hepatitis. 21 be removed -- about your dad. If we look about six Q. He developed hepatitis around that time. 22 22 lines down, it talks about the presence of 23 23 A. The next day. an inhibitor: 24 Q. We will come on to that in a moment. We will just 24 "We presently have him on very large doses of

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Hemofil in the region of 6,000 units a day."

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look at the next few documents.

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(2) Pages 5 - 8

1 The bottom of the letter says: Tony, and it says: 2 "I would be very interested to know if there has 2 "I am writing to inform you that one of our 3 3 haemophiliac patients developed the been any previous hint of an inhibitor with this man." hepatitis-associated antigen at the beginning of 4 4 Then we see a reply at page 19, please, Henry. 5 This is a reply from Dr Colvin to one of the other 5 September." 6 6 As I say, we will come on to the hepatitis, but doctors in Wales, 30th August 1977. He says this: 7 "Professor Bloom's letter about Barry Farrugia 7 we see that record there: 8 8 is very disappointing news. We have really had no "He was formerly a mild haemophiliac who 9 9 indication that he was developing an inhibitor, as in required very little treatment and in the last year he 10 has only had the blood products outlined in the 10 the past he has only had one or two treatments a year. 11 I suppose we might have wondered when he presented on 11 attached sheet. These are all cryoprecipitate. 12 1st August with a spontaneous bleed in the right 12 "Unfortunately he has also developed forearm, but this seemed to improve with 13 an inhibitor to Factor VIII, which is very 13 14 cryoprecipitate and we thought no more about it until 14 disappointing." 15 Professor Bloom's telephone call." 15 Then he talks about cryoprecipitate being 16 checked but wanting to know about it. So from Dr Colvin's perspective, no previous 16 17 indication of --17 The observation you make in your statement is 18 18 that whilst it is true that Dr Colvin had only treated A. He treated him a few weeks earlier and it was a good 19 response and obviously the bleed stopped. But, yes, 19 him with cryoprecipitate, in fact he had received 20 the fall in the boat just basically triggered that 20 Factor VIII, as we have seen, from Professor Bloom in 21 21 Cardiff by this time. 22 22 Q. Then if we go to the next letter, which is page 20, A. Yes. I honestly don't believe the cryo was 23 please, Henry, it's a letter of 14th September from 23 administered because it is not in the records, yet the 24 Dr Colvin to the regional blood transfusion centre. 24 records are so conclusively correct of everything that 25 You have drawn attention to this in your statements, 25 he received apart from that one batch. So to me 10 your father being jaundiced. 1 that's ringing alarm bells. 1 2 2 Q. Then just to complete this series of correspondence, A. Uh-huh. 3 could we have page 23, please. This is another letter 3 Q. You have said you recall seeing him very jaundiced on 4 of 14th September, this time from Dr Colvin to 4 several occasions, including after that first 5 Professor Bloom, and if we pick it up in the second 5 administration of Factor VIII. 6 paragraph, second line: 6 A. He always seemed to be very swollen as well. Whenever 7 7 he was jaundiced he was quite swollen, always seemed "As I mentioned in my last letter, he was 8 8 formerly a mild haemophiliac and we had no real 9 9 warning of the development of the inhibitor. Even Q. We will not go to the records for this, but you have 10 more surprising is the development of HBsAg positive 10 recorded in your statement and it is in the records that he had his first positive Australia antigen test 11 hepatitis when he had only received tiny quantities of 11 12 cryoprecipitate, all donors being checked by the RIA 12 in 2nd September 1977. 13 method at Brentwood. I am checking up on this." 13 A. Yes. Q. It was following the sequence of events we have just 14 A. I have a problem with this, because this almost seems 14 15 like he has written off to the blood laboratory 15 looked at that your father was from then on treated 16 16 stating that the hepatitis B was from cryo, yet he with Factor VIII. 17 didn't receive cryo, he received --17 A. Even though he had an inhibitor. It is like they have 18 Q. Well, he received cryo earlier in the year. 18 gone against their own advice. Dr Colvin wrote 19 A. Yes. 19 saying, "Why are you giving this man Factor VIII? He 20 Q. But your point is the hepatitis developed really quite 20 has developed an inhibitor to Factor VIII", but they 21 suddenly after he received the Factor VIII for the 21 carried on using it. It is just ... 22 22 very first time. Q. If we go, Henry, please, to page 13 in this exhibit. 23 23 A. Yes, and I believe they should have been checking the Sorry. That's the wrong reference. Don't worry. 24 Factor VIII, not the cryo. 24 The records show that in the years that 25 Q. There are references in the records at this time to 25 followed, your dad received commercial Factor VIII

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(3) Pages 9 - 12

1 products, primarily Armour, but also some others. porcine was stopped. 2 A. Yes. 2 Q. Now, there is no evidence from your dad's notes that 3 3 Q. Occasionally NHS Lister products. he was given any warnings of risks of infection from 4 A. I believe the Lister products were only administered 4 Factor VIII? 5 1983/1984, yes. 5 A. From the notes, no, but I will also recall 6 6 Q. In March 1981 he went on to home treatment, but not on a conversation with my elder brother, and it was 7 a prophylactic basis, just again in response to 7 relating to when my father told him of his illnesses 8 8 bleeds. and my brother said to my father, "Were you not 9 9 A. I wouldn't know. I don't ever recall seeing my father warned?" and my dad said, "If they had warned me, 10 giving himself treatment. I mean, we may have been 10 I wouldn't have took it". 11 taken out of the home, I don't know, but ... 11 I do remember seeing my dad as a child with 12 Q. Your statement records that but you have taken it from 12 an icepack and I think Distalgesic, they were called 13 the records, and it is there in the records. 13 then. I remember them because we were told. "Don't 14 You have also noted an occasion on which he was 14 touch them, they are really strong". So, yes, mainly 15 given porcine Factor VIII. 15 he would rest, icepack, and it was mild. It would 16 A. Yes. He went on a trial for 12 months. Unfortunately 16 clear up. 17 Dr Colvin went on holiday -- and, again, I am taking 17 Q. Now, having continued to receive Factor VIII 18 this from the records; I was a child, I wouldn't have 18 concentrates since 1977, we can see from his medical 19 known any of this. He went onto the trial of porcine 19 records that by May 1984 your dad was starting to 20 and I think he was near enough a year in and Dr Colvin 20 become physically unwell. 21 had gone on holiday, left a junior consultant in 21 A. Yes. 22 22 charge. Before they administered the porcine, they Q. Henry, could we have 1218011, page 37, please. 23 always give him a Piriton injection, and it was 23 If we look towards the bottom of the page and 24 24 the entry for 23rd May 1984, we can see there's working. They forgot to administer that Piriton 25 injection and he just -- severe reaction and the 25 a record of an attendance at the Haematology 13 14 1 Department, and it refers a few lines down: 1 Then it says, "Non-A, non-B". 2 2 "Intermittent nausea, especially when hungry. Then we see a question mark after the reference 3 Feels bloated. Appetite reduced. Has lost half 3 to lymphocyte count, "? pre-AIDS". Then we see 4 4 a stone in the last three months. Bowels normal. No a reference to tests being undertaken. 5 jaundice. No change in stools or urine." 5 We know from our documents your dad's blood was 6 Then it refers to two weeks ago: 6 taken on 2nd July 1984 --7 7 "Had a bout of vomiting and diarrhoea." A. Yes. 8 8 At the bottom there is a reference to: Q. -- for a test, the then HTLV-III tests. If we have up 9 9 "Feels depressed. Not sure whether it is due to on screen, please, 1218004 -the nausea or vice versa." 10 10 A. Can I just pick something up on that? Q. Yes, sorry. Could we go back to it, please. 11 There are a number of records throughout 1984 11 12 which show your dad reporting that he is not feeling 12 On that last. What I find quite disturbing is that 13 very well. 13 they're -- I mean, I was a child. I don't know what A. That's correct, yes. 14 was actually discussed in that consultation when my 14 15 Q. If we go over the page, please, Henry, to page 38, and 15 dad went there. I do know that at that point he was 16 16 we pick it up on 2nd July 1984, halfway down the page: told about the non-A, non-B, but also I see there it's about the pre-AIDS: 17 "Feeling much the same in himself. Sleeping a 17 18 lot. Generally feels bilious without any vomiting." 18 "Keep under review. Avoid alcohol. Refer to 19 Then you will see the words: 19 Professor Jones. Notify John Craske." 20 "Results: abdominal ultrasound -- liver plus, 20 They should have been notifying the patients 21 21 first, not the doctors. He should have been told, spleen." 22 22 So he had an enlarged spleen. yes. 23 23 A. Uh-huh. Q. Just picking it up towards the bottom of that page,

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Q. The opinion that's there set out, "Continuing

hepatitis". Then there is a query about hepatitis B.

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(4) Pages 13 - 16

the entry for 8th August, we can see there it talks

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about malaise, lethargy, weight loss for investigation

of abnormal liver function tests, question chronic active hepatitis. We will pick that up in some subsequent correspondence.

If we then go to 1218004, please, Henry, we can see a letter dated 9th October 1984 from Dr Richard Tedder to Professor Collier at the London Hospital Medical College. It says this in the second paragraph -- well, we will pick it up in the first paragraph:

"You may remember we spoke about this patient a month or so ago. I am awfully sorry to discover that we have not sent results in writing to you. I am afraid that I had filed the results pending delta testing. These will be done soon but I do not know when.

"Since this man is a haemophilic, we have tested him for HTLV-III. We have also received specimens from the AIDS haemophilic surveillance group. Not surprisingly he is HTLV-III positive. This result does not appear on the form. My apologies for causing this delay."

So the blood sample taken on 2nd July, the positive test was reported here after a delay for which there is an apology in October 1984.

A. Yes.

- Q. No, if there is a point you want to make now, please
- A. It's a point I want to make, and it is something that was in the litigation, so it was drawn to me, it's not something that I know, it was drawn to me. But this is January 1985. I don't know what was medically known then, but there is reference to -- that the steroids were actually -- they shouldn't have been given.
- 10 Q. Because of the HIV diagnosis.
- A. They knew at that point when those steroids were giventhat he was HIV positive.
- Q. What the records don't tell us is the point in time at
   which Dr Colvin was notified directly of the HTLV-III
   result.
- 16 A. Yes.
- Q. But it seems -- if we look at 1218011, please,
  page 58, this is a letter dated 25th February 1985, so
  this is the following month, and we know from this
  letter that Dr Colvin knows of the anti-HTLV-III
  positive result. We can tell from this, I think, that
  your dad by this time has been told.
- A. Yes, he was told on 13th February, I believe. But,
   again, I have only learned that when I received the
   medical notes. I wasn't aware of any of this.

Q. The records show -- and, again, we don't need to go to all of them -- that your dad was told in February of 1985.

- A. That's right, yes, yes.
- Q. If we just pick things up in January of 1985, first of all -- 1218006, please, Henry -- we can see here a letter of 31st January 1985. It is from Professor Leonard Jones to Dr Colvin. There has been an investigation in relation to your dad's liver disease. There's reference to the hepatitis A IgG antibody being positive, which means that he has probably had this infection at some time.

Then there is a reference to hepatitis B results. He says that:

"... makes persistent infection unlikely. To confuse matters further, antibodies to the CMV and EBV viruses are both weakly positive."

Then he says this:

"I think he must have active chronic hepatitis."

And the recommendation is made in relation to keeping under review the steroid treatment which by then your father had been placed on because of the hepatitis.

A. Yes. Sorry, can I just point out at this -- no, I will pick it up --

Q. We will come back to what you knew at a later stage. You didn't know any of this at the time, but it tells us here:

"He has developed an inhibitor to Factor VIII, has chronic active hepatitis and is now anti-HTLV-III positive with evidence of marked immunosuppression. He is obviously a prime candidate for AIDS, a fact of which he is fairly fully aware."

Then there is the reference to the steroid treatment and then to developing severe warts on the hands, which are getting worse. Then it says this:

"Although he looks fine, I fear the long-term prognosis is not very good, but anything which brings symptomatic relief from his various problems would be worthwhile."

We know from the records that your dad was started on Septrin in May of 1985.

- 18 A. Yes.
- Q. Then we can see if we pick things up at 1218005,
  please, Henry, this is April 1986 and we can see by
  this time that your dad is physically and mentally
  very unwell. This is a letter of a referral from
  Dr Colvin to a consultant psychiatrist, Dr Parks, and
  the significance of that will become apparent.

**A.** Yes.

(5) Pages 17 - 20

1 Q. But it says this: axilla." 2 "Mr Farrugia has moderate haemophilia with an 2 Then this: 3 3 antibody to Factor VIII." "When I saw Mr Farrugia yesterday morning, he 4 4 Refers to hepatitis B: and his wife spoke of recent black moods, 5 "... also anti-HTLV-III positive and is 5 uncontrollable crying, general hostility and 6 6 aggressive behaviour, and he very sensibly requested completely familiar with what this means. He really 7 began to feel unwell about two years ago when he 7 a psychiatric opinion." 8 8 complained of nausea and epigastric pain, and on So that's how things were by April of 1986. 9 9 examination it was noted that his liver and spleen A. Yes. 10 10 were enlarged. He was depressed at the time." Q. And your dad was then seen by a psychiatrist on 11 Then it refers to a previous depressive illness: 11 11th April 1986. Can we have up on screen, please, 12 "At the consultation two years ago the diagnosis 12 1218008. This is a letter back to Dr Colvin from 13 13 was really chronic active hepatitis. For a short time Dr Parks, the consultant psychiatrist. It talked 14 he was given steroids at the suggestion of 14 about him being accompanied by his wife, Cheryl: 15 Professor Leonard Jones, but when it became apparent 15 "He talked openly and frankly about his feelings 16 that he was anti-HTLV-III positive our enthusiasm for 16 of anger and depression which have become increasingly this approach dwindled rapidly. He has had no 17 17 difficult to cope with recently ..." 18 18 steroids for some time. Then if we go over the page, please, to the 19 "Other medical problems have been perianal 19 second page, Henry, the paragraph in the middle of the 20 abscess, low back pain and severe warts on the hand. 20 page: 21 I have continued to see him regularly and there has 21 "In February 1985 the patient was told that he 22 22 had active HTLV-III virus in his blood. His immediate been a general slow deterioration in his condition, 23 with enlargement of the liver and spleen, 23 reaction was to feel numb. 'It didn't hit me for 24 24 quite a while'. In April 1986, however, he developed thrombocytopenia, a dry cough which responded to 25 25 a cough and was told that the prognosis was not good. Septrin, and now some lymphadenopathy in the right 21 1 He felt that the news was broken gently to him and 1 that was to say goodbye to the family. When he 2 2 tried to maintain a relatively normal kind of life. returned, they felt he was too well to be re-admitted, 3 From time to time he found feelings of deep despair 3 but I think he was re-admitted a couple of days later, 4 4 breaking through and found himself becoming I mean -- yes. 5 increasingly irritable at such times." 5 Q. We will look at those, because I know it is important 6 Then it talks about finding sleeping difficult 6 to you that the impact of his diagnosis and illness on 7 7 your dad's psychiatric health is made clear. and suffering vivid dreams. 8 8 On 22nd April your dad was admitted to A. Yes. 9 9 a psychiatric ward under the Mental Health Act. Q. So we will look at a couple of references is in the A. That's right. 10 10 notes and then we will look at the psychiatric report. 11 Q. If we have, please, up on the screen, Henry, 1218012, 11 Henry, still in 1218012, could we have page 12. 12 page 17, we can see at the very bottom of the page. 12 You have picked up in your statement, Tony, when 13 This was an assessment carried out for the purpose of 13 you read these notes, you picked up your dad being deciding whether to admit your dad under Section 2 of 14 asked questions about being sad. 14 15 15 the Mental Health Act. It says: A. Yes. 16 16 "I think that Mr Farrugia is in need of Q. To you it was obvious why he was sad, because of the 17 psychiatric treatment, and that as he keeps leaving 17 diagnosis and prognosis he had. 18 the ward and is too vulnerable to be allowed to do so, 18 A. Yes. 19 detention is appropriate. Section 2 application 19 We just see here, "Mood". It talks about your dad's 20 signed." 20 comment: 21 So he was detained under the Mental Health Act 21 "Sometimes sad, but I can cry and this improves 22 22 and he remained in hospital until early August of that things." 23 23 Then if we go to page 23, please, Henry, in the vear? 24 A. Yes. They took him out to go on holiday to Wales and, 24 same exhibit, we can see in the entry halfway down the 25 I mean, from knowing more now as an adult, I think 25 page a neurology assessment and the reference to

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(6) Pages 21 - 24

4		AIDC related an early along the c	4		VThe national consumption by lead control AE manufact
1		AIDS-related encephalopathy.	1		"The patient was probably last well 15 months
2		Now, if we could then, please, have up on	2		ago after receiving the information he was HTLV-III
3		screen forgive me while I check the reference	3		positive. The patient was at first 'accepting and
4		still in exhibit 12, Henry, page 2, please.	4		rational', but six months later more 'irritable,
5		This is a document produced by the psychiatric	5		short-tempered and aggressive'. The patient began
6		team following your dad's discharge from hospital. It	6		shouting without provocation, much to the despair of
7		is dated 10th September 1986, and we can see the	7		his wife."
8		diagnosis: organic brain syndrome/psychogenic	8		It refers again to the referral to Dr Parks, and
9		psychosis. We see the reason for referral on the	9		then the patient's wife returning to find his
10		first page:	10		behaviour robot-like and more aggressive.
11		"The patient was initially referred to Dr Parks	11		"The patient was holding conversations with
12		on 10th April on account of recent black moods,	12		himself and repeating what was said to him three or
13		uncontrollable crying, generally hostility and	13		four times. The patient's boss telephoned his wife on
14		aggressive behaviour."	14		21st April 1986, giving more evidence of bizarre
15		It refers to him being seen by Dr Parks. We	15		behaviour the previous week, for example staying at
16		have seen that, on 14th April. Then:	16		a client's house until 1.30 in the morning and
17		"The patient continued to deteriorate. On	17		insisting on fixing her porch light, which was not
18		20th April 1986 his wife became concerned about his	18		defective."
19		robot-like actions, abrupt and aggressive behaviour,	19		There is a reference to sleep disturbance and
20		shouting episodes and talking to himself."	20		nightmares. Then we can see a description of your
21		That's the point at which he was admitted under	21		dad's mental state on admission. Is it okay for me to
22		the Mental Health Act.	22		read this?
23		Yes.	23	Α.	Yes, put it up.
24	Q.	If we go to the next page, please, Henry, under the	24	Q.	Mental state on admission. Talks about him refusing
25		heading "History of present illness", it says this:	25		at first to be interviewed.
		25			26
1		"The patient was still in possession of his	1		me?'
1 2		"The patient was still in possession of his knife after dinner, which when taken from him he said,	1 2		me?' "Mood much calmer.
2		knife after dinner, which when taken from him he said,	2		"Mood much calmer.
2 3		knife after dinner, which when taken from him he said, 'That's my library book'. The patient also looked	2 3		"Mood much calmer. "Guilt/low self-esteem/suicide item no
2 3 4		knife after dinner, which when taken from him he said, 'That's my library book'. The patient also looked menacing, pointing to one of the nurses and said, 'Do	2 3 4		"Mood much calmer. "Guilt/low self-esteem/suicide item no ideation.
2 3 4 5		knife after dinner, which when taken from him he said, 'That's my library book'. The patient also looked menacing, pointing to one of the nurses and said, 'Do you trust me? I am not going to rape you'.	2 3 4 5		"Mood much calmer. "Guilt/low self-esteem/suicide item no ideation. "Effect perplexed, un-cooperative at times.
2 3 4 5 6		knife after dinner, which when taken from him he said, 'That's my library book'. The patient also looked menacing, pointing to one of the nurses and said, 'Do you trust me? I am not going to rape you'.  "Talk answers far from the point. The	2 3 4 5 6		"Mood much calmer. "Guilt/low self-esteem/suicide item no ideation. "Effect perplexed, un-cooperative at times. "Insight poor."
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1	A.	That's right.	1		after that, we see your dad being seen again by the
2	Q.	He was officially discharged in terms of the	2		doctors and admitted back into hospital.
3		psychiatric admission, but it is said it is probable	3		Can we have, Henry, please, 1218011, page 46.
4		he will need further assistance in terms of his	4		So we have got an entry at the top of the page,
5		physical state?	5		1st September 1986. It describes your dad as weeping
6	A.	That's right, yes.	6		on arrival:
7		So that's late August 1986. If we have up on screen	7		"Says he doesn't know why he is sad. Rang his
8		then, please, Henry, page 37 of this exhibit,	8		wife 15 times today. Begged her not to go to work.
9		exhibit 12, this is after your dad has returned home.	9		"No other real symptoms.
10		It is a letter from the social worker requesting	10		"Moderate vomiting. Pathologically excessive
11		a referral to a day hospital. It just gives us some	11		eating."
12		insight again as to how your dad is feeling at this	12		A little further down it says this:
13		time.	13		"Looks awful. Opinion: HIV-related symptoms and
14	A.	Uh-huh.	14		signs with candida, depression, incipient hepatic
15		It refers to him having recently spent several months	15		failure, nosebleeds."
16		as an inpatient at the ward at the London hospital	16		Then there is a reference to arranging for
17		following a nervous breakdown. Then it says this:	17		further assessments of him the following day. We see
18		"Mr Farrugia is now the home and feels lonely	18		that on 2nd September the psychiatrists feel that Mr
19		and isolated, as his wife is at work during the day.	19		Farrugia's present problems are really medical.
20		Although Mr Farrugia is by no means demented, he is	20		If we look further the down, the bottom entry,
21		rather confused at times, has a poor memory and cannot	21		5th September 1986:
22		concentrate sufficiently to occupy himself during the	22		"Admitted to London hospital."
23		day. This leaves him feeling anxious and frustrated	23		That was your dad's final admission to hospital.
24		as well as lonely."	24	Α.	That's right, yes.
25		In early September, so only a couple of days	25		We will just look at one further entry in the records,
		29			30
		20			00
1		if it's okay with you. Tony	1		was abusive. I don't remember when it all started
1 2	Α.	if it's okay with you, Tony. Yes	1 2		was abusive. I don't remember when it all started.  I know that there's reference in my dad's medical
2	A. Q.	Yes.	2		I know that there's reference in my dad's medical
2		Yes. It is in 1218011, page 71, please, Henry. This is the	2 3		I know that there's reference in my dad's medical notes in 1981 that we were seen by child psychologists
2 3 4		Yes. It is in 1218011, page 71, please, Henry. This is the notes taken by Dr Colvin or on Dr Colvin's behalf	2 3 4	Q.	I know that there's reference in my dad's medical notes in 1981 that we were seen by child psychologists because of our "delinquent" behaviour.
2 3 4 5		Yes. It is in 1218011, page 71, please, Henry. This is the notes taken by Dr Colvin or on Dr Colvin's behalf I think on 5th September 1986, the day of his	2 3 4 5	Q.	I know that there's reference in my dad's medical notes in 1981 that we were seen by child psychologists because of our "delinquent" behaviour.  Can I take it back slightly earlier than that.
2 3 4 5 6		Yes. It is in 1218011, page 71, please, Henry. This is the notes taken by Dr Colvin or on Dr Colvin's behalf I think on 5th September 1986, the day of his re-admission to hospital. It refers to problems	2 3 4 5 6	A.	I know that there's reference in my dad's medical notes in 1981 that we were seen by child psychologists because of our "delinquent" behaviour.  Can I take it back slightly earlier than that.  Yes.
2 3 4 5 6 7		Yes. It is in 1218011, page 71, please, Henry. This is the notes taken by Dr Colvin or on Dr Colvin's behalf I think on 5th September 1986, the day of his re-admission to hospital. It refers to problems including confusion, depression, crying and dizziness,	2 3 4 5 6 7	A.	I know that there's reference in my dad's medical notes in 1981 that we were seen by child psychologists because of our "delinquent" behaviour.  Can I take it back slightly earlier than that.  Yes.  Before we do so, just to bear in mind you make
2 3 4 5 6 7 8		Yes. It is in 1218011, page 71, please, Henry. This is the notes taken by Dr Colvin or on Dr Colvin's behalf I think on 5th September 1986, the day of his re-admission to hospital. It refers to problems including confusion, depression, crying and dizziness, "All problems worrying".	2 3 4 5 6 7 8	A.	I know that there's reference in my dad's medical notes in 1981 that we were seen by child psychologists because of our "delinquent" behaviour.  Can I take it back slightly earlier than that.  Yes.  Before we do so, just to bear in mind you make a number of statements about your dad's wife, your
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2 3 4 5 6 7 8 9		Yes. It is in 1218011, page 71, please, Henry. This is the notes taken by Dr Colvin or on Dr Colvin's behalf I think on 5th September 1986, the day of his re-admission to hospital. It refers to problems including confusion, depression, crying and dizziness, "All problems worrying".  It describes him as looking weary and tired and pale. Under the heading "Mood", it records your dad	2 3 4 5 6 7 8 9	A. Q.	I know that there's reference in my dad's medical notes in 1981 that we were seen by child psychologists because of our "delinquent" behaviour.  Can I take it back slightly earlier than that.  Yes.  Before we do so, just to bear in mind you make a number of statements about your dad's wife, your stepmother, in your statement. You know she has provided a statement in response.
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2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21	Q. A. Q. A.	Yes.  It is in 1218011, page 71, please, Henry. This is the notes taken by Dr Colvin or on Dr Colvin's behalf I think on 5th September 1986, the day of his re-admission to hospital. It refers to problems including confusion, depression, crying and dizziness, "All problems worrying".  It describes him as looking weary and tired and pale. Under the heading "Mood", it records your dad saying this:  "I feel sad because I am going to die. Crying at times. Thinking about dying."  Bottom of the page:  "I feel sad because I am dying."  Then your dad died on 22nd September 1986. That's right, yes. Tony, we have been talking about your dad's story because you wanted that story to be told. Yes, definitely, yes. I just want to ask you, if I can, about what was then	2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21	A. Q. A. Q. A.	I know that there's reference in my dad's medical notes in 1981 that we were seen by child psychologists because of our "delinquent" behaviour.  Can I take it back slightly earlier than that.  Yes.  Before we do so, just to bear in mind you make a number of statements about your dad's wife, your stepmother, in your statement. You know she has provided a statement in response.  Yes.  Which, of course, will be published on the Inquiry website as a matter of fairness to all. You know I am not going to go into the detail of which of those accounts is right or wrong  Yes.  or whether the position lies somewhere in between.  First of all, you were one of twins.  Yes.  We are going to hear from David in a moment. 1218014 is a photo of the two of you. We can see there you
2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22	Q. A. Q. A.	Yes.  It is in 1218011, page 71, please, Henry. This is the notes taken by Dr Colvin or on Dr Colvin's behalf I think on 5th September 1986, the day of his re-admission to hospital. It refers to problems including confusion, depression, crying and dizziness, "All problems worrying".  It describes him as looking weary and tired and pale. Under the heading "Mood", it records your dad saying this:  "I feel sad because I am going to die. Crying at times. Thinking about dying."  Bottom of the page:  "I feel sad because I am dying."  Then your dad died on 22nd September 1986. That's right, yes. Tony, we have been talking about your dad's story because you wanted that story to be told. Yes, definitely, yes. I just want to ask you, if I can, about what was then happening to you during this time and then what	2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22	A. Q. A. Q. A.	I know that there's reference in my dad's medical notes in 1981 that we were seen by child psychologists because of our "delinquent" behaviour.  Can I take it back slightly earlier than that.  Yes.  Before we do so, just to bear in mind you make a number of statements about your dad's wife, your stepmother, in your statement. You know she has provided a statement in response.  Yes.  Which, of course, will be published on the Inquiry website as a matter of fairness to all. You know I am not going to go into the detail of which of those accounts is right or wrong  Yes.  or whether the position lies somewhere in between.  First of all, you were one of twins.  Yes.  We are going to hear from David in a moment. 1218014 is a photo of the two of you. We can see there you have got to tell me which of you is which, I am
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2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22	Q. A. Q. A. Q.	Yes.  It is in 1218011, page 71, please, Henry. This is the notes taken by Dr Colvin or on Dr Colvin's behalf I think on 5th September 1986, the day of his re-admission to hospital. It refers to problems including confusion, depression, crying and dizziness, "All problems worrying".  It describes him as looking weary and tired and pale. Under the heading "Mood", it records your dad saying this:  "I feel sad because I am going to die. Crying at times. Thinking about dying."  Bottom of the page:  "I feel sad because I am dying."  Then your dad died on 22nd September 1986. That's right, yes. Tony, we have been talking about your dad's story because you wanted that story to be told. Yes, definitely, yes. I just want to ask you, if I can, about what was then happening to you during this time and then what	2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22	A. Q. A. Q. A.	I know that there's reference in my dad's medical notes in 1981 that we were seen by child psychologists because of our "delinquent" behaviour.  Can I take it back slightly earlier than that.  Yes.  Before we do so, just to bear in mind you make a number of statements about your dad's wife, your stepmother, in your statement. You know she has provided a statement in response.  Yes.  Which, of course, will be published on the Inquiry website as a matter of fairness to all. You know I am not going to go into the detail of which of those accounts is right or wrong  Yes.  or whether the position lies somewhere in between.  First of all, you were one of twins.  Yes.  We are going to hear from David in a moment. 1218014 is a photo of the two of you. We can see there you have got to tell me which of you is which, I am

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1 the back. 2 A. Yes. I think David is on the table. I am sure he had 3 the tan shoes, but then I don't know. I don't know.

Q. Well, we can see you are identical twins.

5 A. Yes, we were.

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6 Q. And you were dressed identically.

7 A. Yes, apart from the shoes. That was ... yes.

8 Q. And you were about ten years old.

9 A. I was ten and a half when that was taken, yes.

Q. Now, your dad had split from your mother in 1973 when 10 11 you were --

12 A. 18 months old.

13 Q. He remarried. As I said, we are not going to go into 14 the rights and wrongs of any of it. As a matter of 15 fact, you grew up for a number of years thinking your 16 stepmother was your birth mother.

17 A. Yes, we were so young.

18 Q. Your actual birth mum you met a few times, but she was 19 introduced as an aunty when visiting the house.

20 A. Yes. That's all been explained to me since then.

21 Q. Whatever the ins and outs and rights and wrongs, it is 22 fair to say there were elements of your childhood that 23 were difficult.

24 A. Very difficult, yes.

25 Q. In 1984, when you were 13, you ran away from home a

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1 and took you into care.

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A. Yes. I was saying at a friend's house. I had been there a few weeks. I think we were in the process of -- because his mum was happy for me to be there, and my mum was happy for me to be there. I think we were in the process of getting the child benefit changed from my mum to my friend's mum so that there was -- and I was going to live there. Everybody was happy with that. I mean, obviously I didn't know what was going on in the background. I didn't know my dad was ill. And I just remember coming out of the house, it was on the first day of the holidays, and where we lived you had to come down a ramp to get to the road, and I remember coming down the ramp and there was a car parked there. There was three people in the car. There was two men and a woman in the back of the car. They were all suited and booted. They got out of the car and said, "Are you Anthony Farrugia?" I said, "Yes". They said, "Can you come with us". I didn't question it; I got in the car with them and they took me into care.

Q. After that you lived in a children's home until you were 16 years old.

24 A. No. It was just before actually, I think. I think 25 the date that I actually left the children's home was

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number of times.

2 A. Yes.

> Q. In November of 1984, you ran away again. It was very cold. You didn't return home until 3.00 in the morning.

6 A. Only because I was cold.

Q. Your dad was pretty cross when you got back. After that it was suggested you go and stay with your birth mother for a period of time.

10 A. I was asked, I was asked, yes, if I wanted to go and 11 live with my mum. By then we had been told. My mum 12 lived in Marsh Farm and at that age I thought I was 13 moving to a farm with loads of animals. So yes, 14 I wanted to go.

15 Q. So you moved to live with your mum, but that 16 arrangement didn't last very long.

17 A. I think the psychological trauma that I had suffered 18 at the hands of my stepmum, I wasn't really being fair 19 to my mum and I think I took it out on her. And she 20 was brilliant, but I didn't know her. I didn't know 21 her. And I think at that point then I was -- we were 22 damaged. We were damaged. My mum got a damaged child 23 back.

24 Q. So by the June of 1985 you were staying with a friend. 25 Then in the summer holidays social services turned up

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1 around about April or May of 1987.

2 Q. Now, you have described in your statement your dad 3 coming to visit you with your brothers in 1985 around 4 the time of your birthday, I think, and then he came 5 back a week or so later, and that's when he told you 6 that he was HIV positive.

A. Yes. I had moved into the children's home in Luton, which is actually right across the road from my real mum. So that was quite nice. We were able to 10 continue that relationship. I mean, that relationship 11 was built on and I eventually returned back to her. 12 But I went into the children's home. Although I had 13 been taken in August, I was sent to like a holding 14 home before they found me a permanent place. It was 15 right next to my school as well, so it made sense for 16 me to go there.

> So I think I arrived at The Brambles in -- it was just after we had gone back to school. So it was the first or second week of September. Then my father came to visit me with my twin brother and his wife and my younger brother actually on my birthday, and then the following week they came back again. I don't think I questioned it. I am questioning it now as an adult and what I know, but then I didn't.

> > I mean, this was at the time -- so AIDS was just

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(9) Pages 33 - 36

starting to come into my eyesight at that point through television. Rock Hudson had died on 5th October. It was heavily all over the news, "the gay plague". Still no link. I was a child. Then my dad came back and told me he had HIV.

Q. And you say this:

"I was on my own in a children's home at the time and I had no support available to me."

You were distraught at this information.

- A. Well, I think from what we had seen on the news -- I mean, I know from speaking to other people when I joined the campaign that there were snippets coming out earlier, but why would I have -- you know, to me it was nothing. Then with the Rock Hudson and the 1985 and then the diagnosis from my dad, I think at that point, when he told me, I knew he was going to die.
- Q. And you have said in your statement that in hindsight
  you can see that it was when he began to get ill in
  1984 that things started falling apart at home.
- A. The situation in the family home got really bad in
  July 1984, and it was only when I got the medical
  notes in 2012 that I was able to piece that together,
  and I think that was the key.
  - Q. You have got a memory of sitting in a hospital garden,

1 you saw your dad.

- 2 A. I never saw him again, no.
- Q. You were due to see him in the September, but by thattime he had died.
  - A. Yes. The home got a phone call around about 18th September and, I mean, it ties in now with the medical notes that he was transferred to isolation three days before he died, so the call came to the home to get me down there. They sat me down and said, "Your dad's in isolation. You need to gown up. You need to wear a mask". I never had a problem with that

We arranged for me to go on the Monday after school. I went to school on the Monday, came home. I came home from school. The key worker said to me, "We are just waiting for social services and then we will take you". They didn't take me. They took me down to a room and told me.

- Q. They told you your dad had died.
- 20 A. Yes, that morning.
  - Q. After your dad's death -- and, again, we are not going to go into the rights and wrongs of it -- the family essentially was split up and your brother David, and he will tell us more about it in a movement, he was also placed into care.

1 eating an ice-cream with your dad.

A. That's right, yes. So when dad was sectioned, 14th April I think, the home arranged for us to -- for me to go and visit. They had their own minibus. So they loaded all the children into the minibus. All of us got, we all got into the minibus, two members of staff. They drove down to London Whitechapel and dropped me and my key worker off and the children went to the local park. I visited my dad and the children went off and they came back and picked us up later.

But, yes, we went across the road for something to eat. I mean, dad wasn't eating. He was awfully skinny, really, really skinny, and for a 6'2" man, that was quite shocking to see. So he didn't eat, but we got I think -- I don't know whether they were Mr Whippy or whether it was a scoop, but we got ice-cream and went back across to the hospital garden, and my dad asked me for a bit of ice-cream. I handed it and the nurse stopped me and said, "You can't share that with him". He had loads of -- I think at that point he had candida and he had loads of ulcers in his mouth, which could have been bleeding. So I understand, but it is quite difficult at that age to be told you can't share an ice-cream with your dad.

Q. I think I am right in saying that was the last time

**A.** Uh-huh.

- Q. But the two of you were not in care together. You
   were separate. You stayed where you were, he was
   placed in care locally for his school.
- A. Yes. We were roughly about 80 or 90 miles apart.
   I was Bedfordshire. David stayed in the area where we
   lived.
- Q. One of the things you are very critical of is the lackof support from social services --
- 10 A. Oh, we just didn't exist.
- **Q.** -- at that time.
- 12 A. After he died, or even before he died, there was no -13 I mean I was in a children's home and they were
  14 lovely, you know. That's a real highlight of my
  15 childhood. You know, that was a godsend. It really
  16 was. It was a great place. They were very
  17 supportive, but there was no -- you know, they weren't
  18 geared up for this.

So, no, you know, I could talk to them, but again, you know, I didn't know what I know now. So as a child, yes, it is devastating. You have lost your dad. You don't understand. But, you know, you have to get on. And, as I say, at that point the whole family imploded. You know, the home was gone.

Q. All your childhood possessions.

40 (10) Pages 37 - 40

- 1 A. Everything.
- 2 Q. You don't have any of them.
- 3 A. Nothing, no.
- 4 Q. Over the years you built a life for yourself.
- 5 A. Yes.
- Q. Work, marriage, kids. 6
- 7 A. Yes.

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- 8 Q. But it's clear from your statement that what happened 9 to your dad and the ramifications for the family has 10 continued to dominate your life.
- 11 A. Yes. Because of the -- I mean, I learned about my 12 uncle, Uncle Vickie. I was told three weeks after my 13 father died that he was positive as well, and then 14 subsequent years later Uncle Dave. So, yes, it has 15 destroyed the whole arm of that family completely.
- 16 Q. You talk in your statement about coming to listen 17 while people would make AIDS jokes and having to laugh 18 because you had not told people about --
- 19 A. I knew some really good jokes. You had to join in. 20 You had to. You know, you didn't want to alert people 21 to, "Oh, why is he upset because we are telling AIDS 22 jokes?" So yes, as much as I feel bad about it, yes, 23 I told loads of jokes. It was sort of a way of 24 coping, of shutting it out.
  - Q. In 2008 your aunt prompted you to have a look at the

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it or not. When I got the notes, the first day I turned to was 22 September 1986 and read them backwards. So it took me a while to learn what had gone on, because I was reading them backwards. I think around about 2012, maybe -- no, no, it was later than that. It was 2014. So we were then --I was campaigning -- not campaigning, but I was trying to help raise some funds for Factor IX through Bruce. So I was just trying to -- my family were donating. We were just going nuts trying to raise this money to get this show. And obviously I was reading these notes as well and I was learning about what had gone on. I developed a pain in my stomach and I went to the doctors. That was quite -- she was totally honest with me. She was a lovely doctor actually. She is the only doctor I've ever trusted. Unfortunately she's left the practice now and I haven't sought medical help for a long time. She sort of listed, "These are the four things it could be". I was in terrible pain. It was on her telling me some of these of what it could be. I mean, cancer -- I am a smoker, so bowel cancer was mentioned and at that point I was reliving those notes of watching my dad deteriorate and how we suffered as children, and then that was

relaying in, if I died, my children, because they were

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1 Tainted Blood website.

- 2 A. That's right, yes. I think it was on the back of --3 I think Archer was due to be published in 2009 and 4 I think there had been a bit of activity in the press, 5 and that's where we learned of Tainted Blood, the 6
- 7 Q. That's what prompted you to request your father's 8 medical records.
- 9 A. Not right away, no. I actually just -- I sat and --10 I sat for about two years just watching this site, 11 watching people's conversations, reading the 12 timelines, trying to take it all in of what had 13 happened. So it was 2010 that I applied for his 14 medical notes from London Whitechapel.
- 15 Q. And it was reading those that taught you what your 16 father had gone through.
- 17 A. Yes. I mean, I knew about the HIV, but it was at that 18 point then I had learned he was hepatitis C as well. 19 We had no idea. I didn't even know all these people 20 existed.
- 21 Q. And you have said in your statement that reading 22 through your father's medical records, becoming aware 23 of the truth of what really happened to him, made you 24
  - A. Oh, yes. I mean, I read the notes backwards, believe

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So, yes, I got really, really unwell. I had several medical procedures at that time, because just everything was going wrong. I had lost about 5 stone. I developed psoriasis. I developed this rash that we just didn't know what it was. We know now. So I endured -- I was coughing up blood. I was really worried, you know, and reading those notes just put everything into perspective. I don't want my children to go through that.

So I was diagnosed with IBS. So basically everything else was ruled out. I had to have a colonoscopy and an endoscopy -- not at the same time. I did actually say that to the doctor, "Make sure you clean it before you put it in my mouth". I said to him, "Please don't smile, otherwise we will be having words in the car park". I didn't want him to be enjoying it. I was just trying to be jokey.

They found nothing. They ruled out everything. So they diagnosed me with IBS. But unfortunately, you know, I had been coughing up blood, so I had to have chest x-rays. As a smoker, that was bloody worrying. Actually I was a complete arsehole with the hospital, because I just would not wait for the results. I was ringing them every -- "I want the results. I want

(11) Pages 41 - 44

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them now". It was on the chest x-ray being clear, I actually -- I had just nicked -- I had an injury in the throat and that's where the blood was coming from.

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They also diagnosed me with chronic urticaria, so basically I was just getting covered in hives every time I visited this.

Just to say, Sir Brian, when you announced the Inquiry, the urticaria has gone. Still got the IBS and I've still got the psoriasis, but yes, it was all -- and the doctor actually pulled me into the office. By then my doctor had left and gone to another practice and I was seeing a locum. She actually sat me down. She was actually quite horrible but in a nice way. She said, "We have done so much investigative work. There is nothing wrong with you", and I think it was at that point then that I became --I have still got the IBS. I have still got the psoriasis. The urticaria was still there at that point. I mean that was chronic. It was awful. But I knew I wasn't dying. I think that made me stronger and I was then able to come back to -- because I did step away for a while. I think it was at that point then -- I just remember it was a few weeks into this feeling awful I actually rang up Sue Threakall, breaking down on the phone, and she rang the Hepatitis

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nearly 50, you know. I am not going to live until I'm 100. I would hope that the 40-odd years that I have lived under this -- and I probably won't live another 42 years -- it would be nice to know that I would live more of my life free of -- and yes, that's difficult for me. You know, I have lived so far nearly all my life under this. I would hope that this would end soon and I could have the rest of my life normal, normal, although it will never be normal. It will never be normal. You know, we have got constant reminders every day. We have got 4,763 dads. Every haemophiliac is a reminder. It is the same for all

- Q. You are part of a group, Fatherless Generation.
- A. That's right. Yes, yes. I think we might change the 15 16 name of that as well.
- 17 Q. To what?
- 18 A. To the Fatherless Generations. We believed it was 19 just a generation of children, but we are still adding 20 them now. We have still got children being added to 21 the group. People are still dying. We added 22 a 16-year-old only a few weeks ago -- lost her dad. 23 Yes, it's shocking. Our group is just going to grow.
  - Q. You observe in your statement, Tony, that other than the support or the counselling you have just

C Trust, or it may have been Caxton, and she actually got me the counselling, which actually didn't help, because it's very difficult when you are talking to someone that ain't got a clue what I'm bloody going on about, because they don't know, and I actually felt that although it didn't help with what I'd been through, it just made me more determined to keep going, you know, to keep fighting and to stick with it. Because at that point I had pulled away. I couldn't cope with it anymore.

Q. You said in your statement:

"It is worse for me now than it was when I was a child, because I understand more now. At the moment I am not sure if this has ruined my life or defined it."

16 A. That's right, yes. How much longer is it -- I have 17 spent more of my life -- although I was not aware of 18 what was going on as a child, what happened to me as 19 a child and subsequently all the years -- yes, we were 20 quiet, we were not active, but yes, it was still 21 there, and other family members were dying.

> I have actually spent more of my life -- I'm nearly 50 -- you know, this has been going on since I was probably 6 years old. I would like to hope that we could conclude this and that I will spend -- I am

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1 identified which was actually organised with the 2 assistance of Sue Threakall, you were never --3 A. Yes. Do you know what, that's really funny, actually, 4 because I was hearing Sue the other day and I felt so

5 bad, because when she went to get it, it was gone. We 6 had used all the money up. I felt really guilty, 7 because she done that for me and I know many others, 8 and then when she came to her time, the money was 9

10 Q. The point you make in your statement is that at the 11 time you were going through this all during your 12 childhood and young adulthood you were never offered 13 any counselling or support, even though social 14 services were heavily involved in your life.

15 A. Yes, there was nothing, absolutely nothing. That's 16 not taking anything away from where I was in that 17 children's home. They were lovely, you know, but they 18 weren't qualified to deal with it. And it was 19 emerging, as well. You know, it was emerging. Yes, 20 not a lot was known, as in there was no support, yes.

Q. I just wanted to ask you about your experiences in relation to the financial support schemes and trusts, and again without going into any questions --

24 A. Yes.

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Q. -- relating to family disagreements about those

gone.

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48 (12) Pages 45 - 48 1 matters.

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Your experience has been that as the child of someone whose father was infected and who died, there is and was very little by way of financial support.

A. I will actually correct you on that. There's nothing. There is nothing. Very little doesn't even come into it. The children are completely -- I mean, bearing in mind my father died before the trusts were even set up, and they have never recognised that before these trusts were set up, people were dying.

I know there is support through the -- for the victim, that that victim is allowed, if the children are under the age of dependency that there is a -that there is an amount of money that is paid for your children, but unfortunately by the time the trust was set up, I was an adult. So, yes, we pretty much went through those last four years of our teens, there was no support, there was nothing, and it's never been recognised either.

- Q. If we just have up on screen, please, 1218013, page 10 -- and, again, this is not about whether things should have been done differently at a family level.
- 24 A. Yes, yes, yes.
- 25 Q. But this is about what was done by the MacFarlane

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1 a similar magnitude referred to later.

- A. This was the special category mechanism payment that was set up and run by the Haemophilia Society. 1988 I think it was set up. The government put I believe £10 million into like an emergency fund. "All these people are dying, we had better". So it was £20,000 and I believe this was just for HIV victims at the time, yes.
- Q. Again, I am not going to ask you about the detail of the sums involved.
- 11 A. Yes.
- 12 Q. But the point you have made as a point of principle in 13 your statements is you think that the children of 14 those who were infected, your Fatherless Generation, 15 were overlooked and forgotten and let down by the 16 trusts.
- 17 A. Yes, definitely, yes.
- 18 Q. Can I then ask you just a little about your uncles.
- 19 A. Yes.
- 20 Q. I would like to have back on screen, please, the photo 21 and I think it is 015. Sorry. We will put that one 22 back in a minute, the picture of your dad. It must be 23 1218016 then, please. There we are. The picture of 24 your uncles. David is going to say a little about 25 them and we have the statements from their family

Special Payments Trust --

2 A. Sorry, can I just ask you where you got this, because 3 I lost it.

- 4 Q. You gave it to us.
- 5 A. Did I?
- 6 Q. Yes.
- 7 A. Oh, that's probably why I lost it. I thought I had 8
- 9 Q. It is very kindly exhibited to your second witness 10 statement, Tony.
- 11 A. Ah, right, right.
- 12 Q. You will see there it is a letter dated 10 May 1990 13 from the MacFarlane Special Payments Trust, addressed 14 to you.
- 15 A. That's right.
- 16 Q. It talks about the making of an ex gratia payment of 17 £20,000 to your father. Then there was a discretion 18 given to the trustees of the trust as to how the money 19 should be allocated. We can see from this they 20 decided that the main beneficiary should be your 21 father's widow and that you and your brothers would 22 get £1,000 each.
- 23 A. That's correct.
- 24 Q. Again, your statement and your brother's statement 25 deals with the amounts of some very -- amounts of

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A. My knowledge on who they actually were is obviously as I was a child growing up with these people.

So this picture was Merchant Navy. I think they left the Merchant Navy. My Uncle Dave went to London Underground and my Uncle Vickie stayed within the dock system. I don't know where the docks would have been. Canning Town? Yes, Canning Town. Vickie stayed with the docks and I don't remember the dates, but there was a severe accident with Vickie, and again I don't know the full details of it. It was before I was born. But I believe it was some time in the 1960s. 1966. I don't know whether there was a storm. They were in port. Whether it was a storm, rough, the boat was rocking, I don't know, but one of the metal doors of the ship flew open and -- oh, it was the hatch, and basically his head was in a real mess, mild haemophiliac. Again, my knowledge is patchy, and I will keep looking over there.

So as far as I know he was packed in ice. He was packed in ice. He was in hospital for many, many, many months. I have also been told that there were medical reports in magazines all over the world about this haemophiliac that had survived this horrific head injury. He was a mild haemophiliac. He survived it.

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(13) Pages 49 - 52

1		He had to learn to read, write, walk, talk, because	1		die and I weren't going to go through that".
2		all that function had been wiped out, but he learned	2	Q.	David was diagnosed with hepatitis C.
3		and he survived that, only to be	3	Α.	24th December, Christmas Eve.
4	Q.	He was infected with HIV and hepatitis C.	4	Q.	Your aunt's statement says that none of her three
5	A.	That's right, yes, yes.	5		brothers would have taken the treatment if they had
6		My Uncle Dave, he left the merchant navy and	6		been warned of the risk of any possible infections.
7		became foreman of London Underground at St James's	7	Α.	That's right.
8		Place or whatever it's called. Yes. They were	8	Q.	They had led almost normal lives as haemophiliacs.
9		both they all were, you know, they were good	9	A.	They would have rested, they would have iced, they
10		people. They had you know, we all had families.	10		would have taken painkillers.
11		It's been destroyed.	11	Q.	Victor died in August 2002. David died in April 2012.
12		But I know my Uncle Dave suffered. I know he	12	Α.	
13		was scared. He was scared. You know, he had watched	13	Q.	So all three brothers.
14		his younger brother die, he had watched his older	14	A.	So for us it has been and it is still ongoing, you
15		brother die, both from AIDS. I know from speaking to	15		know, we have other family members infected. We have
16		him I was very close to him yes, it did affect	16		been burying our dead for 33/34 years. Yes, it's
17		him.	17		been again, as I was referring to the 4,763 dads
18		Actually he told me a story of when he went for	18		which the children have got, you know, this is
19		testing. I don't know when it was, but he said to me	19		a constant reminder, constant reminder of what
20		that he had already planned his day. He had already	20		happened to my dad again and again and again, and then
21		seen my dad die. He knew that Vickie was infected.	21		with all these people, again and again and again.
22		He went for testing and he said to me he said, "If	22		It's just an assault.
23		I would have been diagnosed HIV", he said, "I would	23	0	Those are my questions, Tony. I am going to ask
24		have just come out of the hospital and jumped in the	24	Q.	Mr Snowden if he has got anything further.
25			24 25		
23		Thames", he said, "Because I just watched my brother	20		Henry, could we have up on screen, please,
		53			54
1		exhibit 12, page 5. Just one matter that Mr Snowden	1		They have lost family as well. I can't read this, so
2		asks me to raise, Tony.	2		Sean is going to read it.
3		This is back in the psychiatric report that we	3	SE	AN: "There's a darkness in my heart that I cannot lay
4		looked at, and the point which Mr Snowden asks me to	4	OL.	to rest.
5		note with you is under the heading of "Prognosis",	5		"Tainted Blood on the conscience of the NHS.
		where it refers to the possibility that your dad will	6		
6			7		"To you they were numbers, secrets locked away. "But for the families who watched them suffer
7		have further problems, it says this too:			
8		"His wife and family will also be in need of	8		each and every day.
9		much support, counselling"	9		"The trauma still lives on.
10	Α.	That never happened.	10		"How can they be at peace when you dare not
11	Q.	But the need for that was identified before your dad	11		speak their names, for the fear it may release.
12	_	died.	12		"You feel you do not have the time nor the
13	Α.	Yes. Yes. It never happened. It never happened.	13		crayons to explain.
14		We've been I don't know, we are the can that has	14		"Well we're here to tell the world, we will not
15		been kicked down the road, aren't we? Yes, there's	15		let them die in vain.
16		been no support, nothing. Matter of fact, I think	16		"My dad was strong in mind and heart but this
17		they wanted us just to disappear.	17		battle he could not win.
18	Q.	I know there is something more you want to say and I	18		"He bravely fought and suffered the hep C that
19		think Sean is going to say on your behalf as well. We	19		you gave him.
20		will just put the picture of your dad back for that	20		"We have seen this pain before as you gave my
21		purpose.	21		uncle just the same.
22	A.	Yes.	22		"Along with numerous HIV of whom we dare not

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speak their names.

serve.

"Hushed if we try to talk, a D notice you'll

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Q. Thank you very much, Henry.

A. So I'd like to start with something that I was sent by

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one of the children. I am not going to name them.

(14) Pages 53 - 56

1		"So we're invisible, without a voice, and our	1	that going red helped us get press for the campaign.
2		stories can't be heard.	2	Through doing the campaign stuff, many of you
3		"But as silent as the sunrise we will stand	3	have become very, very good friends. Also those who
4		together and shine.	4	have lost their fathers to Factor products. I would
5		"For our silent voices will be seen with our	5	like to take a little moment to talk about our group,
6		picket boards and signs.	6	the Fatherless Generation.
7		"I hope our spirit and our courage will mirror	7	Before 2017 only a handful of us knew each
8		their bravery and strength.	8	other, but after the Panorama programme that year,
9		"We will fight for their justice regardless of	9	more and more of us connected, realising that we were
10		our journey's length.	10	not alone. There are now over 120 of us, and that
11		"Their lives were taken so tragically, please	11	number is still growing, who all know the lifelong
12		show us that you care.	12	pain of losing a parent to this scandal. We know what
13		"So we can somehow move forward without this	13	it's like to have to lie about how your parent died,
14		sorrow and despair.	14	what it's like to hear AIDS jokes, what it's like to
15		"Give us justice, give them dignity and give us	15	feel that you cannot tell anybody what happened
16		the answers we deserve.	16	because they'll think you're a lunatic.
17		"Let them know that we have seen this through	17	The children of dead haemophiliacs have been
18		and our voices have been heard."	18	treated appallingly. We have always been excluded
19	Α.	Right. I would like to say something. I would like	19	from ongoing support. Even now, we get nothing. We
20		you all to bear with me.	20	probably avoided making a scene or a fuss over this
21		Before this Inquiry was announced, some of you	21	because we didn't want the government to take away
22		may have known me as the man who paints his face red	22	from the infected.
23		at protests, or "going red", as I call it. I couldn't	23	We see how the government have saved money
24		have done the investigative stuff, it was just too	24	excluding the children. The government created
25		much for me, that others have done, but I was told	25	arguments, watching the infected and widows fighting
		57	20	58
		31		30
1		about scraps over who deserved what. While all this	1	affected, some of us our entire lives. But no matter
2		happened, we sat silently, scared to suggest that we	2	what tweaks they make, we never get anything. It is
3		should be recognised. The dying fears of our fathers	3	the same for the parents who lost children as well.
4		were confirmed.	4	But we must always remember that the worst
5		Many in our group have psychological trauma that	5	affected by this scandal are dead. Schemes will not
6		has ruined their education and left them unable to	6	help the dead. Schemes have been used to play the
7		work or, at best, they have never reached their full	7	haemophilia community against each other, and no
8		potential. We have all lost far more than just our	8	scheme will ever give these people independence.
		parents.	9	We want the government to set up a full
9		,		
10		Some in our group never knew a life before the	10	compensation panel like in Ireland. It is often said
11		Contaminated Blood Scandal. They were born into it	11	by victims and their families that the government will
12		and it is all they have ever known. For them their	12	wait until everybody is dead before paying
13		lives were not just turned upside down one day; they	13	compensation so that it will be cheaper. In the
14		were damaged from the beginning.	14	Republic of Ireland the compensation panel was set up
15		The government has never taken into account the	15	in a way that the compensation provided to a bereaved
16		family turmoil that happened, how our families were	16	family was paid to the infected person as if they were
17		torn apart. People broke up and got divorced. When	17	still alive. The full claim did not die with that
18		the government say they are supporting affected	18	infected person. This was because if this was not the
19		people, what this really means is they are supporting	19	case, then the government would have saved money by
20		the widows. It is as if we don't exist.	20	waiting for so many people to die before doing
21		If your parents divorced before your dad died,	21	something.
22		then there is no widow and the government save money,	22	We don't know yet if compensation will ever be
23		because you are excluded entirely.	23	paid, but if it is, this must be something that
24		The government always talks about infected and	24	happens here too. It might be exceptional in law, but
25		affected, but when they tweak the schemes, we are	25	I think we can all agree that this is an exceptional
		59		60 (15) Pages 57 - 60
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(15) Pages 57 - 60

1 event in the very worst of ways. because it sold off Revlon Healthcare in the mid 1980s 2 I also want to talk about the pharmaceutical 2 after people began to be told about HIV. Revion was 3 3 companies. As well as BPL, some of the pharmaceutical not always just a cosmetics company. Revlon 4 4 companies that sent infected Factor products here are Healthcare's company Armour supplied Factor products 5 Bayer, Baxter and Revlon Healthcare. Unfortunately in 5 to this country which killed people with hepatitis and 6 6 this country the press are too scared to mention the AIDS. It is now time for those companies to at least 7 names of pharma for fear that they will get sued. We 7 acknowledge what happened. They need to stop hiding 8 8 can't name the killers of our parents. People are us from their history. 9 9 told just not to mention the pharmaceutical companies' As guilty as the Department of Health is, at 10 names in interviews, and if they do, the press just 10 least they accept this happened. The same cannot be 11 cut it out. 11 said for companies like Revlon. They cannot get away 12 At the opening hearings last September, the 12 with this anymore. 13 Inquiry said it had asked five pharmaceutical 13 Before I say the next bit, I would like to thank 14 companies for documents, but they did not name those 14 Des and Danny at Collins Solicitors and all of the 15 companies. The government also never names those 15 people that work for Collins. You have been amazing. 16 companies, such as Bayer, Baxter, Revlon Healthcare, 16 You really have. We can't thank you enough for when they speak about this. The silence on this must 17 17 believing in us. But I also it would not thank our end and we must once and for all be able to name our 18 18 counsel, Brian Cummings, and Stephen Snowden. I want 19 parents' killers. 19 to thank them for their Inquiry work but also the 20 On top of the confused press reports that often 20 group legal action which was placed at the court one 21 show bags of blood instead of Factor products, this is 21 week before this Inquiry was announced. 22 22 part of the reason why what has happened to the There is something in one of the group legal 23 haemophilia community is so poorly understood by the 23 action hearings last year that people might not know 24 24 about, and I want to say something about that today. general public. 25 Revlon now distances itself from the scandal 25 A lot of people here, including myself, have a very 61 62 1 low opinion of Kenneth Clarke from when he was Health 1 those who do have the money and the power will. 2 2 Minister, and we want him to give oral evidence. Part We are not on an equal footing with government, 3 of this is that in 1983 Kenneth Clarke said there was 3 health services or pharmaceuticals in this Inquiry. 4 no conclusive evidence that AIDS is transmitted by 4 We need to remember that the government and civil 5 blood products. Obviously this is not true. The term 5 service never wanted this Inquiry. In November 2016, 6 "conclusive evidence" was used by the government a lot 6 Nicola Blackwood, who was the Health Minister, said in 7 7 in the 1980s about AIDS. Last year, at one of the the House of Commons: 8 8 legal action hearings, Justice Martin Spencer said "The Prime Minister has been very clear that we 9 9 that the use of words like "conclusive evidence" is do not believe a public inquiry would provide further 10 somewhat disingenuous if they had evidence on the 10 information." 11 balance of probability that there was such a link. 11 I think we can all agree from the hearings so 12 I think Kenneth Clarke needs to give us answers, 12 far that she was not correct, but we are used to 13 and just for the record, there is no way this man 13 ministers who deny us justice. In 1999, Baroness Hayman said a public inquiry 14 should ever be Prime Minister; he should be in prison. 14 15 15 was not the way forward. In 2000 John Denham said: We are all obviously pleased that this Inquiry 16 16 is happening, but there is an unfairness that puts us "All the information is in the public domain and 17 all at a disadvantage. Pharmaceutical companies have 17 I do not believe that anyone's interests would be 18 billions of dollars. The government have open access 18 served by a public inquiry." 19 to taxpayer money, and the health services. But we 19 In 2001 Lord Hunt of Kings Heath said: 20 have to apply for everything. We are not allowed 20 "There would be nothing to be gained from 21 legal funding for the investigation into this Inquiry, 21 a public inquiry." 22 In 2002, Dr Filkin said: 22 and this seems very unfair. We know that victims in 23 23 the Grenfell Inquiry have had the same problem. "I do not believe that there is benefit to 24 I think this needs to change so that we can 24 anyone from a public inquiry." 25 independently review the Inquiry reports, because 25 In 2003, Lord Warner said:

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(16) Pages 61 - 64

1		The government do not accept that any wrongtui	ı		Another inquity would not be in the best
2		practices were employed and we do not consider that	2		interests of the sufferers and their families as it
3		a public inquiry is justified."	3		would be costly."
4		In 2004, Lord Warner also said:	4		All these ministers denied us the truth. They
5		"Wrongful practices have not been employed. We	5		were all wrong. Thank you.
6		do not believe that this public inquiry is justified."	6	SIF	R BRIAN LANGSTAFF: Can I say I don't think there is
7		In 2006, Caroline Flint said:	7		a single person working in this Inquiry and this
8		"We do not consider a public inquiry is	8		includes me who does not think that the Inquiry is
9		justified."	9		fully justified, whatever the result may be.
10		Sorry, bear with me	10		Secondly, can I say and assure you that so far
11	Q.		11		as the investigation is concerned, we have all the
12	Α.		12		money and resources that we need. That has been
13		me a minute. I seem to be missing thank you.	13		promised to me by Parliament. It is promised under
14		Excuse me for this.	14		the last if you call it the last administration,
15		In 2006 Caroline Flint said:	15		the last Prime Minister, and it has been promised
16		"We do not consider a public inquiry is	16		under the current Prime Minister, and I take
17		justified."	17		government at its word on that and I am busy spending
18		In 2008, Lord Darzi of Denham said:	18		that money in pursuit of what may be the truth.
19		"The government do not accept that any wrongful	19		I won't spare the pennies on that, even though I have
20		practices were employed and therefore a public inquiry	20		an obligation to safeguard the public purse generally.
21		is not justified."	21		Can I turn from that to you and your evidence,
22		In 2012, Anna Soubry said:	22		because it is I think particularly difficult to talk
23		"After all this time there is no justification	23		about the loss of a childhood, the loss of a whole arm
24		for a public inquiry."	24		of the family, as you put it, only to be followed by
25		In 2016, Jane Ellison said:	25		the consequences of your father's death, because the
20		65	20		66
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1		increasing knowledge of what may have happened to him	1	SIF	R BRIAN LANGSTAFF: David, please.
2		has brought its own problems.	2		DAVID JOHN FARRUGIA (sworn)
3		You spoke about wishing to be normal. It is	3		Questions by MS RICHARDS
4		a matter for reflection that in your search for	4	MS	RICHARDS: David, we are going to put up on screen
5		normality, you are here giving evidence in what is not	5		again your dad's photo. 1218015. Thank you.
6		a normal position for anyone to be in, and I think you	6		David, we have just heard from Tony. You are
7		deserve a tribute for that. So thank you.	7		twin brothers. I am not going to go over any of the
8	A.	Sir Brian, I would just like to thank yourself and	8		records or any of the evidence that Tony has given.
9		I would like to thank Jenny especially, and I'd like	9		What I wanted to ask you about, first of all, are your
10		to thank the rest of the Inquiry team. Thank you.	10		memories of your dad becoming ill, first of all with
11		Thank you.	11		hepatitis.
12	SIF	R BRIAN LANGSTAFF: Thank you very much.	12	Α.	Yes. The earliest memory would probably be I'd say
13		R BRIAN LANGSTAFF: We will take a break now for	13		1975, 1976. We was living in Ilford. I just remember
14		20 minutes. Depending on how long David takes we	14		him being yellow, puffy. I believe he spent a few
15		will go on until we finish, and you must not feel	15		days away from the family home in hospital. Obviously
16		under any pressure but depending on how long that	16		I didn't know why, you know, being so young.
17		takes, we may take a late lunch today, so I am telling	17	Q.	I think you had estimated it in your statement as
18		people now in case it alters their eating habits in	18		being 1976 or 1977, but the date doesn't really
19		the next 20 minutes. 11.55.	19		matter. Some time in the late 1970s.
20		(Witness withdrew)	20	Α	Yes, yes.
21	(11	.34 am)	21		Then you have a memory of your dad wanting to watch
22	,.,	(Short break)	22	-4.	a World in Action programme. What can you tell us
23	(12	.02 pm)	23		about that?
24	-	R BRIAN LANGSTAFF: And it's David, is it?	24	Δ	I believe it was obviously before he told me he was
25		RICHARDS: It is.	25		HTLV-III or, you know, he had AIDS. I believe it
		67	20		
		<b>5</b> 1			00 (17) Pages 65 - 68

- would have been early 1985. I remember, being kids,
  we were chopsing, as you do, and he was telling us to
  be quiet so he could watch telly. But, again, we
  didn't connect it, so ...
- Q. It was in September 1985 that your dad told you of his diagnosis. What can you recall?
  - A. Yes. I used to be into athletics, keen runner, used to run for Essex Beagles. I had returned home one night after some track events and he sat me down and said, you know, he was -- I think he may have used the word "AIDS", he may have used the word "HTLV-III". I do remember asking, you know, if he was going to die, and his answer was he didn't know. So ...
- Q. Then you have said in your statement that not long
   after that you began to put things together from media
   reports about AIDS and realised how serious this was.
- A. Yes. As Tony said, it was coming out in the media,
  Rock Hudson and "the gay plague" splashed all over the
  newspapers. I do remember my dad telling me that
  night not to tell anyone. Obviously, you know, I went
  to school the next day and I did tell someone, and
  before the end of the day the whole school knew.
- 23 Q. You said you then got picked on at most lunchtimes.
- 24 A. Yes, most lunchtimes.

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25 Q. People would say your dad was gay, "bent" or he "takes

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ambulance turning up. Two men got out, and it was along the lines of if he didn't get in the ambulance, they would put him in a straitjacket. Obviously my stepmum and my eldest brother Vince and myself was trying to coax him to go to hospital, that they'd make him better, and I think eventually, probably after a couple of hours, we did manage to get him into the hospital and he was admitted then to the mental ward. You know, I think you have already read the statement of when he was admitted about his pens and stuff like that and knife and fork.

- Q. You have recalled in your statement some incidents before that at home, your dad not wanting to leave a customer's house at work because --
- A. Yes, I think that was in the lead-up to it as well.
   Obviously my stepmum had told me about it in years after that, you know, he had gone to a customer's house and insisted her light was broken and stayed there until 1.30 in the morning and there was actually nothing wrong with the light.
- 21 Q. And walking down the street totally naked.
  - A. Yes. I believe that was -- that may have been after he had come back out from the mental ward. I believe my stepmum had gone to Wales for a week for a bit of a break, you know. Times were hard. And I can just

1 it up the arse".

- A. Yes.
- 3 Q. It got to the extent that the bullying was such that
  4 your dad had to have a meeting with the head of year
  5 about it.
- A. I believe he went up to the school and it wasdiscussed, yes.
  - Q. But it got even worse after your dad died.
- 9 **A.** Yes, after he died. Obviously there was another two 10 years of me still being at school, because he had died 11 a couple of weeks into my last two years at school. 12 So when I did return a couple of weeks after he died, 13 it just continued, so ...
- Q. We have looked at the records with Tony of how your
  dad's physical and mental health deteriorated between
  1985 and 1986. You were there when your dad was
  sectioned under the Mental Health Act and taken to
  hospital. What can you recall?
- A. Obviously I can't remember -- I can remember that
   night, but the events leading up to it -- I believe he
   had left hospital and walked home from Whitechapel all
   the way to Dagenham. I think he had stopped at his
   works. There was a meeting there and he wanted to be
   there, and then he came home and I think he sort of
   went downhill from there then. I remember the

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- remember -- I think I was sitting in the living room.

  I heard the front door go and the next minute he was

  walking down the street naked. So I had to run down
  and -- it was almost like I was the adult and he was
  the child.

  Q. You also described him being aggressive, not at you
- Q. You also described him being aggressive, not at youbut --
- 8 A. Yes. I can remember he was -- he had a technical 9 drawing pad. I do believe he was being educated. He 10 had gone to college to, you know, further his career 11 in the gas board. He probably believed that they 12 would find a cure for it and that he'd carry on 13 living. So I think he continued with the studies, but 14 obviously when it all went -- you know, he went 15 mental, basically. He was drawing it on a pad and 16 I remember there was a red circle in the middle, and 17 having researched it, it was known as the red button 18 syndrome. He was explaining to me about pushing it. 19 I didn't understand, you know. I didn't understand.
  - Q. His physical appearance changed.

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A. Yes. He went grey, you know. At 36 years old, his hair was going grey. You know, he had lost a lot of weight. And I know -- the thing I do remember him eating excessively, he ate a jar of pickled onions my nan had made and then was violently sick after. We

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actually took him fishing that day to the Royal Military Canal in Kent. I look back now and have a little laugh. I was trying to teach him how to fish. He was striking them so hard all he had on his rod was a pair of lips. He ripped the fish's lips off. We was trying to get him to -- but, you know, he wasn't right then, so ...

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- **Q.** You didn't see him for the two weeks before he died.
- A. I believe I saw him on the Saturday, without looking at my calendar and going back, I saw him on the Saturday two weeks before he died. Just going off the top of my head, it would have been probably 8th or 9th September, he had come home on the day, and I never saw him again after that.
- Q. After your dad died in September of 1986, whathappened in terms of your living arrangements?
  - A. Well, my relationship with my stepmum had been bad for a long time, you know, probably a good; year.
    I believe a lot of it was probably what was going on at the time, you know. A lot of people's behaviour changed. I made the decision that I didn't want to live there anymore. So my Uncle Dave sat me down and said I had a list of choices. Obviously being with him wasn't one of them, because they were so far away from my school. So that wasn't an issue. I didn't

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- I developed a really bad sore throat and a chest infection. Obviously I was worried about it and my doctor -- I was with my key worker at the time and my doctor had suggested that it was maybe an idea to have an HIV test, and I wouldn't say that the care home made me, but I was a child, and, you know, the way it was put to me it was like it was a good idea. So I eventually did have the HIV test, which obviously I already knew would come back negative. So ...
- Q. The family was then fragmented, and we won't go into any rights or wrongs about that, but Tony was in care in the Luton area. You were in care in the Dagenham area.
- A. Dagenham East, yes.
- Q. Other members of the family were elsewhere, and
   although you had some contact with your twin, it was
   a few years I think before the two of you were back in
   regular communication.
  - A. Yes. When I was living with my aunt, you know, I did use to go up every couple of months. Whether the financial side of that was an issue, I didn't know about that. So I was probably seeing Tony, you know, every three or four months for, you know, maybe one or two days and then I'd come home again. That went on until I was nearly 18, so -- and obviously my other

want to go to Luton, because I knew the relationship with my mum wasn't good with Tony, so that wasn't something that I wanted to do. So I said to him, "Put me into care", so ...

- Q. And you wanted to stay in your school and have at least that continuity to complete your education.
- 7 A. Yes, that was the -- you know, dad had always said, 8 "Do well at school, get a good education". So 9 I thought if I stay where I am, I am not going to be 10 uprooted. I wouldn't have to make new friends and 11 change. The school already knew what was going on. 12 If I was supposed to go to another school, if I talked 13 about it, it would all happen again. So it was easier 14 to stay where I was with people who knew what was 15 going on, so ...
  - Q. An issue arose whilst you were living in care about you having to be tested for HIV.
- A. Yes. I believe when my Uncle Dave approached the care home they asked for an HIV test. He told them to F
  off. He said, you know, "What are you insinuating?
  He is not a haemophiliac, so he's never been treated with product. Are you insinuating that he got it
  sexually?" Anyway, it didn't happen. I didn't have the HIV test.

When I went back to the second children's home.

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- brothers, I never saw them. Paul I never saw until he
  was 16 years old. He was 3 when dad died, and I never
  saw Vince until 2008, so some 22 years after my dad
  had died. It wasn't because there was a falling-out
  between us. We just went separate ways and we got on
  with our lives.

  Q. You then I think did end up in 1989 living for
  - Q. You then I think did end up in 1989 living for a period of time with your birth mother --
- 9 A. Yes, yes.
  - Q. -- because financially you had no support and couldn't live anywhere else.
- 12 A. Yes. It did dawn on me that the care home just wanted 13 to get me out, you know. It was like once you get 14 a job, you go into independent living. I would have 15 been 17 at the time. It was living with two other 16 boys in a three-bed maisonette, and there was a family 17 of social workers that lived downstairs. So we were 18 kept, you know, I would say an eye on. It was usually 19 just to make sure we would come home I think. 20 Normally after three months if you prove that, you 21 know, you could be responsible, they would give you 22 your own key and you could come and go as you pleased, 23 but I was on a YTS scheme at the time. You know, it 24 wasn't a lot of money. It was £29.50 I recall and my 25 rent was £25 a week. So they did reduce it to 12.50

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a week, but, you know, living off £15 when you've got to, you know, eat, clothe yourself and get to work, it just became impossible. So I rung my mum up and said could I live up there and I went up there in the January of '89. I wasn't there long, probably three months. We just didn't get on, you know, and funnily enough I actually went to live with the friend's mum that Tony had gone to live with, and I was there for probably just under a year, and then I met my wife, married, children. So it was, you know, just get on with it really.

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- Q. You say in your statement that up until about 2005 you
   just tried to get on with your life and not think
   about what had happened to your dad.
  - A. We didn't know about all this, you know. We knew that three haemophiliacs in our family had been infected, as we found out as time went on, but we didn't know about anybody else, and it wasn't until probably 1991 when the HIV litigation started that we then found out it was 1243 haemophiliacs, and then it was possibly the mid-'90s, maybe '96/'97, I believe my Uncle Dave told us he was hep C positive, and we then found out that it was 4763 haemophiliacs. So ...

I mean, it wasn't until probably 2029 (sic) when I -- I had kind of heard about the Archer Inquiry.

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the police, so it didn't go any further, but I think I knew then in 2014 that this wasn't about me in the driving sense. I was angry about other things, and I do believe that that was probably the turning point for me. So I packed the driving school in. I wound it down over a few months and then just decided to get out of England. So I moved to Wales.

- Q. What's the job that you found in Wales?
  - A. When I first went there, I was doing a bit of carpentry work with my brother, labouring, but I was struggling with that, because, you know, I had a little bit of a bad back. I went to an agency in Swansea and they said, "Oh, we've got this company here. They're looking for some people to go and do a little bit of night work". When she told me what it was, it was like "no". I didn't tell her why, you know. It was to do with viruses. Then she rung me back up a couple of days later and said they'd got me an interview for the job that I had applied for, but would I mind going down to this place just for a couple of nights just to help them out. I thought, "Well, you know, there can't be any harm in it. I'll go down and see what it's like", and I'm still there. So ...
- Q. It's a company that makes HIV tests --

I was off to the States for my honeymoon and we was watching the telly that morning. I can't remember who. It might have been Haydn. It might have been Gareth. They was on the BBC News and they'd spoken about the Archer Inquiry. I left it there. I went on holiday and then I came back. I don't know why I did it. I just got my laptop out. Why I put in "Tainted Blood" -- probably because I'd heard about it and it was all there. It was only then that I began to find out what really had gone on. So ...

As Tony said, I spent a few years not saying anything, just standing on the sidelines, looking through timelines, and then my dad's medical notes turned up and it all went from there really.

- Q. There came a point after a number of years where you felt you needed a fresh start and you moved to Wales.
- 17 Yes. I had been working as a driving instructor from 18 2002, and I think all this just built up from probably 19 2010 when I started to become actively involved, you 20 know, visiting Parliament, visiting my MP, meeting all 21 these people here, you know, one at a time, sometimes 22 a group of them. It just got too much for me and 23 I kind of got into a bit of a shall we say fight with 24 a member of the public that had pulled out in front of 25 me. So we'd had a -- you know, neither of us went to

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- 1 A. They do various.
- 2 Q. -- and other tests.
- 3 A. We do. We do. Most of the viruses that the 4 haemophiliacs have seen, we make all the tests for 5 them. So ...
- Q. We've heard from Tony that there was no support from
   Social Services or in the form of counselling for him.
   What position did you find yourself in?
- 9 A. The same. You know, it was almost like we were told 10 to get on with it as children. You know, the care 11 home was good. Then looked after me, but I suppose 12 not mentally really. You know, we never really spoke 13 about anything. There was never any contact from any 14 group out there, you know, the Haemophilia Society. 15 You know, it was almost like we'd just been pushed 16 into the long grass, and I believe it was when Tony 17 contacted the Hepatitis through Sue Threakall, he gave 18 me the number and I contacted them. I had some 19 counselling leading up to the Penrose Inquiry. It 20 didn't help. It did for bereavement, but they 21 couldn't answer my of the questions we had, because 22 they didn't know. So ...
  - Q. You have spoken a little in your statement about your Uncle Vickie --

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25 A. Yes.

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Q. -- and your uncle Dave.

A. Yes. Obviously we found out two or three weeks after my dad had died that Uncle Vickie was also HIV positive. You know, it was devastating, you know. We'd lost our dad and now we were going to lose an uncle. You know, over the next 12/13 years I did keep my distance, because I found it hard. I did see him, but it got more difficult and more difficult as you see how frail he was getting. You know, he suffered terribly. So -- and I think the last time I saw him was probably three months before he died. So I couldn't face it.

With my Uncle Dave, well, he'd stepped up, hadn't he? You know, he had almost -- you know, he was like our dad, and I think that was probably what pushed me over the edge in 2012. It took a couple of years, but I think when we lost him, you know, that was the third one. So it was difficult. Again I avoided him, you know, probably for the last 18 months he was alive. So, you know, it has been tough.

Q. In terms of the MacFarlane Trust and other support schemes the observation you've made in your statement is that as the child of someone who had died but who by the time the schemes were set up is just on the cusp of adulthood --

I have learnt the names of as we have gone along. It was just a little extract here that I wanted to make aware to the Inquiry. So I am just going to read it.

Can I name who ...?

Q. Yes, you can.

A. The actual statement I believe is Dr Peter Jones. I will just skip the first little bit, but he goes on to say:

"When I buy fishfingers from Sainsbury's, I know where they have come from, and I know where my honey comes from, but I don't know where blood products come from. I also know that as well as hepatitis B manufacturers knowingly imported blood products that were known to be HIV positive. I also know that within the European Community I have documentary evidence that there has been relabelling of blood products, unknown to the Committee on Safety of Medicines. These things go on whenever you get a product which is being sold for profit and they are bound to happen."

21 MS RICHARDS: Thank you. Sir Brian.

SIR BRIAN LANGSTAFF: Thank you very much. You don't waste words I think, but you have added a lot of colour and support in many ways, although you have a slightly different perspective on what happened,

A. Uh-huh.

Q. -- you received no money in your own right.

A. No, only, you know, what you saw in that letter and there was some -- there was a payment where it was technically like child support, you know. I think the figure was around £632 per year, but we was under the age of 18. There was a Category G payment of £2,000. Obviously at the time that came I was married, I had children and I used the money to put a deposit down on a house. That was it really. You know, there was --I have never gone to them anyway, because we've always been of the belief or we've always had the attitude back from them, "Well, you're an adult now", you know. So I just don't waste my time. There is no point. You know, you're just going to have a door slammed in your face. So ...

Q. Those are the questions I have for you, David. I am going to ask Mr Snowden if there is anything else he would like me to ask. There isn't. I think there is something else that you wanted to say.

A. Yes. Obviously I started looking into things, you
know, ten years ago and I found a document. It was
a PDF document. It was "The History of Haemophilia".
I believe it was written in 1991. Lots of doctors
present. Some I knew the names of. Obviously others

because you've got different memories from your
 brother, and I see your evidence together, as it were,
 as one, even though you've told it separately. Thank
 you very much indeed.

A. Thank you.

## (Witness withdrew)

SIR BRIAN LANGSTAFF: We were thinking of having a late lunch. The uncertain time of the next witnesses to give evidence means I think it is sensible to have it early rather than late. My apologies to anyone who overate at the last break as a result, but the lunch is being set up as I speak. We will take an hour's break, but please no more than an hour, because we have a full afternoon. As I've said, we will be here till we finish and no-one who is giving evidence should feel under any pressure to speed up just because they think it's late and it's Friday. I'm here. We're here. So 1.30 back, please, promptly.

(12.27 pm)

(Lunch break)

21 (1.35 pm)

22 SIR BRIAN LANGSTAFF: How would our next two witnesses

23 wish to be known?

24 MS FRASER BUTLIN: Ros and Juliet.

SIR BRIAN LANGSTAFF: Ros and Juliet, please.

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MS FRASER BUTLIN. You have received blood and blood protects regularly since them.  17 weeks of by your manu, Juliet, and your dad, who is no longer with us.  18 MS COPER: Yes.  19 MS COPER: Yes.  19 MS COPER: Yes.  19 MS COPER: Yes.  19 MS FRASER BUTLIN. You have described Ros as being your prefet baby.  20 MS FRASER BUTLIN: And, Juliet, you have described Ros as being your prefet baby.  30 MS BATTEN: Aboutley.  31 MS FRASER BUTLIN: We have a photo of you as a young cited to be your prefet baby.  32 MS FRASER BUTLIN: We have a photo of you as a young cited to your prefet.  33 MS FRASER BUTLIN: We that after the adoption, you fet:  44 One of the secure you fet twenty strongly that the adoption may support in relation to the adoption process.  33 MS FRASER BUTLIN: We have a photo of you as a young your prefet baby.  34 MS FRASER BUTLIN: We that after the adoption of the adoption may support in relation to the adoption process.  35 MS FRASER BUTLIN: We that after the adoption of the adoption may support in relation to the adoption process.  36 MS FRASER BUTLIN: We that after the adoption of the adoption may support in relation to the adoption and you give the social worker that the regular sort of clinical - clinic nurse would come.  37 MS FRASER BUTLIN: We have a page we didn't ready adoption of the plant of clinical - clinic nurse would come.  38 MS FRASER BUTLIN: We have a deptore of the white week and the plant in touch with the Hearncyphile Society, it was all the plant of the plant of clinical ready white hearn and said. Thave got a beby, I have adopted to her fire week there were never to make any think and the plant of the plant of the clinic with the plant of	1	ROSAMUND MARY COOPER and JULIET RUTH BATTEN (affirmed)	1	just eight months old.
3 MS FRASER BUTLIN: You have received blood and blood possess of the pour man, Juliet, and your dad, who is no longer with us. 5 In SCOOPER: Yes 6 MS FRASER BUTLIN: You have seption of you as a young of MS FRASER BUTLIN: And Juliet, you have described Ros as being your perfect beby. 6 MS FRASER BUTLIN: And Juliet, you have described Ros as being your perfect beby. 7 MS FRASER BUTLIN: But the after the adoption, you fet: 10 MS FRASER BUTLIN: But the after the adoption, you fet: 11 site the cover of a book you have written about Ros. 10 MS FRASER BUTLIN: But the after the adoption, you fet: 11 site the cover of a book you have written about Ros. 11 MS BATTEN: Aboutively that the street he adoption you fet: 11 site the cover of a book you have written about Ros. 12 adoption process. 13 MS BATTEN: Aboutively in relation to the adoption process. 14 regular confort of incined — of limit rurse would come 11 site of the regular confort of incined— of limit rurse would come 14 in touch with the fleening discorder was an own and what, because there was a new baby there. 15 Nobody came. Look Rosamont orund to be clinic. 16 Lidin's how a soull work of path and the work of the path and and the strength in the condition, and when we clid get in the path of the path and and the strength in the condition, and when we clid get in the path of the path and and the strength in the condition, and when we clid get on the regular condition and what, because there was a new baby there. 15 Nobody came. Look Rosamont orund to the clinic. 16 Lidin's how a soull work of plant the bleeding disorder or a child with it. or any family anywhere that any and a short by a short by the path and a bout by and a short by which happened by be in the next nead and burst into the path and and Than by an about him had been added to a short by the work of the writes when short had 20 is a bout by and and an on. Soit was quite is loading. 12 Ms BATTEN: Because Ros. you were diagnosed with a short by an additional process of the path and a short by an adi				
12 weeks od by your num, Juliet, and your dad, who is no hoppy rishty us. 15 MS COOPER: Yes. 16 MS COOPER: Yes. 17 MS PRASER BUTLIN: And, Juliet, you have described Ros as 5 MS COOPER. Yes. 18 being your perfect beby. 19 MS BATTEN: Absolutely. 19 MS BATTEN: Absolutely. 19 MS BATTEN: Absolutely. 10 MS PRASER BUTLIN: But that after the adoption, you fet: 10 story of gits with bedening disorders was not explored adoption process. 10 MS PRASER BUTLIN: But that after the adoption, you fet: 10 story of gits with bedening disorders was not explored adoption process. 10 MS PRASER BUTLIN: The story of gits with bedening disorders was not explored and put of gits explored by those around your sufficiently head or understood by those around your adoption process. 10 MS BATTEN: Absolutely. 10 MS BATTEN: Absolutely. 10 MS BATTEN: That's correct. For many years we didn't really understand the condition, and when we did get in touch with the Neemphilas Society, if was all about boys. All their fleature was no lows and men. 10 MS BATTEN: That's correct. For many years we didn't really understand the condition, and when we did get in touch with the Neemphilas Society, if was all about boys. All their fleature was not bey and men. 10 MS BATTEN: That's correct. For many years we didn't with the papered to be in the next road and but set into an advertise of the process. 10 MS BATTEN: Absolute the process. 10 MS BATTEN: Absolute the process of the process of the process. 10 MS BATTEN: Absolute the process of the pro				
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07	24		24	-
87 88 (22) Pages 85 - 88	25	been sort of thinking for a while. When you look at	25	them having to defrost six bags of this stuff as
		87		88 (22) Pages 85 - 88

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1	opposed to getting two little vials of treatment was	1	sorts of things in a consultation. He may have said,
2	totally different. So I had a sense it was sort of	2	"We will be sending some off". But I don't recall
3	convenience and obviously, "This is the best thing to	3	that, and I think if I had recalled it, it would have
4	move you on to".	4	been in my diary. I would have made a note of it
5	MS FRASER BUTLIN: Juliet, do you recall any advice being	5	possibly.
6	given to you about any risk of infection?	6	MS FRASER BUTLIN: Were you ever specifically asked for
7	MS BATTEN: Absolutely not, no. I just wonder about that	7	your consent for Ros to be part of research work?
8	treatment change. Was it when you were doing your own	8	MS BATTEN: That's a difficult one. You see, it's
9	injections, home treatment?	9	possible because of the Von Willebrand's. We would
10	MS COOPER: Yes, it was, it was around the time I started	10	have loved to have known a lot more about it, and if
11	wanting to home treat, so maybe it was related to	11	that research was into that so if the research
12	that.	12	subject wasn't mentioned, then I guess I didn't know
13	MS FRASER BUTLIN: Before we leave these records, if we	13	what was going on.
14	look at the very last line, there is a reference to	14	MS FRASER BUTLIN: Ros, when you went to university your
15	"Dr Craske's research work not a centre".	15	treatment moved to Huddersfield, and then back again
16	If we go to page 10 of the document, at the top	16	to Manchester at a later stage and then more recently
17	of the page we can see "Unique IDs" and "Sample date",	17	to Birmingham.
18	sample dates taken in March 1985. Again we can see:	18	You discovered that you were infected with
19	"Dr Craske's research work not"	19	hepatitis C. How did you find out that you had been
20	I think it then says "not a Haemophilia Centre".	20	infected?
21	MS COOPER: I would say so, yes.	21	MS COOPER: It was during my first year at university and
22	MS FRASER BUTLIN: Were you either of you aware of being	22	I had been having problems with my ankle, which was
23	part of any research work by Dr Craske?	23	a target joint for some years, and I had had some
24	MS BATTEN: Not by his name. It may have been that the	24	investigations in Manchester and they had said there
25	doctor at Pendlebury, Dr Evans, may have said all	25	wasn't really anything they could do about it.
	89		90
	09		30
4	I think I want to Ct Thomas to got a good of	4	a had warring the gave and having that I conft
1	I think I went to St Thomas' to get a second	1	a bed, wearing the gown and hearing that, I can't
2	opinion. So I came down to St Thomas' and they	2	remember anything else. I can't remember the
2 3	opinion. So I came down to St Thomas' and they investigated it with a view to seeing what was going	2	remember anything else. I can't remember the operation. I can remember trying to get down the
2 3 4	opinion. So I came down to St Thomas' and they investigated it with a view to seeing what was going on. Discovered a bony cyst on the underneath of my	2 3 4	remember anything else. I can't remember the operation. I can remember trying to get down the stairs at St Thomas' when we were trying to go home
2 3 4 5	opinion. So I came down to St Thomas' and they investigated it with a view to seeing what was going on. Discovered a bony cyst on the underneath of my calf bone and said that they could investigate to	2 3 4 5	remember anything else. I can't remember the operation. I can remember trying to get down the stairs at St Thomas' when we were trying to go home with my crutches, and that's kind of it from that.
2 3 4 5 6	opinion. So I came down to St Thomas' and they investigated it with a view to seeing what was going on. Discovered a bony cyst on the underneath of my calf bone and said that they could investigate to remove that, basically, operate and remove that. So	2 3 4 5 6	remember anything else. I can't remember the operation. I can remember trying to get down the stairs at St Thomas' when we were trying to go home with my crutches, and that's kind of it from that.  MS FRASER BUTLIN: Since then you have obtained some
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2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24	opinion. So I came down to St Thomas' and they investigated it with a view to seeing what was going on. Discovered a bony cyst on the underneath of my calf bone and said that they could investigate to remove that, basically, operate and remove that. So I had a couple of sort of pre-emptive appointments where we talked about what we were going to do. Went down for the operation, which was my summer holidays from university. Mum came with me. We went on the train. Got to St Thomas's, and the day of the operation I had sort of got myself gowned up. I had had a chat with the anaesthetist, things like that. Mum disappeared off. She was going to go to Kew, were you, I think?  MS BATTEN: I can't remember.  MS COOPER: And then she was going to come back after the operation, and as I am sat waiting, one of the doctors came to have a chat and talk to me about my hepatitis and what precautions they were going to take. I had no idea what they were talking about at that point.  MS FRASER BUTLIN: You said at that point you were shell-shocked by the information that you had hepatitis C.	2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24	remember anything else. I can't remember the operation. I can remember trying to get down the stairs at St Thomas' when we were trying to go home with my crutches, and that's kind of it from that.  MS FRASER BUTLIN: Since then you have obtained some medical records, and you found document 0343008, please. You found what you believe to be the first blood test result in which hepatitis C was detected dated 9th December 1992. So probably taken during those initial appointments in the workup towards the operation.  A. I think from the notes that's correct, because you can see in the notes what they have requested and hepatitis is one of the tests they have requested. I wouldn't necessarily say that is the first time I was tested for it because what I haven't got is any of my notes from RMCH, Pendlebury Children's Hospital, and I have never been able to get hold of those.  So my feeling is that if they would have tested me for that at St Thomas' and had a positive result, if they had any sort of doubt that I already they obviously thought I already knew about it with the way they dealt with it. They didn't sit me down and say,

1	have had it done. This is the result". I mean, maybe	1	non-B, but we don't know what it is".
2	that's because that didn't happen anyway. But there	2	So when we saw him after the St Thomas',
3		3	obviously I think I can't remember if we had known
	was I think perhaps an assumption on their part that		•
4	it was already in my records and they were sort of	4	about the hep C being around. We certainly knew that
5	reiterating the testing, because that's what you do	5	the AIDS virus was going to be around because the
6	when you go to a new hospital. So I can't say for	6	hospital invited us to go for meetings about it.
7	sure when I was first tested, because I have no	7	I had noted those in my diary. I remember one of them
8	evidence. I have no notes.	8	particularly because we were on holiday in Lancaster.
9	MS FRASER BUTLIN: After your ankle operation you went	9	I went down to Pendlebury, which was only a matter of
10	back to Manchester	10	down the motorway, and went to one of the meetings.
11	MS COOPER: Uh-huh.	11	My husband also went to another one, probably at the
12	MS FRASER BUTLIN: and had an appointment with your	12	hospital. I guess that was the it may have been
13	treating doctor, Dr Evans.	13	the Haemophilia Society or it may have been the
14	MS COOPER: Yes.	14	hospital. I think it was the hospital that organised
15	MS FRASER BUTLIN: Ros, you don't remember much of what	15	those. So when the hep C was there with absolutely
16	you were told, but, Juliet, you do have	16	nothing to say, "Where has this come from? We have no
17	a recollection.	17	idea", all he could tell us on that occasion when we
18	MS BATTEN: Yes. Obviously we wanted to know what this	18	both went was that it was did he say it was
19	was all about. We hadn't heard of the hep C. We had	19	something like a 20-year incubation and it wasn't
20	heard of non-A, non-B, and that had been told us	20	anything to worry about. So we thought, "Okay,
21	I think my memory tells me right it was at the review	21	nothing to worry about", at that time.
22	clinic in Manchester, which is a different hospital,	22	MS FRASER BUTLIN: You have said in your statement that
23	which happened every year. I can almost see myself at	23	you didn't know what hepatitis C was. You didn't
24	the end of the team of people coming back to the	24	think it would have a big impact and everything at
25	doctor and them saying, "Well, there is this non-A,	25	that stage was downplayed with you.
	93		94
	•		•
1	MS COOPER: Uh-huh.	1	your childhood notes other than what was sent to your
2	MS FRASER BUTLIN: Ros, since then you have tried to find	2	GP, which is what we have looked at
3	out when you were tested for hepatitis C and whether	3	MS COOPER: Yes.
4	1992 was really the first time or whether actually	4	MS FRASER BUTLIN: and what you have provided to the
5	there had been earlier tests for non-A, non-B or	5	Inquiry.
6	anything like that, and you have tried to obtain your	6	MS COOPER: Yes. I have the stuff that the UKHCDO has,
7	childhood hospital records. What have you been told	7	which I have no idea on accuracy, and I have obviously
8	about them?	8	the stuff that was corresponded with my GP.
		9	One thing that I have recently discovered in the
9	MS COOPER: We can't remember exactly when, but some years		·
10	ago mum and I decided we would try to get hold of the	10	last week which may or may not be helpful is that
11	notes to see what they did say, to see if there was	11	having been desperately still searching in advance of
12	any sort of useful information in them, I suppose, and	12	this to try to get some information, it looks like
13	mum phoned my specialist nurse, who was still working	13	Manchester City Council archives might hold patient
14	at Pendlebury, who was also a personal friend at that	14	records from the late 1800s, it said, to something
15	point, and said, "Look, we would like to get the	15	like 1990-something. So I intend to follow that up.
16	notes. Do you think that's possible?" You were told,	16	MS BATTEN: Could I just chip in on that?
17	"Yes, that's fine, I will get back to you". What did	17	MS FRASER BUTLIN: Of course.
18	she then say?	18	MS BATTEN: Because I think when she said they had gone
19	MS BATTEN: I can't remember. It was some weeks probably.	19	down a black hole, it sounded very end of the road.
20	I know that when I next spoke to her, probably on the	20	If she had said, "They don't keep records after
21	phone, or maybe at a next appointment, I don't know,	21	a number of years" or "They have been transferred", or
22	she came and she was bothered. She said, "I have had	22	if she had said something else, I guess we would have
23	a really good hunt around for the notes and they have	23	tried to follow that. This black hole is all I see.
24	gone down a black hole".	24	The notes have gone down a black hole.
25	MS FRASER BUTLIN: So you have got nothing in relation to	25	MS COOPER: The sense we got was she was very surprised by
	95		96 (24) Pages 93 - 96
	30		90 (24) Pages 93 - 96

that at the stage. And this was quite an early stage when people weren't necessarily frying to get their robus.  **Memore of the stage				• •
notes:  MS FRASER BUTLIN: For you, when you saw Dr Evans at  MS ATTEN: That's right. I mean, every Christmas it  MS ATTEN: That's right. I mean, every Christmas it  seemed there was a children's party. I remember him  got you are not sure because you don't have your  records in they had known you were infected before  you went to Si Thomas!  MS COOPER: I think that's what! shought, yes, and it's  partly because of how Si Thomas!  MS COOPER: I think that's what! shought, yes, and it's  partly because of how Si Thomas!  MS COOPER: I think that's what! shought, yes, and it's  partly because of how Si Thomas!  MS COOPER: I think that's what! shought, yes, and it's  partly because of how Si Thomas!  MS COOPER: I think that's what! shought, yes, and it's  partly because of how Si Thomas!  MS COOPER: I think that's what! shought, yes, and it's  partly because of how Si Thomas!  MS COOPER: I think that's what! shought, yes, and it's  partly because of how Si Thomas!  MS COOPER: I think that's what! was said or not said in  MS COOPER: I think that's was said or not said in  MS COOPER: I don't know. I can't recall. Sorry.  MS BATTEN: Can I say, all along we definitely trusted all  MS COOPER: I don't know. I can't recall. Sorry.  MS COOPER: Ws. yes  MS FRASER BUTLIN: Rocause you have said in your  MS FRASER Buttlin: Because you have said in your  MS FRASER Buttlin: Ms. yes in the not knowing  about the hepatitis C, the possibility that they know  and diffile lely you, has had a huge impact in terms of  your washing to must have a soft animality and hosted a number of events for  I was	1	that at that stage. And this was quite an early stage	1	MS BATTEN: That's right, yes.
4 MS FRASER BUTLIN: For you when you saw Dr Evans at 5 seemed there was a children's party. I remember him capture in the because you don't have your 6 op 1-you are not sure because you don't have your 6 saying he warned to run this party for his patient's records - is they had known you were infected before 7 because he could see them injoying themselves, not 7 because the ST Thomas's were about it. 10 bring he because he could see them injoying themselves, not 10 party because of how ST Thomas' were about it. 10 bring he because he was also 11 brought it must be on my records. It must be 11 a doctor. They invited the patents to go along for 2 something known about because they assumed I knew 2 something known about because they assumed I knew 2 something known about because they assumed I knew 2 something known about because they assumed I knew 2 something known about because they assumed I knew 2 something known about because they assumed I knew 2 something known about because they assumed I knew 2 something known about because they assumed I knew 3 something known about because they assumed I knew 3 something known about because they assumed I knew 3 something known about because they assumed I knew 3 something known about because they assumed I knew 3 something known about because they assumed I knew 3 something known about because they assumed I knew 3 something known about because they assumed I knew 3 something known about because they assumed I knew 3 something known about because they assumed I knew 3 something known about because they assumed I knew 3 something known about because they assumed I knew 3 something knew 4 something knew	2	when people weren't necessarily trying to get their	2	MS FRASER BUTLIN: at the Pendlebury to bring the
Menchester after your ankide operation, the sense you 6 gg - you are not sure because you don't have your 7 records - is they had known you were infected before 8 you went to Si Thomas? 8 MS COPER: I think hatted thought; yes, and it's 9 there to talk to each other. I think went concor 10 party because of how Si Thomas? 11 Hought it must be on my records. I must be 11 an advantage of how Si Thomas? 12 something known about because they assumed it know. 13 something known about because they assumed it know. 14 the meeting with Dr Evans, there was a sense they had 15 known. 15 WS FRASER BUTLIN: And from what was said or not said in 16 MS COOPER: I don't know. 16 Jahn helped him with the Life helped become marrow 17 MS BATTEN. Can I say, all along we definitely trusted all 18 the doctors all Pendlewur, Malye, thinking about it now, that was when the alam halls began to ring when 19 in which was then the alam halls began to ring when 20 it was played down. Do you feel that? 21 MS COOPER: Yes, yes 22 MS FRASER BUTLIN: Bocases you have said in your 23 statement, Julier, that Dr Evans became a personal 24 friend of the family and hosted a number of events for 25 the families at the Nanchester Royal - 26 same, Julier, that Dr Evans became a personal 27 statement, Julier, that Dr Evans became a personal 28 same, Julier, that Dr Evans became a personal 29 same, Julier, that Dr Evans became a personal 20 statement, Julier, that Dr Evans became a personal 21 statement, Julier, that Dr Evans became a personal 22 statement, Julier, that Dr Evans became a personal 23 ratio of the family and hosted an number of events for 24 most patient of the family and hosted an unaber of events for 25 the families at the Nanchester Royal -  97 some different from the people you 28 same difficial runse specialist, and you went for 29 treatment but you also - they were the people you 29 same difficial runse specialist, and you went for 29 treatment but you also - they were the people you 39 taked to that point. They were the people you 40 sa	3	notes.	3	parents and children together socially.
got — you are not sure because you don't have your for records — is they had known you were infected before 7 because he could see them enjoying themselves, not 8 you went to St Thomas! 8 having needles atuck in them. And the parents were 9 MS COOPER: I think that's what I thought, yes, and it's 9 there to talk to each other. I think we went once or 1 thought it must be on my records. It must be 11 a doctor. They writed the parents to go along for social mitted proteins to be because the year amount of 12 something known about because they assumed knew. 12 social time toggether there. Also, whe was a same they had 14 statistics. He had charge of bone marrow patients as well and he wanted some statistics done, I think, and 16 MS COOPER: I can't know. I can't recall. Sorry. 16 MS EATERS BUTLIN: Can't ag, all along we definitely firsted all 17 swap played down. Do you feel that? 20 will be about the hepatistic C. the possibility that they knew and can't tell you, has had a huge impact in terms of your ability to trust doctors. 18 MS COOPER: Yes, yes. 21 MS FRASER BUTLIN: Because you have said in your statement, Juliet, that Dr. Evans became a personal 23 relationship to sort of somebody who doesn't have familied in the families at the Manchester Royal. 25 most patient but you also — they were the people irright 13 most patient but you also — they were the people irright 13 most patient but you also — they were the people irright 13 most patients contracted hepatitis C from their first restment, Juliet, that Dr. Evans became a personal 23 relationship to sort of somebody who doesn't have fall when the proper irright 13 most patients contracted hepatitis C from their first restment but you also — they were the people irright 13 most patients contracted hepatitis C from their first restment but you also — they were the people irright 13 most patients contracted hepatitis C from their first exposure to concentrate. 18 most patients contracted hepatitis C from their first exposure to hoppolal, it let like an extension	4	MS FRASER BUTLIN: For you, when you saw Dr Evans at	4	MS BATTEN: That's right. I mean, every Christmas it
records - is they had known you were infected before you went to St Thomas',  MS COOPER: I think that's what I thought, yes, and it's  more partly because of how St Thomas' were about it.  Hought it must be on my records. It must be something known about because they assumed I knew.  See something known about because they assumed I knew.  See something known about because they assumed I knew.  The meeting with Dr Evans, there was a sense they had the meeting with Dr Evans, there was a sense they had the meeting with Dr Evans, there was a sense they had the meeting with Dr Evans, there was a sense they had the meeting with Dr Evans, there was a sense they had the meeting with Dr Evans, there was a sense they had the meeting with Dr Evans, there was a sense they had the meeting with Dr Evans, there was a sense they had the washed some statistics done, I think, and John heped him with that. He heped me with the book as well and he wanted some statistics done, I think, and John heped him with that. He heped me with the book as well.  MS COOPER: I don't know. I can't recall. Sorry.  MS BATTEN: Can I say, all along we definitely trusted all the doctors at Pendlebury. Maybe, thinking about it the doctors at Pendlebury. Maybe, thinking about it the doctors at Pendlebury. Maybe thinking about it the doctors at Pendlebury. Maybe thinking about it the splayed down. Do you feel that?  MS COOPER: Yes, I mean, if s kind of a different it was played down. Do you feel that?  MS FRASER BUTLIN: Because you have said in your  S statement, Juliet, that Dr Evans became a personal  MS FRASER Buttlinis: Because you have said in your  S statement, Juliet, that Dr Evans became a personal  S as an experiment, Juliet, that Dr Evans became a personal  S as a series of the family and hosted a number of events for the families at the Nanchester Royal -  S as a series of the family and hosted a number of events for the families at the Nanchester Royal -  S as a series of the family and hosted a number of events for the families at the Nanche	5	Manchester after your ankle operation, the sense you	5	seemed there was a children's party. I remember him
west to St Thomas*  MS COOPER: I think that's what I thought, yes, and it's there to talk to each other. I think we new that ore or the parents were about it.  If bought it must be on my records. It must be the parents were about it.  If hought it must be on my records. It must be the parents be on my records. It must be the parents to go along for social time to because they sew made I have.  See State Status. And from what was said or not said in the meeting with DF Evans, there was a sense they had the meeting with DF Evans, there was a sense they had the meeting with DF Evans, there was a sense they had the meeting with DF Evans, there was a sense they had the meeting with DF Evans, there was a sense they had the meeting with DF Evans, there was a sense they had the meeting with DF Evans, there was a sense they had the meeting with DF Evans, there was a sense they had the meeting with DF Evans, there was a sense they had the meeting with DF Evans, there was a sense they had the meeting with DF Evans, there was a sense they had the meeting with DF Evans, there was a sense they had the meeting with DF Evans, there was a sense they had the meeting with DF Evans, there was a sense they had the meeting with DF Evans for a short period with some bone marrow patients as well and the was availed and the meeting with the DF Evans for a short period with some bone marrow patients as well and the meeting with the DF Evans for a short period with some bone marrow patients as well and the was availed and the meeting with the DF Evans for a short period with the meeting with the DF Evans for a short period with the DF Eva	6	got you are not sure because you don't have your	6	saying he wanted to run this party for his patients
MS COOPER: I think that's what I thought, yes, and it's partly because of how St Thomas' were about it.  If bought it must be on my records. It must be something known about because they assumed I knew.  MS FRASER BUTLIN: And from what was asked or not said in 13 Dr. Evans for a shot period with beone her marrow the meeting with Dr. Evans, there was a sense they had the meeting with Dr. Evans, there was a sense they had the meeting with Dr. Evans, there was a sense they had the meeting with Dr. Evans, there was a sense they had the meeting with Dr. Evans from what was asked or not said in 13 Dr. Evans for a shot period with bene meaning with Dr. Evans, there was a sense they had the meeting with Dr. Evans, there was a sense they had the meeting with Dr. Evans from the meeting with Dr. Evans, there was a sense they had the meeting with Dr. Evans from the meeting with Dr. Evans, there was a sense they had the meeting with Dr. Evans, there was a sense they had the meeting with Dr. Evans, there was a sense they had the meeting with Dr. Evans, there was a sense they had the meeting with Dr. Evans, there was a sense they had the meeting with Dr. Evans the meeting about it as said in the well and the wasted some statistics done, I think, and the wasted some statistics done, I think, and the wasted some statistics done, I think, and well and he wanted some statistics done, I think, and well and he wanted some statistics done, I think, and well and he wanted some statistics done, I think, and well and he wanted some statistics done, I think, and well and he wanted some statistics done, I think, and well and he wanted some statistics done, I think we well and the wanted some statistics done, I think, and well and the wanted some statistics done, I think was well and the wasted and definitely into wasted done in the said was a sall of the pastist of the family and hosted a number of events for your ability to trust doctors.  MS COOPER: Yes. I the analyse and the pastist of the pastist of the pastist of the pastist of the	7	records is they had known you were infected before	7	because he could see them enjoying themselves, not
partly because of how St. Thomas' were about it.  10 twice to his house, he and his wife, she was also a control that the parties of the parties. It must be so my records. It must be so my my must be dependent of the parties	8	you went to St Thomas'.	8	having needles stuck in them. And the parents were
11 I thought it must be on my records. It must be something known about because hey assumed I knew. 12 social time together there. Also, my husband helped something known about because hey assumed I knew. 13 MS FRASER BUTLIN: And from what was as aid or not said in 13 Dr. Evans for a short period with some bone marrow the meeting with Dr. Evans, there was a sense they had the meeting with Dr. Evans, there was a sense they had the meeting with Dr. Evans, there was a sense they had the meeting with Dr. Evans because sense they had the meeting with Dr. Evans, there was a sense they had the meeting with Dr. Evans because you have said in your about the hepatitis C, the possibility that they knew and didn't tell you, has had a huge impact in terms of your ability to furst doctors. 14 MS COOPER: Yes, yes 15 MS COOPER: Yes, Unean, it's kind of a different retainment, Juliet, that Dr. Evans became a personal 23 retainment, Juliet, that Dr. Evans became a personal 23 retainment of the family and hosted a number of events for 24 friend of the family and hosted a number of events for 24 friend of the family and hosted a number of events for 24 friend of the family and hosted a number of events for 24 retainment but you also they were the people you 25 talked to that point. They were the people you 25 talked to that point. They were the people you 25 talked to that point. They were the people you 26 talked to that point. They were the people you 27 treatment but you also they were the people you 28 talked to that point. They were the people you 29 talked to hat point. They were the people you 29 talked to hat point. They were the people you 30 talked to hat point. They were the people you 30 talked to hat point of your point you had an a hospital environment, it didn't eled strange to me 30 talked to hat point. They were the people you 30 talked to hat point. They were the people you 30 talked to hat point. They were the people you 30 talked to hat point. They were the people you 30 talked to hat point. They were the	9	MS COOPER: I think that's what I thought, yes, and it's	9	there to talk to each other. I think we went once or
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the meeting with Dr Evans, there was a sense they had known.  15 MS COOPER: I don't know. I can't recall. Sorry.  16 MS COOPER: I don't know. I can't recall. Sorry.  17 MS BATTEN: Can I say, all along we definitely trusted all the doctors at Pendlebury. Maybe, thinking about it the doctors at Pendlebury. Maybe, thinking about it 18 MS FRASER BUTLIN: Ros, you have said the not knowing now, that was when the alarm bells began to ring when 19 about the hepatitis C, the possibility that they knew it was played down. Do you feel that?  18 MS COOPER: Yes, yes.  20 MS COOPER: Yes, yes.  21 MS COOPER: Yes. I mean, it's kind of a different relationship to sort of somebody who doesn't have striend of the family and hosted a number of events for 24 a medical condition, in terms of we'd grown up with, the families at the Manchester Royal - 25 in our case, the same doctor, and most of my life the 97 98  1 same clinical nurse specialist, and you went for 1 treatment but you also - they were the people you 2 talked to that point. They were the people you 2 talked to hat point. They were the people you 2 talked to hat point. They were the people you 2 talked to hat point. They were the people you 3 talked to hat point. They were the people you 4 have offloaded to. And, yes, if fell the — when 1 was offloaded to. And, yes, if fell the — when 1 was offloaded to. And, yes, if fell the — when 2 have offloaded to. And, yes, if fell the — when 3 hospital environment, if clidn't feel strange to me 3 a sort of 10-year-old or what have you. It just 4 have offloaded to. And, yes, if fell the — when 4 hospital is environment, if clidn't feel strange to me 3 hospital environment, if clidn't feel strange to me 3 hospital environment, if clidn't feel strange to me 3 hospital environment, if clidn't feel strange to me 3 hospital environment, if clidn't feel strange to me 4 hospital environment, if clidn't feel strange to me 5 hospital promption unurse was offlicted.  19 Gut or hospital promption and to feeling like 12 hospital promption unur	12	something known about because they assumed I knew.	12	social time together there. Also, my husband helped
MS COPER: Idon't know. I can't recall. Sorry.  MS BATTEN: Can I say, all along we definitely trusted all the doctors at Pendlebury. Maybe, thinking about it now, that was when the alarm belis began to ring when it was played down. Do you feel that?  MS COPER: Yes, yes. MS COPER: Yes. M	13	MS FRASER BUTLIN: And from what was said or not said in	13	Dr Evans for a short period with some bone marrow
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the doctors at Pendiebury. Maybe, thinking about it the spatial sout the hepatitis C, the possibility that they knew and didn't tell you, has had a huge impact in terms of your ability to trust doctors.  MS COOPER: Yes, yes.  MS COOPER: Yes, wes.  MS COOPER: Yes, wes.  MS COOPER: Yes, wes.  The families at the Manchester Royal 97  98  The same clinical nurse specialist, and you went for the families at the Manchester Royal 97  1 same clinical nurse specialist, and you went for the families at the Manchester Royal 97  98  The same clinical nurse specialist, and you went for the tell the point. They were the people you talked to that point. They were the people I might that was offloaded to. And, yes, if tell tike when they were the people I might that have offloaded to. And, yes, if tell tike when they of the thonesplat, if tell tike and wethers of the tell you were infected.  MS COOPER: Yes.  MS FRASER BUTLIN: That was your understanding then of probably when you were infected.  MS COOPER: Yes.  MS FRASER BUTLIN: That was your understanding then of probably when you were infected.  MS COOPER: Yes.  MS FRASER BUTLIN: That was your understanding then of probably when you were infected.  MS COOPER: Yes.  MS FRASER BUTLIN: That was your understanding then of probably when you were infected.  MS COOPER: Yes.  MS FRASER BUTLIN: That was your understanding then of probably when you were infected.  MS COOPER: Yes.  MS FRASER BUTLIN: That was your understanding then of probably when you were infected.  MS COOPER: Yes.  MS FRASER BUTLIN: That was your understanding then of probably when you were infected.  MS COOPER: Yes.  MS FRASER BUTLIN: That was understanding then of probably when you were inf	15	known.	15	well and he wanted some statistics done, I think, and
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it was played down. Do you feel that?  MS COPER: Yes, yes.  MS COPER: Yes, yes.  MS COPER: Yes, yes.  MS COPER: Yes, yes.  MS COPER: Tyes, yes.  MS COPER: Tyes.  MS CO	19		19	
MS COOPER: Yes, yes.  MS FRASER BUTLIN: Because you have said in your  statement, Juliet, that Dr Evans became a personal  friend of the family and hosted a number of events for  the families at the Manchester Royal  gray  same clinical nurse specialist, and you went for  treatment but you also they were the people you  talked to that point. They were the people you  talked to that point. They were the people might  have offloaded to. And, yes, it felt like when  when a hospital environment, it didn't feel strange to me  as a sort of 10-year-old or what have you. It just  felt normal. That was in part down to the  relationship we had with the doctors and the nurses.  But obviously after finding that out and being  But obviously after finding that out and being  but I remember having a conversation with definity mey never necessarily when, but I remember it was one of the many specialist  definitely make a huge difference, and frust in the  care providers was kind of huge. It was a huge part  of our lives as, I suppose, a disabled person.  Wischest Paul III. Ros, when you were told about the  sent you information from the National Haemophilia  of uniformation from the National Haemophilia  Wischest Pour lives as, I suppose, a disabled person.  Wischest Paul III. Ros, when you were told about the  sent you information from the National Haemophilia  Paul Dabase, and he indicated that the thought it was most likely that the 1982 batch of Factor, that holiday in  Laurion  Wischest Paul III. Ros, when you were told about the  diskely that the 1982 batch of Factor, that holiday in  the basis that epidemiological evidence suggested that  we have necessarily being told the full story, it did  definitely make a huge difference, and frust in the  sent you information from the National Haemophilia  paul set providers was kind of huge. It was a huge part  found a letter from Dr Charles Hay from 2003, when he  sent you information from the National Haemophilia  paul set providers was kind of huge. It was a subge				
MS FRASER BUTLIN: Because you have said in your statement, Juliet, that Dr Evans became a personal friend of the family and hosted a number of events for the families at the Manchester Royal  same clinical nurse specialist, and you went for treatment but you also they were the people you talked to that point. They were the people I might have offloaded to. And, yes, it felt like when have offloaded to. And, yes, it felt like when leave offloaded to. And, yes, it felt like when have offloaded to. And, yes, it felt like an extension of home, because it was so familiar. Even though it was as a sort of 10-year-old or what have you. It just for influent or relationship we had with the doctors and the nurses.  But obviously after finding that out and being but relationship we had with the doctors and the nurses. But to obviously after finding that out and being we were necessarily being told the full story, it did definitely make a huge difference, and trust in the definitely make a huge difference, and trust in the care providers was kind of huge. It was a huge part of our lives as, I suppose, a disabled person.  MS FRASER BUTLIN: Nature the first time anybody had been of the many specialist have were necessarily being told the full story, it did definitely make a huge difference, and trust in the care providers was kind of huge. It was a huge part of our lives as, I suppose, a disabled person.  MS FRASER BUTLIN: Ros, when you were infected.  MS FRASER BUTLIN: Nature the definitely make a huge difference, and trust in the sent you information from the National Haemophilia found a letter from Dr Charles Hay from 2003, when he sent you information from the National Haemophilia found a letter from Dr Charles Hay from 2003, when he sent you information from the National Haemophilia found a letter from Dr Charles Hay from 2003, when he sent you information from the National Haemophilia found a letter from Dr Charles Hay from 2003, when he sent you information from the National Haemophilia found a letter fr			21	
statement, Juliet, that Dr Evans became a personal  4 friend of the family and hosted a number of events for  5 the families at the Manchester Royal  97  8 most patients contracted hepatitis C from their first  2 treatment but you also they were the people you  2 talked to that point. They were the people I might  4 have offloaded to. And, yes, it fell like when  4 have offloaded to. And, yes, it fell like when  5 I went to hospital, it fell like an extension of home,  6 because it was so familiar. Even though it was  6 MS COOPER: That was the first time anybody had been  7 a hospital environment, it didn't feel strange to me  8 as a sort of 10-year-old or what have you. It just  9 I do remember having a conversation with  10 relationship we had with the doctors and the nurses.  11 But obviously after finding that out and being  12 so very unsure of what happend, and not feeling like  13 we were necessarily being told the full story, it did  14 definitely make a huge difference, and trust in the  15 care providers was kind of huge. It was a huge part  16 of our lives as, I suppose, a disabled person.  17 Q. Within the records you obtained from the GP you also  18 found a letter from Dr Chartes Hay from 2003, when he  19 sent you information from the National Haemophilia  19 Database, and he indicated that he thought it was most  10 I was senious, and although you were indected, on  10 SCOPER: Unsure or very quickly realised  11 the dormanian that the 1990 purpose of the indicated that he thought it was most  10 Like the man year of the diagnosis; you were very you were old about the  11 diagnosis, you were very worried about the peature of our lives as, I suppose, a disabled person.  12 I was serious, and although you were told about the  13 diagnosis, you were very worried about the peature of the most positive and probably had it for about 18 years already.  14 MS COPER: Uh-huh.  22 I would probably had it for about 18 years already.  14 MS COPER: Uh-huh.  25 Cope in the with the second you obtain		•		•
friend of the family and hosted a number of events for the families at the Manchester Royal  97  98  1 same clinical nurse specialist, and you went for 1 most patients contracted hepatitis C from their first treatment but you also they were the people you 2 exposure to concentrate.  3 talked to that point. They were the people I might 3 MS COOPER: Yes.  4 have offloaded to And, yes, if felt like when 4 MS FRASER BUTLIN: That was your understanding then of probably when you were infected.  5 I went to hospital, it felt like an extension of home, 5 probably when you were infected.  6 because it was so familiar. Even though it was 6 MS COOPER: That was the first time anybody had been 7 a hospital environment, it didn't feel strange to me 7 specific about it and obviously had the ability to do 8 it because he had access to records I didn't have.  9 felt normal. That was in part down to the 9 I do remember having a conversation with 10 relationship we had with the doctors and the nurses. 10 a nurse, I can't remember where or necessarily when, 11 But obviously after finding that out and being 11 but I remember it was one of the many specialist 12 so very unsure of what happened, and not feeling like 12 haemophilia nurses who said, "You will have had this we were necessarily being told the full story, it did 13 from your very first injection". I took that at the 14 definitely make a huge difference, and trust in the 14 time to mean cryoprecipitate. What that then led me 15 care providers was kind of huge. It was a huge part 15 to think was, "Okay, so every single injection I have 16 of our lives as, I suppose, a disabled person. 16 add, have been pretty much having a dose of hepatitis C".  9 MS FRASER BUTLIN: was how you came to be infected, on 24 Can you tell us something of the emotional the emotional in the basis that epidemiological evidence suggested that 5 impact on you of that diagnosis?		·		
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(25) Pages 97 - 100	20		20	100
		99		(25) Pages 97 - 100

1	MS COOPER: Yes, I did the initial sort of, "Oh, yes, you	1	couldn't say, "Have you got it? Have you not got it?"
2	could have it for 20/30 years with no problem". It	2	But you were looking at everybody going, "Oh, my God.
3	was all very sort of making light of it, kind of	3	These are my mates. I have met them in the last few
4	thing. Then I did start to do the maths, because	4	years. Some of them have got the virus". I hadn't
5	I did realise potentially it was once this person	5	got the virus. That to me was weird, frankly, because
6	said it was in every treatment, well, I have had	6	the amount of treatment I had had was the same as
7	treatment for a long time, for nearly 20 years.	7	these other guys. But that's why I think the
8	That's 20 years. So does that mean tomorrow or the	8	cryoprecipitate was a deliberate decision, because all
9	next day I start getting symptoms of this thing that	9	these other guys who had had the same amount of
10	could potentially give me liver cancer and kill me?	10	treatment as me had HIV. I didn't.
11	I had no idea.	11	Then to go on and develop hepatitis C, it was
12	The other thing I did have was a background of,	12	like not dodging a bullet and then standing in
13	like mum said, the HIV crisis within the bleeding	13	front of another one, but kind of you had a knowledge
14	community. Previous to this I used to go to North	14	of the devastating impact of a virus and here was
15	Wales on adventure holidays with about 28 little boys	15	another one, and we actually knew less about this than
16	that were all bleeders and me, because I thought	16	we did about HIV.
17	I shouldn't miss out, and we used to have a great time	17	MS FRASER BUTLIN: You have said in your statement you had
18	because we were able to do sort of adventure	18	always been a very optimistic person who had overcome
19	activities and there would be nurses there, and the	19	the obstacles of Von Willebrand's. Suddenly it was
20	kids who could inject themselves could do it, and	20	a huge shock and it took away a lot of that
21	that's what made me want to do it because I saw them	21	positivity.
22	and thought, "I need to do this".	22	MS COOPER: Yes, I was kind of thinking about that and
23	I remember one year going, and it was after HIV	23	I don't think that that effect was immediate. I think
24	and it was in the blood. I remember having	24	that took time, because I think initially I did think,
25	conversations with some of the other guys. You	25	"Okay, maybe I will sort of buck the odds and I will
	101		102
	and the Mark and Marilla Early Thomas	4	for 40 months
1	go on a long time and it will be fine". There is	1	for 12 months.
2	an element of denial, "I have not got this, I will get	2	MS COOPER: Uh-huh.
2	an element of denial, "I have not got this, I will get on with my life and forget about it and try to ignore	2 3	MS COOPER: Uh-huh. MS FRASER BUTLIN: And you appeared to have cleared the
2 3 4	an element of denial, "I have not got this, I will get on with my life and forget about it and try to ignore it". But my kind of feeling was: I have been born	2 3 4	MS COOPER: Uh-huh.  MS FRASER BUTLIN: And you appeared to have cleared the infection after three, but then it returned.
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pretty accommodating. So we had a discussion about it. They said, "Okay, explain to us what it is". I said, "It is three injections a week, they have told me it is flu-like symptoms. Might feel a bit rough the day after, probably work the day after that", and they said, "That's fine. Just see how you go. You can always work part time on the days you are feeling okay".

I was really pleased, because at that point I was social secretary for the whole branch in

I was really pleased, because at that point
I was social secretary for the whole branch in
Cheedale. I loved the job, absolutely loved it,
organising events, looking after staff members going
through difficulties, running various committees. And
before I had the interferon, I would probably say
I knew maybe 80% of the staff members by name, because
I had made the effort to learn their names.

So, anyway, I started the interferon with all these great intentions, and within a few weeks I was falling asleep at my desk. I was feeling horrific, and I wasn't having every other day off, I was literally saying, "I am sorry, I just cannot come to work" because of the nature of the hideousness of the treatment.

I went through the 12 months' treatment and I stuck with it, because I had gone PCR negative, and

biopsy in 2001. During the procedure they hit your portal vein.

Juliet, you were woken at 1.30 in the morning and told to get to Birmingham as quickly as you could.

MS BATTEN: Yes. I think that was probably the worst day of my life. We knew that Ros had gone for the biopsy and she had pushed for it. She had always been told not to go for a biopsy. It was very bad doing a biopsy on any haemophiliac or anybody with a bleeding disorder, it was very dangerous. Ros said, "Well, it is my liver and I want to know what the state of it is, and the best way is to have a biopsy". I said, "Yes, you carry on, you go for it, if it will find out something and tell us what your state of health is".

So John and I were at home in bed. The phone rang at 1.30 in the morning and the nurse on the other end said, "Your daughter" -- I can't remember all the words. She was very, very kind. She spoke very slowly. She knew we were half asleep. She said, "Your daughter is in intensive care at the Queen Elizabeth Hospital in Birmingham", and we were then living in [redacted], "she wants you to come down". I thought, "Okay, she's going to die".

So John and I got up. We made a cup of tea. We got into the car. We knew that Adrian was there, we

I was being encouraged by MRI, at this point, to stick with it because of that. Even though they were saying, "Oh, yes, you are having extreme side effects, but what do you want to do?" I was determined I was going to do it because I wanted rid of the virus, basically.

Then after the 12 months, within three months it had come back. I don't think at that stage I was back at work because I wasn't well enough to go back to work. I think maybe -- and it wasn't just a case of, "Oh, I am devastated that it has come back", although obviously I was; it was that I felt like I was still on interferon. I still had the sense that my bones were rotting. I still had the hot and cold sweats. I still had a feeling like I had an iron headband across my head all the time. I couldn't literally move because I felt like I was made out of lead.

So I couldn't go to work, even though I really wanted to, and they were brilliant for the first few months, but they couldn't just hold my job open on the complete unknown of when I was going to get better, so I ended up losing that job.

MS FRASER BUTLIN: You retrained in IT and managed to maintain some work for a period, and we'll come back to that a little bit later. You then had a liver

knew that Adrian had been called as well. We drove down the motorway. It was February. It was dark anyway. It was a dark, black journey, and I still see it as that. There were big black lorries all the way down the motorway. We were discussing Rosamund's funeral. Ros had talked about the possibility she might die because of the bleeding. If she was in a road accident or something, that could very well have happened. She had discussed the hymns she would like for her funeral, and we couldn't remember what they were.

When we got to the hospital, we had difficulty finding our way in, because a lot of the gates were shut. It was about 3 o'clock in the morning by this time. Luckily Adrian had come down to one of the doors. He was wearing a red anorak and we could spot him straight away, and he took us in.

There was Ros in intensive care having -- I don't know -- six pints of blood taken out of her abdomen. But she was confused. She thought, "Oh, it is nice to see you, mum and dad. What are you doing here?" She was confused and very, very poorly.

I stayed at the hospital I don't know how long, but at one point I met with Dr Wilde in the corridor and he was sort of wringing his hands. I can remember

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1 him saying to me, "If anything happens to Ros, I will career at the time and I had actually lost my flat and 2 2 resign. I have done all the right things for her. had to move in with friends. I had done this 3 3 She is not supposed to be in this state", and so on, retraining, which I had paid for myself through 4 4 a career development loan. I had got a job with and that was it. I was just distraught. I had to 5 stop work straightaway. I was supposed to be working 5 a company in IT, because I thought if I did IT, then 6 6 I would be fine, because I could work from home on and I had to keep ringing in and saying, "I can't come 7 to work, I am with Ros". I know she needed me to be 7 a sickbed like this. I had done all that with a view 8 8 there, because Adrian was working. to sort of trying to get my life back. I was then 9 9 But it was just horrible, and all the time having to contemplate another course of interferon, 10 10 thinking she wouldn't have needed all this if she'd pegylated interferon and Ribavirin, because that's 11 not had a bleeding disorder, if she had not been given 11 what the hospital in Birmingham wanted me to do. So 12 hepatitis. So this was all unnecessary. We shouldn't 12 I wasn't prepared to do that unless I was able to 13 13 have had to go through this. assess the state of my liver. 14 MS FRASER BUTLIN: You obviously took a long time to 14 The second thing was that because Ade and I by 15 recover from that, but when you did, the biopsy had 15 that stage had sort of thought about the fact that we 16 shown that your liver was in a good state at that 16 probably wanted a family, I wanted to know how I was, 17 17 point. and that was really the only way of doing it. I am 18 18 MS COOPER: Yes, yes. Do you mind if I just say a bit a bit sort of laugh in the face of danger. I do tend 19 more about the biopsy? It seems like a cavalier 19 to sort of push the barriers of being a bleeder, 20 decision that someone with a severe bleeding disorder 20 because, as many haemophiliacs will probably say, you 21 whose advised against having a biopsy would actually 21 do. You don't accept the limits put on you. You want 22 22 push for a biopsy. Well, the reason I did that was to kind of push against them. 23 because -- two things. 23 So another thing was I had faith in the team at 24 24 Birmingham that they would manage it correctly and First of all, I had had the interferon treatment 25 and it had nearly killed me, and it had taken away my 25 I was on a good sort of clotting factor support. The 109 110 1 issue was when they did the biopsy that they 1 internet". She referred me to somebody but did say in 2 2 ultrasounded my liver, drew a little cross and then the letter, "Ros is very fond of the internet". The 3 stuck the needle in without actually doing it through 3 person who she referred me to to look at this 4 4 a vein or doing it with a scan going on at the same treatment said, "It is not something I have ever come 5 time. They changed their procedures after me. 5 across, but I don't see how it would help". It did, 6 MS FRASER BUTLIN: As you say, there were discussions 6 actually. 7 7 ongoing about further treatment with pegylated MS FRASER BUTLIN: During those discussions before you 8 8 interferon. went on the interferon, what did you tell the doctors 9 MS COOPER: Uh-huh. 9 about your wish to have a family? 10 10 MS FRASER BUTLIN: You had also been looking at other MS COOPER: At that point I kind of pushed back the 11 interferon and pushed it back, because I was trying to 11 options for treatment at this point and you had gone 12 to your GP to discuss them. Since you got your GP 12 sort of establish my career again. I was working in 13 records you found a letter relating to one of those 13 IT and I was actually enjoying it far more than 14 appointments where the GP noted you were very fond of 14 I expected to and doing quite well. We were due to 15 the internet. 15 get married in 2003. I kind of thought, "Okay, well, 16 MS COOPER: I think it might have been a bit later on, 16 thats a good milestone. If I can do the treatment 17 because I think it was after the treatment and I was 17 before we get married, then that potentially could be 18 still really unwell or more unwell, and, yes, I was 18 a really good sort of start to married life". 19 looking at -- you know, desperately looking for 19 We did discuss having a family. It was 20 something that would help me recover from this, 20 something -- for me as an adopted person, for some 21 whatever it was, post-viral fatigue or 21 reason it was incredibly important to have my own 22 22 post-interferon, and yes, I had -- because I was child. I didn't really as a child growing up have any 23 23 ambition. I didn't want to be a nurse. I didn't want trying to sort of run things past the doctor and 24 saying, you know, "Any chance I could get this through 24 to do this. But I did want to be a mum. That was 25 the NHS? It is something I have read about on the 25 something I was very clear on, that I really wanted to

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4	be a mum. Therefore when we were talking about the	1	at night I would be lying in had and feel this eart of
1	be a mum. Therefore, when we were talking about the		at night I would be lying in bed and feel this sort of
2	interferon with the specialist, it was because	2	crawling sensation, then it would be there, and then
3	I wouldn't have done it except for the fact that	3	it would be down there. It was just horrid. There
4	I wanted to be clear of the virus when I got married	4	wasn't anything they could do or give me, but it
5	and then when we started trying for children.	5	started on the treatment, so I put it down to the
6	MS FRASER BUTLIN: And the doctors were aware of that	6	treatment, and it was continuing and continuing.
7	thinking.	7	Another thing I got on the Ribavirin was that
8	MS COOPER: Absolutely. It is not documented, but I am	8	was the first time I experienced anger and depression.
9	100% sure they were.	9	MS FRASER BUTLIN: We will come to the mental health
10	MS FRASER BUTLIN: You underwent treatment with pegylated	10	impacts in just a moment.
11	interferon and Ribavirin.	11	MS COOPER: Oh, yes.
12	MS COOPER: Yes.	12	MS FRASER BUTLIN: But in terms of the physical effects,
13	MS FRASER BUTLIN: And you have cleared the virus.	13	you have had difficulties with chronic fatigue
			•
14	MS COOPER: Yes.	14	syndrome, high blood pressure, insomnia.
15	MS FRASER BUTLIN: But since then you have had a number of	15	MS COOPER: Yes.
16	physical health problems.	16	MS FRASER BUTLIN: Sore throats and inflammation of the
17	MS COOPER: Yes.	17	filters in your kidneys, and a number of other
18	MS FRASER BUTLIN: Can you tell us about them.	18	physical effects.
19	MS COOPER: I kind of got on very good terms with my GP,	19	MS COOPER: Yes. The fatigue has been the worst. I hate
20	because after having the treatment, again it was like	20	the word "fatigue" because a lot of people think, "Oh,
21	the first course of treatment in that I felt like	21	you are tired". I have been in situations where
22	I was still on the interferon, so I was still having	22	I have been hugely anaemic because of my bleeding,
23	huge fatigue problems and feeling dreadful and	23	and that is a level of tiredness. Fatigue that I have
24	something that they diagnosed as formication, which is	24	had is beyond that even. It is a case of you feel
25	a sensation of things crawling on your skin. Mostly	25	like literally somebody else is lying on top of you
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	113		114
1	when you are in bed and you cannot move your head off	1	now and this persists now my worst fear about
2	the pillow or your hand to actually sort of switch the	2	doing this was not actually sitting here and talking;
3	light on. Yes, and it's been that, it's been sort of	3	
	-		it was remembering the stuff I've got written down,
4	widespread pain.	4	because I can have a recipe in front of me, read that
5	I did a lot of going back to my doctor to	5	I need three I don't know three onions, turn
6	basically say, "Surely either the hepatitis has come	6	away and then I have forgotten that it is three
7	back it must have come back", and they would retest	7	onions. So it takes me ten minutes of going backwards
8	me and I am fine, "or the interferon is still there."	8	and forwards and going, "Hang on, what was that? Then
9	"No, it is out of your system within three months." I	9	what do I do with them? Do I chop them or slice them?
10	had been back to followup appointments with the	10	Do I chop them?"
11	hepatology team and that was their line, "It is not	11	It sounds silly, but it is huge to me, because
12	the treatment, you are fine, you have got PCR	12	I did have a good memory. I am probably coming across
13	negative". I felt like I was then going mad because I	13	quite well and quite articulate, but I can assure you
14	was thinking it's all in my head. "What's wrong with	14	that takes a lot of effort, and now it's a case of
15	me? I need to pull myself together, for goodness	15	I can do this, but it will have a huge impact. It
16	sake", you know. It wasn't that simple.	16	might mean that I am actually incapable of coherent
17	MS FRASER BUTLIN: You have had brain fog	17	conversation for a week. And it's a kind of pay-off
18	MS COOPER: Yes.	18	situation. It is not that I can just do things. It
19	MS FRASER BUTLIN: memory issues, difficulties with	19	is weighing up: what have I got to do? What have
	•		
20	concentration.	20	I then got to do? Can I actually do both things? No,
21	MS COOPER: Yes.	21	I can't.
22	MS FRASER BUTLIN: They were through the treatment but	22	MS FRASER BUTLIN: One of the major issues for you has
23	also since then.	23	been the impact on your fertility. You have had two
24	MS COOPER: Yes. I mean, that's why I gave the example of	24	attempts at IVF since finishing the treatment.
25	my work where I knew all these people's names, and	25	MS COOPER: Yes.

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1	MS FRASER BUTLIN: Neither of them worked. You then took	1	bleed that actually required a blood transfusion
2	a break from that treatment because you were just	2	potentially because the cryoprecipitate didn't stop
3	exhausted and unwell.	3	it. That was every month. So after a number of years
4	MS COOPER: Uh-huh.	4	I was put on hormone tablets, which were initially
5	MS FRASER BUTLIN: You were struggling at that stage also	5	with a seven-day break. That didn't work. Then
6	to finance that treatment, because you had to do it	6	a three-day break. That still didn't work. I was
7	privately.	7	still bleeding like a pig. So eventually it was
8	You then wanted to try to conceive using	8	decided when I was in my late teens that I would just
9	a surrogate. We will come back to the funding of that	9	take them continuously and have no periods. Bliss,
10	in a moment. But you have now been told that you are	10	I tell you.
11	infertile.	11	So what I had to do to try to conceive was to
12	MS COOPER: Yes. Basically luckily I have discovered	12	come off the pill. That was hideous, as you might
13	quite recently a little thing I wrote for somebody who	13	imagine, and I won't go into the detail of that, but
14	asked me, as a Von Willebrand, how had my sort of	14	there were issues with the clotting factor levels, and
15	trying to conceive gone, because they were just	15	the idea was that I was going to have clotting factor
16	interested from a bleeding point of view. I wrote	16	injections to try to at least control the level of
17	down what happened, because even though it is one of	17	bleeding. That didn't work and it actually turned out
18	the most significant things in my life, as an example	18	in the end that was due to the fact that my half life
19	of the memory issues, I can't remember the detail.	19	is a lot shorter. It had never been investigated. So
20	But having looked at that, we waited a few years	20	I actually need two injections a day to have any
21	after me having the interferon treatment to get myself	21	chance of controlling that, which was discovered quite
22	feeling like I was actually physically capable of	22	late, later on.
23	trying to conceive. Then what my problem well, one	23	So we're trying to conceive with this sort of
24	of my major problems as a female bleeder is periods.	24	difficulty, shall we say, and it didn't work, and it
25	When I first started to have them, it was a three-week	25	had been some time, so it was a case of, "We can't
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1	carry on like this". So we went for investigations	1	So we had our first go at IVF after all of that
2	and that was when they discovered that I didn't have	2	and went through the drugs up to the point at which
3	and that was when they discovered that I didn't have very many eggs initially. So then we were referred	2 3	and went through the drugs up to the point at which they check to see how many eggs how many follicles
3 4	and that was when they discovered that I didn't have very many eggs initially. So then we were referred for IVF.	2 3 4	and went through the drugs up to the point at which they check to see how many eggs how many follicles you are developing, I think it is, and there were
3 4 5	and that was when they discovered that I didn't have very many eggs initially. So then we were referred for IVF.  What I've discovered looking at my notes was	2 3 4 5	and went through the drugs up to the point at which they check to see how many eggs how many follicles you are developing, I think it is, and there were barely any. So they said, "There is really no point
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3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22	and that was when they discovered that I didn't have very many eggs initially. So then we were referred for IVF.  What I've discovered looking at my notes was that we weren't immediately given sort of approval for IVF, because one of the haemophilia doctors and somebody else it might have been a counsellor we had this session with them, and they basically said, "Well, if you do actually get pregnant, your risk of losing your life because of the bleeding condition during pregnancy or childbirth is 90%". This was horrifying. I mean, yes, I do take risks, but this was horrendous, and obviously Ade, as my partner, would not want that to be the case. He wouldn't want to proceed if that was the case.  So we ended up getting referred to the Royal Free and getting a second opinion. They said, "Actually, with proper management of Ros's condition, we don't think those are the odds at all". They were prepared to take on me and manage any pregnancy and childbirth I had. So we proceeded with the ethics	2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22	and went through the drugs up to the point at which they check to see how many eggs how many follicles you are developing, I think it is, and there were barely any. So they said, "There is really no point us continuing in this because we can't up the drugs at this stage. We have to decide to abandon this one and then you can use your second lot of funding for the second one". So that's what we did.  The actual process that we went through to get to that point was such that we left it for probably four years before we tried the second time, because emotionally and physically it had been so difficult.  The second time when we went through it they changed the drugs in order to try and make my response better, and at the end of that we'd got two embryos, one of which was frozen, one of which was implanted.  I also had an experience while I was in for my egg extraction, I think it was, where one of the nurses came to me after I had had some tests done and said, "Any possibility you might be pregnant?" and I went "Actually, no, no, there isn't, but what are

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1	We had the implantation and I was willing it to	1	MS FRASER BUTLIN: Because of that, you have said if you
2	work and it didn't.	2	had known that there might have been an impact on your
3	MS FRASER BUTLIN: You decided to try and have surrogacy	3	fertility from the interferon treatment if somebody
4	treatment. Unfortunately that was also unsuccessful.	4	had said to you before you had the interferon that
5	But you had also applied to the Caxton Foundation for	5	there might be an impact on your fertility, you
6	the costs of that surrogacy treatment, and that was	6	wouldn't have undergone the treatment at that stage.
7	refused.	7	MS COOPER: I wouldn't. I would definitely not have done
8	MS COOPER: Yes.	8	it, because the whole thing for me was having a child
9	MS FRASER BUTLIN: We have got the letter. 0343012. It	9	of my own, and having gone through the nearly dying
10	is very short and simply says that the committee had	10	liver biopsy and then being told, "Actually, your
11	met and considered your request:	11	liver is in pretty good condition considering you have
12	"After discussing your case the committee felt	12	had hepatitis C for almost 30 years", that kind of led
13	it was unable to determine the charitable need for	13	me to think, "If I have had it for 30 years and this
14	this purpose."	14	is where I am at, I have probably got plenty of time,
15	And declined assistance.	15	actually", and if that's the case, then, you know,
16	MS COOPER: Yes. I remember getting that and it was just	16	could I have opted to wait and had better treatment?
17	horrific, because it felt like I mean, just the	17	I don't know.
18	letter itself is a punch in the gut, because it is so	18	I mean, it is not an easy thing to say I would
19	non-caring. There's no, "We are really sorry about	19	have definitely said no, because I was so desperate to
20	this, we have really looked into it". I had	20	be rid it, but I certainly didn't know of the risks,
21	previously asked for help with the IVF costs and I was	21	and if I had known it would have taken away any
22	just told it wasn't in their remit, but I thought	22	possibility, I would have not done it.
23	I will just try again, because this is unusual, and	23	MS FRASER BUTLIN: The psychological impact of not being
24	again, we are doing this because we are having to do	24	able to have a child has been really significant. As
25	it, so let's try and see if we can get some help.	25	you have said, during your interferon treatment you
20		20	122
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1	also had significant depression. That has been	1	it, which is part of that. It is not happening to me,
2	a feature really ever since the interferon treatment.	2	really. But it's also yes, I kind of keep things
3	MS COOPER: Yes.	3	in.
4	MS FRASER BUTLIN: Do you want to tell us anything more	4	What then happens is that ever since the
5	about the mental health impact on you?	5	interferon and Ribavirin, things will happen that will
6	MS COOPER: Yes. Like I say, I am an upbeat, positive	6	set me off into an absolute fury, and I kind of liken
7	person and that's generally the impression you will	7	it to somebody possessed, because it feels like that.
8	get of me. But when I was a kid I loved acting, and I	8	It feels like I am a possessed person. One of the
9	loved playing a character because it wasn't me, and	9	things that happened while I was on the second lot of
10	the me was sort of this kid who would occasionally	10	treatment was I was making some lunch for us and I was
11	have to come into school on crutches and get called	11	cutting some vegetables and I think I accidentally
12	a cripple, and it wasn't fun. So if I could be	12	caught my finger with the knife, and literally I lost
13	somebody else, then I would be somebody else.	13	it in that sort of nanosecond and went from being
14	So I kind of developed this method of coping,	14	perfectly happy chopping a carrot to wanting to ram
		15	
15	which was to wear a mask and project this sort of		this knife through my hand, and having to physically
16	persona of being okay. And also I am very aware of	16	sort of it was really weird. That was the first
17	the impact my health has on other people, so my mum	17	occasion it happened. It was really strange. But it
18	and my husband and my brother, and it's very difficult	18	was like I could not control this outburst.
19	for them. So the better I can project an image that	19	I know other people have described it and
20	is me being okay, that's great.	20	described how that gets sort of taken out on others.
21	But the impact of that is that I tend to keep	21	For me it's always been very internalised and it's
22	things in. I don't let them out. I have sort of	22	kind of I still get those outbursts now. It's
23	there is an element of being emotionally sort of	23	always related to me doing myself some damage. So if
24	disconnected, and I can talk to you about this stuff	24	I bang into something it might not even be bad
25	and I don't get kind of emotionally sort of wrought by	25	enough to cause a bleed, but the trigger is there.
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I bit the inside of my mouth the other day just talking and it doesn't really hurt that much. It's not going to cause me a massive problem. But that sets me off. It flicks a switch.

It's very rare that anybody will see this apart from Adrian, because he is the only one who I can sort of be like this -- and he will disappear because he can't actually cope with it. He doesn't know what to do and I don't blame him. I am not sure what to do either. But I get -- I will try to describe it to you. It is kind of hard to describe when I am not in that moment. But it is an urge to hurt myself because I've hurt myself. And it's a guilt thing. It is because I have hurt myself, I might need an injection, and I have the injection because I have got this bleeding disorder, but I have the hepatitis C and this anger because I have had the injections, and the injections I have to have because I have injured myself, and I have just fucking injured myself again.

So it's kind of -- I have this -- it's a self-loathing. I basically rant at myself. I say "I am a fucking twat. I am a fucking twat and I hate myself", and I start having an urge to hurt myself. And that's not me. That's not me. It's been like that ever since the treatment. Thank you, mother.

help", and they said, "We have got a counsellor".

Brilliant. Six weeks' counselling. Mostly him going,
"Oh, my god. What happened? Oh, my god. You are
joking me? Oh, my God". So he was really helpful.

He didn't even touch the skin of it, let along get
underneath. Lovely man.

You know, I have been back a few times to the GP. The most recent thing is you have to fill a form in, so I filled a form in. Go online on some website and then after about six months they said, "Oh, yes, we have got a group therapy that you could go to. It is at Evesham" -- which is sort of 20 miles away from me -- "9 o'clock on a Tuesday morning". Well, I can't function until 11 o'clock, so I wasn't going to be able to drive to Evesham.

The other thing with group therapy, while it is wonderful, you are the worst person in the room if you go to group therapy. You have lots of other people with their problems, which are perfectly valid, and then you start talking about what's happened to you. It feels like you are trying to win some sort of worst trauma competition. So it is unfair to other people.

The best form of therapy I think that I have had is probably with people that have been through the same sort of thing.

Emotion coming out. That's good.

MS BATTEN: Have another one.

MS COOPER: Basically it's this -- I turn into this raving loon where I am basically going, "Fuck, fuck" and I call myself all the names under the sun. I usually have some sort of offensive weapon in my hand, it's usually a knife. I have bent the end over of knives from stabbing them into chopping boards because at least that's not my hand. I have bashed myself around the head thinking, "That will cause a head bleed, that is fine". I know at the time I'm doing it, it's not fine and I'm being an idiot and I don't want to cause a head bleed. But it's how it comes out. That then leads to depression, because after that I am "Ahh, why am I such an idiot?"

It is something that nobody sees, but it is there and it is underneath this mask, and the mask has new become welded, so I can't actually get it off and reveal the underneath. So when it comes out, it is terrifying to me. That is why I have kind of sought help over the years to try to deal with it. I have been given antidepressants. That was kind of it.

I had six weeks' counselling at the GP, because some years ago now I went to them and said, "What's the score? I need some emotional, psychological

**MS FRASER BUTLIN:** In 2012 you were able to access some very helpful psychotherapy.

MS COOPER: Yes. At that point I was not in a great place. I happened to be at the QE. I had had conversations with my lovely nurse, Tracy, and with my lovely social worker, but for some reason I had no idea they had access to a psychotherapist. I was literally going, "I don't know what to do, I need to see somebody". They said, "Oh, you know we have got our Ann, our psychotherapist". I had no clue.

So they referred me to Ann, and I had six months with her and that was excellent. She was a lady who was a GP and in her 20s she had lost her sight, so she couldn't be a GP anymore. So she retrained in psychotherapy, counselling, that sort of thing, and had been doing that. So she had some clue of what it had been like to have something taken away, to have your future potential taken away, your career taken away, and that had been extremely useful until she retired six months in.

MS FRASER BUTLIN: There was no further provision through the hospital, and very recently you applied to the EIBSS for funding for counselling or psychological support, and you received a response to your application. It is 0343013. We can see under the

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1	heading "Counselling":	1	to them actually said "I am desperate".
2	"An application for counselling costs can be	2	MS FRASER BUTLIN: If you carry on through the document,
3	considered if support is not available through your GP	3	Henry, to the third page.
4	or local NHS trust, or if you have been on a long	4	MS COOPER: And at that point I was in a position where
5	waiting list for counselling through the NHS but	5	I was thinking, "Do I take myself to the local
6	require treatment more urgently."	6	hospital and try and get myself checked in?" It wasn't
7	Then there were five bullet points of things you	7	all the time, you know, I wasn't feeling like this
8	needed to provide to be able to apply for the money.	8	continuously, but when I was having these rages, I was
9	For you, that was just too much to cope with.	9	feeling that sort of I don't want to say insane,
10	MS COOPER: Yes. Well, I had applied for a few things.	10	but that's how I was feeling. I was feeling like
11	It wasn't just four things for that, it was also three	11	I needed some intervention. I knew if I went along to
12	things for another thing, they can't do this and they	12	the hospital like this they would just go, "You are
13	can't do that. So that whole sort of letter was	13	fine, don't worry about it". But I was desperate for
14	what's the opposite of encouraging? discouraging.	14	help.
15	There you go. It was one of those things where you	15	Q. You say in your e-mail:
16	read it and you think, "Oh, God".	16	"I need some psychological help."
17	I had a person in mind I was going to ask them	17	You had rung the Inquiry helpline. That had not
18	to pay for which I didn't think would be on their	18	helped:
19	register approved by the Professional Standards	19	"I have asked my GP for help and they referred
20	Authority for health and social care because it was	20	to me a website. I have spoken to my haemophilia team
21	somebody abroad. I was going to have Skype sessions.	21	and they could make a mental health referral, but it
22	I thought, "What is the point? What is the point in	22	would be months before I got an appointment.
23	doing all this stuff that in itself was quite a lot of	23	"I am desperate. If I arrange private mental
24	effort?"	24	health support, is that something I can claim for help
25	I don't think you have said my original e-mail	25	with?"
	129		130
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1	MS COOPER: And maybe they would have considered it. It	1	recombinant Von Willebrand factor and being told,
2	wasn't even saying, "Yes, we will do it", it was	2	"Yes, it is coming, it is coming", but because there
3	saying, "If you do this and this and this and this and	3	are not many of us that require a clotting factor with
4	send it all back to us, we will probably think about	4	Von Willebrand's, it is not something that's
5	it at our next meeting". That wasn't really helpful.	5	a priority.
6	MS FRASER BUTLIN: As part of the mental health	6	MS FRASER BUTLIN: In some notes you prepared for today,
7	difficulties you have described, you also said you	7	you talked about having cleared the virus and the
8	deal with constant fear because you still have to have	8	ongoing effect of it. You quoted Kate Atkinson from
9	treatment with blood-based products. Because you have	9	one of her books.
10	Von Willebrand's	10	MS COOPER: Can I stop you?
11	MS COOPER: Yes.	11	MS FRASER BUTLIN: Of course.
12	MS FRASER BUTLIN: you are still using blood products.	12	MS COOPER: That is in my closing statement, if you want
13	MS COOPER: Yes, yes. That has a massive impact on the	13	to wait.
14	management of my condition, because that's up to me,	14	MS FRASER BUTLIN: That's fine. It clearly struck me as
15	you know. I don't tend to treat for more minor	15	much as it had struck you.
16	bleeds. I go through phases where I don't treat at	16	MS COOPER: Yes. Keep them on tenterhooks.
17	all, because I just don't want to put the stuff in me.	17	MS FRASER BUTLIN: You have talked about the difficulty
18	Again, that sort of plays into how I feel. I feel	18	and your struggles in terms of your infertility, but
19	when I am injecting this treatment that I don't know	19	all of this has also had a huge impact on your
20	what I am injecting. How can I be sure that there's	20	relationship with your husband, Ade, particularly your
21	nothing in it? I have already got vCJD hanging over	21	physical relationship with him.
22	me. Every time something sort of happens it makes me	22	MS COOPER: Yes.
23	think, "Is that starting to develop?" Here I am sort	23	MS FRASER BUTLIN: What do you want to say about that?
24	of putting these still blood products into me.	24	MS COOPER: Basically when I found out with the
25	I have been asking since 2010/2011 about	25	hepatitis C it was pre-Ade. It was a time when I was
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a student but I wasn't sexually active at that point. But I was told when I first was diagnosed that it wasn't something that was sexually transmitted. I was told it was transmitted by blood to blood contact. I thought, "Oh, that's okay". Then, of course, I am a bleeder. Well, that's not okay. I bleed all over the place. Then I thought about it, and thought actually, when I have sex, there is often blood involved because of the nature of it. It is common. It happens with Von Willebrand's. That therefore makes it incredibly risky for me. And that is something that has been in my head ever since. I consider myself in a way to be a danger.

In terms of the relationship that Ade and I have in that sense, we have -- I have discussed this with him and I think he doesn't mind me talking about it -- because of other things, like the fact that I have got insomnia, I have pain at night, I thrash about a lot, I have these crawling sensations and pain from arthropathy as well and stuff like that, we don't tend to sleep together in the same bed because that is very disruptive for him and he needs to sleep. He gets up quite early, so by that point I might have actually gone to sleep and he doesn't want to wake me up. So we have separate beds and separate lives in that

get Rossy sorted", to keep the family thing going.

Once or twice it was an ambulance, everything going.

But when the hep C came along -- I suppose again it was an isolating thing. I didn't know. I started to know about adoption and then I started to know about Von Willebrand's, then along came hep C. Oh, my goodness.

I certainly had problems with some of my mental health when our children were small, because our son who was adopted is still lovely and very lively and I am not going to go down that road, but it caused us a lot of stress, me particularly. So there were moments when I needed to go and have a bit of counselling. But latterly, the hep C coming and the amount of campaigning that we did and the amount of meetings we went to and conferences we went to and everything that we heard about hep C was just -- it almost became routine like everything else, but it was just another horrible thing.

These last few years I have found it even more difficult, because, you know, we have had two inquiries. We have got nowhere. We are still floundering around. We are still the lost cause. We are still in isolation. And these last few years my husband developed terminal cancer. I have been caring

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Also, you know, the sex life hasn't been what it should have been. I do put that down -- you know, I can't be intimate. I am sort of inhibited somehow by it. I don't like that. I don't like not being able to relax and enjoy it. If I am trying to have a moment like that with somebody, you don't want to be thinking "Oh" -- I can't control what happens, whether I bleed or not. So it's a fear. It's a sort of inhibition, I suppose.

MS FRASER BUTLIN: Juliet, we have talked a lot about the impact on Ros, but you said in your statement it has also affected you and your own mental and emotional health, in terms of particularly you have talked about the isolation of the adoption, the isolation of the Von Willebrand's and then the isolation of the hepatitis C.

MS BATTEN: Yes. I mean, the hepatitis C, I suppose I could start there, because the Von Willebrand's we just lived a family life. I think I said to you yesterday that when it came to going to Pendlebury with the Von Willebrand's and the bleeds, sometimes it was a major thing, sometimes it was just, "Oh, we will have some tea and then bring your homework and bring something to read and we will go to the hospital and

for him for five years. I eventually did seek out -my GP suggested I should go and have some anxiety
sorting out, a little course I could go on. I said,
"No, no, I am fine, I don't need that". Ros, as usual
has been brilliant, not telling me everything but
keeping it -- sharing stuff, but I am thinking,
"I know she is not well and I know she is having all
this crap".

I eventually did go along on this course.

I went back to my GP last autumn and said, "I think
I could do with this now. I am a full-time carer and
up to here with everything". Like Ros said earlier,
it was a group course and it was lovely and it was
very, very helpful. I remember we went round and what
were we there for. One of the members -- and I am not
criticising her, but I felt the difference. When
I was with this load of stuff, the possible inquiry,
the campaigning, the hep C, John having terminal
cancer, one of them said, "My cat died", and
I thought, "Is that what you are here for? Is that
all?" And there was me with this load of stuff that
sort of got sorted somehow. It didn't get sorted
totally, but I think I'm prone.

So, you know, if this Inquiry -- and I am sure it won't, but if the results of this send us down

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1	another black hole, I shall probably I don't	1	"I can't, I'm too tired, can you find someone?"
2	know I will probably go under again for a short	2	I said, "No, it is fine, I will work something out".
3	while, but I have huge help and support. But yes,	3	So it's been up and down.
4	there have been a lot of difficulties.	4	MS FRASER BUTLIN: Ros, in terms of your career, you have
5	MS FRASER BUTLIN: You have been caring for John for	5	talked about having lost it and feeling that loss very
6	a number of years. He recently died.	6	acutely. That also means Ade, your husband, is
7	MS COOPER: Yes.	7	the sole breadwinner. He was a farmer but had to
8	MS FRASER BUTLIN: But you and Ros have felt very acutely	8	diversify. You have said he is under huge pressure in
9	that Ros hasn't been able to help you in the way	9	terms of his work and in terms of finances.
10	either of you would have liked because she has been	10	MS COOPER: Just going right back to the beginning when we
11	too unwell to do that. So that's just been another	11	first met, he was a farmer. His family are farmers,
12	factor for you.	12	so he was running the family farm. He wasn't earning
13	MS BATTEN: Yes. When we moved to [redacted] to be near	13	much money. At that point, shortly after I came down
14	Ros and she doesn't remember, but we were always at	14	to live with him, I had got this job in IT and I was
15	home in [redacted] with Paul because we thought he is	15	working up the career ladder, so actually I was the
16	there and he would often come back and need some help.	16	main wage-earner. But then obviously after the
17	Not all the time, but we were there and we have always	17	interferon for the second time, all that changed and
18	been in that situation. When Ros said, "Mum, could	18	I ended up losing that totally. He has had to
19	you come and prop me up for a bit?" I thought, "Yes,	19	diversify. He basically can't farm anymore, because
20	we need to go and do that", so we moved down here to	20	if he was farming, he wouldn't be able to afford to
21	be close. And I was doing some ironing and cleaning	21	pay the bills and that sort of thing.
22	and running around doing things for Ros until John	22	So he is a hard-worker anyway. I was warned off
23	became ill, and then it was more difficult.	23	him by a friend of mine because of how hard he works.
24	She would say, "Oh, I will come and sit with dad	24	Of course I ignored her. But he works himself to the
25	while you go and have a break". Then she would say	25	ground. I know he has put a statement in or is in the
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1	process of putting a statement in. In that he talks	1	telling these people who I don't know what exactly had
2	about the fact that his work is building sports	2	happened to me over the years and all the different
3	pitches, and that can be anywhere in the country, but	3	things that have contributed to where I actually am,
4	he doesn't feel he can do the jobs further away	4	which is not where I want to be by any means, is
5	because he feels he needs to be on hand just in case.	5	horrific, and then having to do it again a year or so
6	He is under enormous pressure. Because of that, he	6	later because my DLA has been changed over to PIP.
7	yes, it creates added sort of tension, I suppose, and	7	When I was first put on DLA I was put on it for
8	added difficulty for us.	8	life because I had a degenerative condition that was
9	MS FRASER BUTLIN: You have been on benefits and you were	9	going to effect my joints. I am not on that anymore.
10	moved over to the PIP.	10	I think it is next year I get reassessed. That's
11	MS COOPER: Uh-huh.	11	going to mess with me, I tell you.
12	MS FRASER BUTLIN: What can you tell us about what	12	MS FRASER BUTLIN: We have looked already at the EIBSS in
13	happened when you were moved over?	13	relation to counselling and Caxton in relation to
14	MS COOPER: I thought it was very interesting what Mark	14	surrogacy, but you have said in your statement there
15	said yesterday about the brown envelope and the	15	have been a number of occasions where you have needed
16	reaction that kind of it felt very familiar to me,	16	help but decided not to apply us because the
17	that, and that does certainly trigger off the same	17	application process feels too intrusive.
18	sort of anger kind of thing. I have had to do an ESA	18	MS COOPER: Definitely. Definitely. I know people have
19	application, which was totally turned down. I then	19	talked about jumping through hoops. It sort of makes
20	had to go to a tribunal. Luckily I had Neil Bateman's	20	it sound almost fun. It is kind of jumping through
21	help. But going to that tribunal was one of the	21	hoops that are on fire while your legs are tied
22	hardest things I have ever had to do. My dad was with	22	together and you are blindfolded. That is kind of how
23	me, actually. It was in the time before my ankle	23	I see it. As somebody else said, it is not a support
24	fusion, so I couldn't even walk. I was wearing a boot	24	mechanism, it is a test mechanism. It is, "Can you
25	all the time. Having to go through the process of	25	actually pass this test and meet these criteria? We
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1	are not going to tell you what the criteria is, but if	1	I cannot make a simple decision to replace a mattress
2	you can perhaps fit into this narrow criteria, we	2	that will actually help with my insomnia that has been
3	might help you".	3	caused by the hepatitis C without (a) getting approval
4	I have had some help, I have to admit. They	4	in a ridiculous way and (b) then having to not
5	paid towards our moving cost when we moved house and	5	actually go out and buy it, because the money is in my
6	a couple of other things, but I avoid them.	6	bank, but let them sort of do that for me. Where is
7	MS FRASER BUTLIN: Those are the questions I have for you,	7	my independence? Where is my right to look after
8	and I know you both want to say something briefly at	8	myself?
9	the end, but before you do so, I am just going to turn	9	MS FRASER BUTLIN: You mentioned vCJD and the uncertainty.
10	to Mr Snowden, who represents you.	10	Have you had any clarity in relation to your position?
11	Mr Snowden has just reminded me of something you	11	MS COOPER: I did get a letter saying I had received
12	mentioned to me yesterday, which was in relation to	12	specific batches. That's also in my UKHCDO notes.
13	the grants and funding, your feelings about having to	13	Having watched that recent television programme that
14	get quotes and the money being paid to the supplier	14	was about vCJD, which was a mistake, that's now
15	rather than to you and how that makes you feel.	15	another fear. I mean, it was always a fear and
16	MS COOPER: Yes. One of the things that is hideous for me	16	whenever I got together with my haemophiliac friends,
17	is the fact that when I was sorry, this is going to	17	we would joke about the fact that our brains were
18	turn into a long story when I was growing up as	18	going and it was the start of CJD. But listening to
19	a person with a disability, hidden or otherwise, what	19	that programme where they're saying potentially that
20	I wanted was my own independence. I was determined	20	can incubate for 20 or 30 years, what does that make
21	I was going to be independent and support myself and	21	my future look like?
22	that's what I did, even with the hepatitis C	22	MS FRASER BUTLIN: In terms of your liver, when was your
23	diagnosis. I get myself a job, I get myself a flat,	23	last liver followup?
24	I support myself.	23 24	MS COOPER: I can't remember. Probably the last time
25	The position I am in now is I cannot do that.	24 25	I requested a fibroscan, because I was worried about
20		25	
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1	it, which I think was probably I don't know	1	were those in authority ordered to destroy evidence?
			Were those in authority ordered to desirely evidence:
2	eight or nine years ago.		
2 3	eight or nine years ago.  MS FRASER BUTLIN: Juliet, I think you had something you	2	If so, shame on you.
3	MS FRASER BUTLIN: Juliet, I think you had something you	2	If so, shame on you.  Two things I found particularly distasteful over
3 4	MS FRASER BUTLIN: Juliet, I think you had something you want to say and then Ros had something to say.	2 3 4	If so, shame on you.  Two things I found particularly distasteful over this time that stick in my head. There are lots, but
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1	I would like to share with you a short poem that	1	me a photograph. It was actually taken by her dad, my
2	I wrote. I haven't got the date, but I guess it must	2	brother Ben, which depicts a derelict millstone. Her
3	have been after that, and I have been doing quite	3	caption was "from millstone to milestone". We must
			·
4	a lot of writing. This was one of the things I found	4	not have our hopes raised, then dashed again. This
5	when I was going through papers:	5	millstone must be removed in our collective next. We
6	"I cried after you voted. I cried and cried.	6	need to reach the milestone that tells us we have
7	You walked through the lobby. It is only a counting	7	arrived at our destination and ending.
8	process. No conscience required. What did you feel?	8	What's in store for Ros, for her future? If
9	Did you just walk through the lobby, be counted, then	9	I feel so much about what has gone on, what can she
10	back to what's next on your desk?	10	possibly be feeling? She has shared a lot with you
11	"I cried after you voted, remembering all the	11	today and I am glad for that, and I managed to leave
12	times I drove my beautiful daughter 12 miles to	12	most of it for her, although I would go on forever.
13	hospital to get her better, 24 miles for each baby	13	I would very much like to thank all the Inquiry
14	tooth as it fell out. They bled and bled. The	14	team as you continue this massive exploration of
15	treatment made her better.	15	people's lives and treatments, as you search for all
16	"I drove the 24 miles when she fell up the back	16	the people and all the documents to help you uncover
17	step and bit her tongue. The treatment made her	17	this dreadful scandal, as described by Lord Winston,
18	better.	18	"the worst treatment disaster in the history of the
19	"I drove her all the countless other times, not	19	NHS". Once more, my sincere thanks to all of you.
20	knowing then what poison was entering her tiny veins.	20	And thanks to all our extended family, close
21	"What did you think as you walked through the	21	friends, lots of them here today. Hello. We couldn't
22	lobby? Not a lot, I guess. No conscience required."	22	have got this far without your support.
23	I have lost the plot now.	23	My most enormous thanks go to Ros. Despite all
24	When my niece, Briony Evans, heard the	24	that she has told you and all that she goes through,
25	announcement of this Inquiry last September, she sent	25	she is always helpful, thoughtful. She is my best
20	145	20	146
	145		140
1	support ever I couldn't be without her particularly	1	anger and passion
1	support ever. I couldn't be without her, particularly	1	anger and passion. "No producers here
2	after John's death recently. There are loads of	2	"No producers here.
2 3	after John's death recently. There are loads of things she helps me with, even if she says she	2	"No producers here. "The cast of thousands self-selected, whittled
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1	death, remortgages the house for income.	1	"This injustice must be recognised, and I, like
2	"Ros, fatigued and aching from her bone-rotting	2	the prompt, sit in the wings, night after night,
3	treatment, waits to find active life again.	3	listening to every word, waiting expectantly for the
4	"[redacted] speaks of stigma suffered by his	4	final curtain, the thunderous applause of justice in
5	family. Cheerfully he continues with [redacted] to	5	recognition of this long-running show."
6	follow up, research any avenue which may open, shed	6	MS COOPER: I am going to do a little quick preamble which
7	new light on this complicated drama.	7	is something I just remembered I had forgotten. It is
8	"Their performances fall on deaf ears. The	8	a recommendation I would quite like you to consider,
9	ever-changing bureaucratic audience in the best paid	9	which you probably already are, to be fair. It is to
10	seats listen, fall asleep, bored by this tangled plot	10	do with the mental health side of things and the fact
11	of anger and emotion, difficulty and hardship.	11	that, as you know, a lot of us have been doing this
12	"The players in their turn rethink, rehearse.	12	an awfully long time and have been through a sort of
13	Soliloquies become entreaties. 'Won't someone listen,	13	very painful rollercoaster ride. I would like to see
14	please? We may be amateurs but is our performance not	14	in the recommendations something about psychological
15	worthy? Does no-one understand?'	15	support almost being mandatory, which is not really
16	"Mousetrap-like, this show runs and runs.	16	on, because we can't force people to do it, but we are
17	"Never a bestseller, the dedicated actors	17	a bunch of people who have dealt with things over the
18	replace those dying as the years roll by in agony.	18	years without support. It is quite difficult for us
19	"Within a waiting audience, a few applaud their	19	in some cases to open up and say we need help, because
20	efforts.	20	we are so used to just putting a brave face on and
21	"The somnolent bureaucrats slowly wake, not	21	getting on with it. But I think it is vital and I
22	altogether ignorant of the facts.	22	think that it is something that really needs to be in
23	"The players wait to hear reaction, hoping for	23	place as soon as possible after the Inquiry or even
24	a final performance of the wrong that can never be	24	earlier than that. It has to be comprehensive and
25	righted.	25	it's got to be qualified people that know what they're
	149		150
1	doing. I think there are some people in this room	1	mere patients.
2	that are looking towards doing that. They maybe don't	2	Truth was twisted, played down and concealed in
3	have the funding to do it, but it is something that is	3	a successful attempt to subjugate the patient, protect
4	vital.	4	the system and promote the consultant. Yes, not in
5	I will be as brief as I can.	5	every case was there corruption, but compliance was
6	I also want to thank everybody who stuck by us	6	rife, and rebellion in the best interests of the
7	and supported us over the last 45 years, many of whom	7	patient and in the name of Hippocratic oath scarce.
8	are here. I would like to thank everyone who has made	8	Another wound was wrought as our blood was being
9	this Inquiry happen. However, I would also like to	9	taken, tested and found to be dirty, and this was kept
10	reinforce how harmful this has been to all those	10	from us. To protect us? Because the risks were
11	infected and affected.	11	unknown and the effects poorly understood? I think
12	The initial damage was done decades ago, when	12	not.
13	decisions were made based on money, power, ego. The	13	We were living as best we could with in many
14	physical damage was done when those priorities were	14	cases a serious genetic bleeding condition. Now that
15	put above human lives, because we were considered to	15	blood, which flowed freely, frequently, could not just
16	have a limited lifespan, because we were, as a patient	16	harm us, but others, and yet we were kept in the dark.
17	group, considered expendable. Whatever it was, the	17	Hazard stickers on our notes, protective measures
18	decision to put safety last and to do harm to those	18	taken at dental appointments, whilst we blithely bled
19	already disadvantaged by their genes was, in my	19	poisonous blood.
20	opinion, akin to the Mengele experiments.	20	The next harm was inflicted in many cases by the
21	Innocently we held our arms out while poisoned	21	method of disclosure, how the devastating news was
22	products were pushed into us by those we trusted.	22	broken, how our already fragile health was managed,
23	With our best interests at heart and a faith in the	23	how the impact to our mental health was planned for
24	doctors, our parents handed us to those doctors in	24	and mitigated.
O.E.	ignorance. Foots doesnod not important anguab for up	O.F.	The final and prelanged abuse that has been

25

ignorance. Facts deemed not important enough for us 151

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The final and prolonged abuse that has been

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inflicted by the Department of Health; the successive saying much but doing nothing administrations; the civil servants wielding their shredders and enforcing silence; the publicly apologetic health ministers showing no sincerity; the supportive MPs toeing the party line whilst espousing our cause. We have been repeatedly injured and discriminated against for the majority of our lives. Where are our human rights?

Then we, the survivors, find ourselves in the period post-infection, post-poison, with no help, little medical advice, no psychological support, still managing our lifelong condition, in itself in some cases life-threatening, becoming aware in horror of our risk to those we love, and of the innocent risk we must have been prior to our finding out. This is where the fatal blow was dealt, to some literally, to others who live on metaphorically. We start to see our friends dying, a vision of our own future manifest before us. Life became a game of Russian Roulette. Would it be me next?

I read a book recently about a fighter pilot in World War II by Kate Atkinson called God in Ruins, and I read this phrase:

"He had been reconciled to death during the war, and then suddenly the war was over, and there was

destiny?

I have not had a future since the day before my ankle operation in 1993. Whenever I had glimpses of a potential future after that, things would obscure them. The interferon, biopsy, infertility, illness. Having any faith that my health will allow me to fulfil any kind of potential is quite hard. It is akin to getting one's hopes up when Lord Archer announced his inquiry, and then having those hopes dashed after his recommendations were ignored, and again when Penrose failed us. The disappointment destroys.

Can I allow myself to feel hope for me, or will it be taken away and will I find that impossible to live with?

Maybe this fear keeps me where I am now. I have learned from experience the world is a dangerous place. I lack any faith in myself. I believe I always let myself down. I have recently learned I may have the power to change those beliefs and fears.

I am working on myself using the emotional freedom technique and Psych K. I hope they help me recover some of my functioning and restore my self-worth, to reinforce the mindset I had as a child

a next day and a next day and a next day. Part of him never adjusted to having a future."

Have I?

We, you and I, are still fighting the war. Not only have I had to reconcile to a death that hasn't come, to the terror of incubating vCJD, to a family that was denied me, but now I have to face up to having a tomorrow, a tomorrow without children and grandchildren, with the diminished health that I have, and the fear of a deteriorating future, but perhaps with a destiny I have yet to discover.

I would like to believe in a tomorrow, a tomorrow that isn't illness, pain, sadness, fighting, fury, isolation, uselessness. If we get the truth, justice and recommendations for a settlement from this Inquiry, would I be able to consider the possibility of a worthwhile future?

I would like to believe my life could have promise and purpose. I'd like to leave a legacy when I'm gone, especially for Ade, my mums and my brother. I am working really hard to envisage a future. I am working really hard to see it as positive -- productive, even. Could my life in limbo be turned into one with purpose? Can I cease to be a victim of my health and instead become the master of my own

that I could overcome everything and that life was worth living.

Mostly I hope that I am able to pursue a meaningful life, contributing to my community, embracing my marriage, feeling a fulfillment I lack, being able to retain some level of independence and self-worth by helping others would have maybe gone through what I have would be my goal. That and writing the sequel to Funny Blood, mum's book.

I was so energised and enthused when I did my training for these techniques earlier this year, but the fatigue, memory loss, lack of confidence and the stresses of dealing with the Inquiry quashed that enthusiasm into a dull throb. Perhaps a positive outcome would enable that throb to become a hum and then a fire in my soul. Perhaps it would go some way to allay my fears of what the future holds. Perhaps I can regain some control over my life, love and destiny.

I owe that to those who don't have that chance, to those who have supported me thus far, but most of all to myself.

**SIR BRIAN LANGSTAFF:** I have a couple of questions, but they are both for Juliet.

MS BATTEN: Okay.

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4	OID DDIAN LANCOTAGE. The fact is accompanied a discussion	4	
1	SIR BRIAN LANGSTAFF: The first is you mentioned a diary	1	did try to start to get a women's group going and did
2	in the course of your evidence right at the beginning.	2	get one going for a while. We wanted to tell the
3	Secondly and it is linked you wrote a very	3	world women bleeders existed because of the background
4	detailed book, and can I thank you publicly for having	4	of the haemophilia, boys, men, boys, men. Suddenly
5	sent me a copy of it to read.	5	there is a girl there. The girl went on an adventure
6	MS BATTEN: Thank you.	6	holiday with the boys. That is why she is always been
7	SIR BRIAN LANGSTAFF: I mention that as well so everyone	7	one of the boys.
8	knows this is material I have had and will consider.	8	So that was that particular reason. I left it
9	What in particular did you wish to achieve by	9	that we got as far as Ros and Ade getting married and
10	writing the book?	10	then Ros is writing the sequel.
11	MS BATTEN: For the book I wished to achieve more	11	SIR BRIAN LANGSTAFF: The link between the diary and the
12	knowledge of women bleeders. That's it in a nutshell.	12	book is this: is there anything which is recorded in
13	In the early days, I think, as Ros grew up	13	the diary which is not reflected in the book?
14	I realised we wanted we wrote articles for the	14	MS BATTEN: Oh, crikey.
15	haemophilia magazines sometimes. I remember going to	15	SIR BRIAN LANGSTAFF: Just generally.
16	our neighbour's garden for somebody to take a photo of	16	MS BATTEN: Well, let me just say that when John and
17	us because I had written an article about the Von	17	I were first married we married 50 years ago we
18	Willebrand's and they wanted a picture, and we were	18	moved house in 1970 to our new home, where we were
19	all in dreadful clothes and we look awful, and we have	19	going to have a family. For some unknown reason
20	ever since been in this copy of the bulletin for the	20	I started to write a diary. So when it came to
21	Haemophilia Society. Oh, there is that awful photo of	21	writing the book, I was able to refer to it. It took
22	us.	22	me hours and hours to go through every entry, and
23	But I think the idea was we would get the Von	23	I marked them all and I have been going through them
24	Willebrand's known more and we would find more, and	24	
2 <del>4</del> 25		2 <del>4</del> 25	again before this Inquiry. So that was the link.
25	although we didn't know very many women bleeders, we	25	I also kept and I can show you the document,
	157		158
1	the actual decument. For some unknown reason, why	1	hit as much as the words that are used. I think you
	the actual document. For some unknown reason why		bit as much as the words that are used. I think you
2	did I keep a diary not a diary, a notebook with the	2	demonstrated that again by showing us when you were
3	visits to the hospital? Which every time we went to	3	describing your trigger points what it can be like,
4	the hospital, I wrote it in this little notebook, and	4	just giving a bit of a glimpse of the Jekyll and Hyde
5	it stops in 1987, I think. Sorry about the rustling.	5	life you have. It is very brave of you to put
6	This is the original book with the names of all the	6	yourself in that position. Thank you very much.
7	cryoprecipitate dates highlight. So I must be	7	(Witnesses withdrew)
8	a diary-keeper I think.	8	SIR BRIAN LANGSTAFF: We'll take a break until 3.35. Can
9	MS COOPER: Is there anything that's not in the book?	9	we start promptly then, please? 3.35.
10	MS BATTEN: I don't think so, no.	10	MS FRASER BUTLIN: There will be no live stream, for those
11	SIR BRIAN LANGSTAFF: Diaries such as that can have	11	who are online, for the next witness, but there will
12	immense value. I shall say no more about it at the	12	be for the final witness.
13	moment. I will speak to you separately about that,	13	(3.16 pm)
14	perhaps, or someone will.	14	(Short break)
15	Can I not only thank you for sending the book,	15	(3.43 pm)
16	but thank you both for the strength which you have	16	SIR BRIAN LANGSTAFF: Now, our next witness, as you know,
17	displayed, I think in both cases a bedrock of quiet	17	is anonymous. She is witness W0407 and will be known
18	strength, demonstrated when you said to your daughter,	18	as Mrs AO. The order in her case reads as follows.
19	"You go for it" re the biopsy, which it is exactly	19	The name and address of witness W0407, the name
20	what she was going to do anyway.	20	of her late husband and the name of any other member
21	MS COOPER: And which was exactly what she didn't want me	21	of the witness's family and any other identifying
22	to do.	22	information, such as the witness's image or
23	SIR BRIAN LANGSTAFF: There you are.	23	a description of their appearance, cannot be disclosed
23 24	I think I said earlier this week that sometimes	23 24	
		24 25	or published in any form unless express permission is
25	it is the way something is said that can convey every	20	given by the Chair of the Inquiry, me, or by the
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Solicitor to the Inquiry on my behalf. Witness 0407 must be referred to only as Mrs AO.

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

Identifying information in this case, may I remind you, might extend to very young members of the general family. So be careful, please.

Mrs AO.

## MRS AO (affirmed) Questions by MS RICHARDS

MS RICHARDS: Sir, I should say we have turned off the live stream so that if the witness wants to use her husband's name when talking about him, she can do so without it being broadcast publicly. Obviously it is covered by the restriction order, so anyone in this room who hears any family names cannot disclose it beyond these walls.

You are here to talk about your late husband and you have described him in your statement as the love of your life.

24 A. Yes.

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Q. You got engaged, I think, only two weeks after you had

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- Q. But in 1980 your husband became ill. What kind of symptoms did he begin to experience?
- A. He started to have hot sweats at night. I have never known it when his side of the bed would actually be so wet we had to change the bed. Never seen -- you talk about -- we talk about being hot at night and sweating in the summer, but the sweats that my husband endured were horrendous.

He then developed something in his eye. He was working. They had a [redacted], which he went away from where we live in a different town. He went to an optician in this small town and they said it's not an optical issue, it is medical. He was sent up to our local hospital. Eventually he had a knock on the door. My local GP was at home and came to tell my husband that he had leukaemia.

- Q. He had AML, acute myeloid leukemia, diagnosed in December 1980.
- A. Yes. We were drip fed for a long time, because he was quite ill at that time, that it would be like treating diabetes. He would have a tablet and, you know, we could live with this for numerous number of years. He did become better, because by that time we had just moved house. My daughter, {redacted] before my husband was diagnosed as what was classified as missed

met.

- A. Yes.
- 3 Q. And you married six months later.
- 4 A. Yes.
- 5 **Q.** That was in 1974.
- 6 A. Yes.
- 7 Q. What was he like?

8 A. What was he like? Well, as I said, the love of my
9 life. Outgoing -- well, we were just a very good
10 couple. We truly believed in -- we were together for
11 four years before we had my son. We had the same
12 aspirations what we wanted for the future and --

13 sorry.

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- 14 Q. It's all right.
- 15 A. We never argued. The only time there was anything 16 that happened between us was when he became ill and he 17 actually flicked a tea towel at me in the frustrations 18 of the illness that he had before it was fully 19 diagnosed, and that was the only thing ever in that 20 time. He was just wonderful. Very hardworking. He 21 worked long hours. There was a family business, which 22 is he was part of. You know, we just -- we had a very
- 24 Q. You had two children, a son and daughter.

good future planned.

25 A. Two children, yes.

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cot death was disabled as a result. We had just moved house and thankfully that also helped him. It gave him something to focus on. We had a lot to do to this house to bring it up to standard and modernise it and it kept his mind on other things.

But as time went on, it became obvious that the only -- it was ironic that the pathologist who dealt with my husband at the local hospital lived two doors up the road. When my husband was very ill I went up and knocked on the door and asked him questions, and he said, "You've got probably five years max". And I had not heard that before. So a transplant --

- 13 Q. A bone marrow transplant.
- A. A bone marrow transplant was technically the only option, yes.
- Q. He had an enlarged spleen which led to surgery in
   September 1982. In November of 1982, he was admitted
   to the Hammersmith Hospital for the bone marrow
   transplant.
- A. We were told that -- well, when my GP came, he was
  gobsmacked that he hadn't picked up the size of my
  husband's spleen when he examined him. Because he had
  been fit and his stomach muscles were so tight, they
  couldn't feel the spleen. But it was part of the
  transplant that he had to have a splenectomy to make

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- 1 the transplant take better. That was what we were 2 told at the time.
  - Q. The bone marrow transplant was undertaken. Your husband was nursed for a significant period of time in isolation in a sterile environment in the hospital.
- 6 A. Yes.

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- Q. He was regularly given platelets through a Hickman line, you recall.
- 9 A. Yes.
- 10 Q. Over the following months he would come home 11 occasionally, but he seemed to be very susceptible to 12 infections.
- 13 A. Yes. I even was allowed to give him his platelets, 14 because during that time in hospital when he was in 15 isolation he could only have two visitors a day. They 16 could stay all day but of course we all had to gown up and go through all that because he had no immunity to 17 18 anything.

The platelets he was given all the time. Once they deemed that the marrow had started to function. then he was sent home. He was definitely home for Christmas, as I have shown you photos of what he looked like at that time, yes, but he did. Because you tend to worry -- my children were very young. Then they would have been like 2 and 4, so they would

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1 pneumonia and was on life support.

- 2 A. Yes.
  - Q. There was one day in June you went to visit him and you returned home, and then there was a phone call.
  - A. Yes. It was very hard, because I used to -- being a mother of two young kids and trying to keep normality for these as well, going up there, and I used to go up most days a week, but this particular day things weren't looking good. Ironically my husband had gone past the six months stage following the transplant when we were told, once you've got to that stage, you have made it. He obviously didn't make it. Although the irony again is he didn't have leukaemia when he died. The leukaemia was cured by the transplant.

My mum categorically told my father in law, "She is not to go up on her own". He came up with me. [redacted]. Obviously it was his son there as well. We have left about 4.00 or -- I know I was home just before 5.00, which is when I got the phone call to say [redacted] had died.

- 22 Q. You think in hindsight, you say, that he knew he was 23 dying, and on that last day you felt he was waiting 24 for you to go home before he died.
- 25 A. Yes, yes.

have the childhood ailments, although it was not 2 obvious, but my husband obviously was susceptible.

- 3 Q. He came down with measles and other infections.
- 4 A.
- 5 Q. You describe him as constantly in and out of hospital.
- 6 A. Yes.

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- 7 Q. He became iller and iller: ulcers, blisters on the 8 skin, loss of hair, general fragility, to the extent 9 he was not physically able to even pick up the
- 10 children and cuddle them.
- 11 A. All they kept telling me it was graft-versus-host 12 disease. He was on anti-rejection drugs like 13 cyclosporine A, I think it was. It is a long time ago 14 now. He wasn't well and I kept being told, "He 15 doesn't seem to want to help himself".

But in hindsight -- and that was my -- because they said, "You have got to keep on at him to make him want to fight this". That has been my biggest regret trying to do that, because in hindsight years later I knew he couldn't do anything about it.

- 21 Q. In June of 1983 he was back in the Hammersmith 22 Hospital, and you describe that as the beginning of 23 the end. His body began to shut down.
- 24 A. Yes, yes.
- 25 Q. His lung collapsed. His organs were failing. He had 166
- 1 Q. Now, you understood that he died effectively from 2 something called graft-versus-host disease.
- 3 A. That's what I was told.
- 4 Q. Which is a medical complication following the receipt 5 of transplanted tissue.

We have his death certificate. Can we have up on screen, Henry, 0407005. If we look at the causes of death, we see there set out: cardiac arrest, cardiogenic shock, renal failure, pneumonia, 10 graft-versus-host disease post-transplant for CG 11 leukaemia.

> You knew it wasn't the leukemia, as you say, that was the cause of his death, because that had been eradicated through the transplant.

- 15 A. Yes, that's what I was told, yes.
- 16 Q. So that was June 1983, and you were left a widow to 17 bring up your two young children, then I think about 5 18 and 3, on your own.
- 19 A. Yes.
- 20 Q. Then in July 1992, nine years later, you received 21 a letter out of the blue from the Hammersmith 22 Hospital.
- 23
- 24 We will have a look at that. It is 0407002, please, 25 Henry.

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We see it is dated 18th July 1992. It is from Professor Goldman and it says:

"You may be a little surprised to hear from the Hammersmith Hospital after the passage of some considerable number of years. Nevertheless, an aspect of your husband's management has recently been drawn to my attention and I would be very grateful if you could make contact with me."

You had no idea what that was about.

10 A. No. no.

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- 11 Q. You did make contact with Professor Goldman and you 12 did go to the hospital to meet him.
- 13 A. Uh-huh.
- 14 Q. What did he tell you?
  - A. He told me that they'd gone and investigated slides that they had kept of my husband and that he had HIV, and that I had to undergo -- or he wanted me to undergo an HIV test, which I did at that time.

I found that pretty horrific, because over the years, and as I showed you the photo of my husband, I became aware at that time in 1984/1985, you saw lots of AIDS victims in magazines everywhere and I kept thinking they looked just like -- my husband looked just like them. So although it was a shock, it sort of reinforced what I had felt intuitively over the

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put it away and move on, because I had nothing -nobody ever told me anything.

- Q. Did Professor Goldman tell you why you were only being given this information in 1992?
- A. I was led to believe at the time that I was -- there was a sum of money that people undergoing this could claim and that he was getting in touch with me to claim this money, because after ten years it was going to be gone. So I only had the year to do all of that. And also he wanted me to go out to the press to try and get other people to come forward for this sum of money.

Being the type of person I was, I did want to do that. I felt morally that I should do. But my mother said to me, "Be very careful", because the profession that I was in, it would have been held against me at that time, and I think she was right, so I didn't do it. Even my visits up to London, I never said -- when I wanted leave of absence from work, I said I was going for women's gynecological problems and not what I was going for because I didn't want anyone to perceive what could have been.

Q. Your mum's concern about you going to the press and saying what had happened was the stigma attached to HIV and AIDS in 1992.

years that he might have been, but I had no proof.

2 I could not do anything about it and get in touch. It

3 is still horrible to hear that, because I was thinking

4 back then you were given ten years, if you were lucky,

5 to live. That's what was out in the press, if you

6 were HIV positive. I thought: what? If I had been

7 infected and nobody had told me all those years

8 before, as you will come on to in a minute -- I know,

9 I will not pre-empt you -- it is horrific. What if

10 I had been and had numerous partners, which I hadn't,

11 but there were so many what-ifs that were going

12 through my head once I knew that.

13 Q. You were told by Professor Goldman that your husband 14 had had HIV, that that had been ultimately the cause 15 of his death.

- 16 A. I think so.
- 17 Q. Or had contributed to it.
- 18 A. Yes.
- 19 Q. And that he had been infected through the platelets 20 given in the course of his treatment for leukaemia.
- A. Yes. 21
- 22 You put it this way in your statement: for nine years 23 you had been soldiering on in ignorance.
- 24 A. Yes. I knew nothing. I mean, I had my gut feelings, 25 but I had no proof or anything, yes. Then you sort of

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- 1 At that time, yes, yes.
- 2 Q. You did have the HIV test yourself. It was clear.

3 But the process of waiting for the result was

4 an anxious one for you.

5 A. Yes, although -- yes, it was, although I kept thinking 6 "I am sure I am okay", yes. But you still don't know, 7 do you?

Q. You were given by Professor Goldman a copy of a study that had been published in a medical journal in 10 March 1987 and you were told that it related to your 11 husband.

12 A. Yes.

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13 Q. We are going to look at that study. It is 0407003, please. We can see the date of the publication. It 14 15 is March 1987, accepted for publication 19 March 1987, 16 and it is entitled:

> "HIV infection due to a platelet transfusion after allogenic bone marrow transplantation." It is reported in the European Journal of

Haematology in 1987.

21 A. Yes.

22 Q. We can see if we just look at the top that the summary 23 talks about a -- it looks like it says 30-year-old --

24 A. It is a 30-year-old man, yes.

25 Q. "... with leukemia received a bone marrow transplant

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1 from his histocompatible sister in December 1982." antibodies to HIV and the subsequent exclusion of 2 2 It talks about his post-transplant course being seropositive donors. However, recipients of blood 3 3 complicated by grade 3 graft-versus-host disease and products donated prior to the introduction of 4 multiple infections until his death from pneumonia. 4 screening may yet develop HIV-related illnesses. If 5 5 the chance of receiving an infectious blood product is Then it says: 6 6 directly related to the number of units transfused, "He was later found to be seropositive for 7 anti-HIV at the time of his death." 7 the patients who require prolonged blood product 8 8 It talks about the retrospective analysis of support [such as your husband] such as recipients of 9 9 stored samples, and then it says at the end: allogenic bone marrow transplants will be at greatest 10 10 "Although it is unclear whether his clinical risk." 11 course was due to AIDS, exposure of an 11 It goes on to talk about a report from France in 12 immunosuppressed patient to HIV may be associated with 12 1985 and an investigation carried out in the United 13 more rapid development of clinical disease." 13 Kingdom. If we look over the page, at the top of the 14 Now, there is more detail about the particular 14 page it says: 15 case in the study itself, but it is clear that this 15 "We report details of the one patient found to 16 refers to your husband. 16 be seropositive for anti-HIV and the events preceding 17 A. Yes, and I was told it was by Professor Goldman, yes. 17 his death 6 months after BMT." 18 18 Q. We will just look at a few passages from it, because Then it goes on to explain in the section headed 19 it is important, Mrs AO, in particular from the 19 "Antibodies to HIV" that samples of sera from the 20 Inquiry's perspective, to see what was being said in 20 patient had been frozen at various times through the 21 1987. So we see in the first column it says: 21 transplant period and were available for analysis, and 22 22 "The risk of acquiring infection with the human goes on to explain the analysis that was undertaken. 23 immunodeficiency virus (HIV) from transfused blood 23 If we go to the next page, please, Henry, and we 24 products has led to the introduction of routine 24 look halfway down the left-hand column, it says: 25 screening of volunteer blood donors for serum 25 "By D plus 120 the patient had received 173 174 1 platelets and red blood cells from a total of 108 1 MS RICHARDS: I am so sorry. My apologies, Henry. It is 2 2 different donors. The regional blood transfusion the page before that. It is my fault for the way 3 centre at Edgware was consulted and investigations 3 I have it printed out. 4 4 were undertaken to identify the source of the virus So the bottom of the paragraph on the left-hand 5 and the passively acquired antibody." 5 side: 6 Then it goes on to set out, under the heading 6 "In retrospect the entire episode may have been 7 7 "Identification of anti-HIV positive blood donor", the due to acute HIV infection and was therefore 8 8 steps that were taken to identify the potential donor mistakenly attributed to GvHD. Secondly, the terminal 9 9 who may have been the source of the HIV infection. multiple infections of this patient may also have been 10 A. Yes. 10 HIV-related." Q. Then under the heading "Discussion" it talks about how 11 11 It goes on to explain why. 12 the HIV infection may have affected the patient. It 12 So we can see from this in relation to your 13 13 husband --"The HIV infection may have been responsible for 14 14 A. Yes. 15 at least some of the problems encountered at his 15 Q. -- investigations undertaken some time after 1985, but 16 16 post-transplant course." clearly before the early spring of 1987, contact 17 And sets out two factors that support a causal 17 having been made with the regional blood transfusion 18 role for HIV in this patient. I won't go through the 18 centre in Edgware, investigations having been 19 detail of it all, but if we go on to the last page, 19 undertaken to try to identify the source of the 20 Henry, having talked about the clinical illnesses that 20 donation, but none of that communicated to you. 21 the patient identified, it said: 21 A. No. 22 22 Q. Did Professor Goldman explain, as far as you can "In retrospect, the entire episode may have been 23 23 due to acute HIV infection and was therefore recall, why you hadn't been told between 1987 and 24 mistakenly attributed to graft-versus-host disease." 24 1992, given that this shows the position was clearly 25 SIR BRIAN LANGSTAFF: I think we are on the wrong page. 25 known by 1987?

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- 1 A. I don't remember anything to do with that, I am 2 afraid, sorry.
- 3 Q. No, no.

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- A. I think I got so -- having to go through all the procedures of claiming this sum of money and all the legalities that were associated with that -- and I don't even think to start with -- I mean, I read the case study, and again, reading it now, I keep going over different things. Why did it take so long? How long was that case study being done before it was published? There is so many ifs and questions that 12 come out from this now. In hindsight, all these years later, it doesn't help, does it?
- 14 Q. You set out in your statement that you think you were 15 told that other recipients of platelets from this 16 donor or products that could be traced back to this 17 donor died.
- 18 A. I don't know if it was that donor, but at the time my 19 husband was in the Hammersmith Hospital, there were 20 several other patients undergoing bone marrow 21 transplants and I was led to believe they had all 22 died. I don't know why -- I mean, what from, whether 23 it is the same. I just presume after -- all those 24 years later, I would presume it was, but I don't have 25 any evidence for that.

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- 1 AIDS, you told only a very small number of people when 2 you learned this news in 1992.
- 3 A. Yes.
- 4 Q. You told your mum, your brother and your 5 sister-in-law.
- 6 A. Yes.
- 7 Q. You only told your children when they reached 8 adulthood.
- 9 A. Yes.

out later".

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- 10 Q. Can you tell us a little -- what was the impact of losing your husband and the father of your children at 11 12 such a young age?
- 13 A. Well, I gave up work when I was expecting my son here, 14 because maternity leave was only just coming in at 15 that time and we didn't understand it all, so we 16 decided it is all right, just -- he said, "I will be 17 the main bread earner, you be a stay-at-home mum". At 18 that time I also -- he said, because we obviously 19 planned for the future, "You might as well pull the 20 money you paid into your pension, pull that out now 21 because it is worth more to us now, we can sort that 22

Well, after his death I had no money. I had to go back to work, and thankfully I had a career that I could go back to, but I couldn't go straight back

Q. You and your husband knew the risks associated with 2 bone marrow transplant.

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4 Q. But you had not been told anything about risks of 5 infection associated with the use of platelets or 6 other blood products.

- 7 A. No, no, no. And as I said earlier, we were just told 8 once you get past six months, you were onto a winner.
  - Q. You believe he died unnecessarily. That's your phrase in your statement.
- 11 A. Yes.

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- 12 Q. That he would otherwise have had a good chance of 13 survival because the bone marrow transplant itself had 14 been successful in eradicating the leukemia.
- 15 A. Yes, but at the time of his death, I was told because 16 of the collapsed lung created by the HIV that he have 17 would have had permanent lung damage. It sounds 18 horrid, but in many ways I just felt that my husband 19 wouldn't have wanted that poor quality of life, and 20 that's what I had in my mind for those years, because 21 I didn't know about the HIV at that time, that he 22 wouldn't have wanted that poor quality of life as he'd 23 been this fit human being, you know. It just was 24 horrendous really.
- 25 Q. Now, because of the stigma associated with HIV and

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in. I had to fight hard. Well, I had my [redacted]. I needed support with that, because I had to earn money. I went back and did [redacted] and then temporary contracts for a while. I couldn't have done that if I didn't have my mother and some very good friends, because also what is horrendous about all of this is my mother was widowed in the February when I was widowed in the March, and it helped me considerably to have mum around.

She -- well, both of us became mother and father to my two children, especially with [redacted]. She had to have lots of time spent on her with [redacted] and things like that, and I was trying to balance my son's wellbeing against her wellbeing, get a career going again, earn the money to provide what we wanted to do for the two children. It took a long time, but I did it.

- 18 Q. Your children grew up without a father.
- 19 A. Yes, and a grandfather, but that's nothing to do with 20 that. Yes. Yes.
- 21 Q. And you have very recently become a grandmother.
- 22 A. Yes.
- 23 Q. And she will not know her grandfather.
- 24 A. No. Exactly, yes.
- 25 Q. Professor Goldman told you of some form of

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1 compensation or financial support scheme that was 2 available from the Department of Health. That, as you 3 understood it, was his reason for contacting you in 4 1992. 5

A. Yes.

6 Q. And you did receive money. You made contact with the 7 Department of Health.

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9 Q. And you did receive a sum of money for you and for the 10 children.

A. Yes.

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Q. You have told us you had to sign an undertaking about that. We have heard about it from other witnesses. but you produced a copy, so we are just going to look that. It is 0407004, please.

> We can see the first page is a letter from the Department of Health, 15th January 1993. It says:

"The Secretary of State has decided that your late husband qualifies for a payment of £80,500 as an infected person with dependant children under the scheme for those infected with HIV through blood or tissue transfer."

Then it sets out a condition attaching to the payment, which included an undertaking that had to be signed by you. If we go over the page, we will see

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meant by matters of policy or operational concerns over the page. So that is what you were asked to sign and you did.

A. Yes.

Q. Because this was money that was going to help you and help your children.

A. Exactly, yes. I mean, maybe to most people it sounds a lot of money, but it is not when it came with loads of restrictions. It was split between my two children and myself. The portion I had I got eventually because I used the solicitors that were for the National Health, wherever it was, came, but the children's sum of money, it wasn't for me. It was put away until they were 18. Then I was able to get hold of it and invest it for them where I wanted it invested, but I had to wait until they were 18 for that.

Q. Just one final question from me: you did tell your children what you had been told in 1992 when they became adults. What was it like for you telling them and what was their response?

22 A. I really can't -- I can't remember. Can you?

**SON:** I don't remember the conversation, no.

A. I did and explained to them. But my son has vivid memories of AIDS adverts on the TV, which made

a copy of the undertaking. It is not the one you 2 signed, because you sent that one back.

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Q. But this is what you were asked to sign and did sign, and it says this:

"In expectation of receiving from the Secretary of State for Health the sum of £80,500, we undertake with the Secretary of State for Health that we will not at any time hereafter bring any proceedings against the Department of Health, the Welsh Office (in Northern Ireland, the Department of Health and Social Services Northern Ireland), the licensing authority under the Medicines Act 1968, the Committee on the Safety of Medicines, any district or regional health authority, any special health authority, any National Health Service trust, any recognised fund-holding practice (in Northern Ireland any health service board) or any other government body as on behalf of the estate or dependants of [your husband] (deceased) involving any allegations of about matters of policy or operational concerns concerning the spread of the human immunodeficiency virus or hepatitis viruses through blood, blood products (whether fractionated or not) or tissue transfer."

Then it goes on to give a definition of what's

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1 an impact on him even before I had ever told him about 2 that, wasn't it? We were talking about that recently. 3 I can't even remember the advert, but it's a famous 4 one. If you google it, you can find it. I tended to 5 block lots of these things out and I tried to 6 obviously go on the positives, you know. Look what 7 we've done basically, where we are.

MS RICHARDS: Do you recall if you had any other communications from Professor Goldman? I think you have shown me a letter which he wrote asking if you had managed to get the financial compensation, I think was the phrase he used, from the Department of Health.

13 A. Yes.

Q. Was there any other communication?

15 A. No, no, no. That was the last, and I can't even 16 remember what I wrote back. I presume I did. Because 17 all of that happened pre-mobile phones, pre-us all 18 having computers in our homes basically. So there was 19 no records in Word that I can go back and look at. 20 No, I don't remember anything.

21 Q. Okay. Thank you. Those are the questions I have for 22 you. Is there anything you'd like to add?

23 A. Well, I have raised some. That report was done, 24 a case study. How long in advance was that? I don't 25 think you can answer that question. Did they look at

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1	the slides to pre-empt that case study? I still don't	1	the contributors to the study.
2	know. Obviously I presumed why they took so long to	2	SIR BRIAN LANGSTAFF: So there can be no question but that
3	tell me was because of that money, but, I mean, there	3	he knew of the contents of the article, and, indeed,
4	is horrendous issues there if I had been infected.	4	being the last-named person, may very well have been
5	There is loads. But other than that, no, I don't	5	a principal author of the paper in the usual medical
6	think so.	6	tradition. In his absence, that's a reasonable
7	Q. I think you know we are trying to find out the answers	7	inference, is it not?
8	to some of those questions.	8	MS RICHARDS: It is a reasonable inference, sir. It is
9	A. Yes, yes. We know that Professor Goldman is no longer	9	an irresistible inference. There are at least two of
10	alive.	10	the other authors who we know to be alive and we will
11	Q. Unfortunately that's the case.	11	be making contact with them. Contact has already been
12	A. The person who wrote the case study is.	12	made with one of them and we will be making contact
13	Q. Yes, and contact is being made	13	with one of the others.
14	A. Yes.	14	SIR BRIAN LANGSTAFF: In the absence of information to the
15	Q with at least one of the authors, possibly more, to	15	contrary, I would naturally conclude, would I not,
16	see what can be found out.	16	that the article was in preparation and ready for
17	A. Yes, which would be wonderful to see. Thank you.	17	submission sometime in 1986?
18	Q. Sir Brian.	18	MS RICHARDS: Yes.
19	SIR BRIAN LANGSTAFF: When you say the person who wrote	19	SIR BRIAN LANGSTAFF: Thank you.
20	the case study, there are a number of names at the top	20	One thing I would like to ask you. You must
21	of the article, one of which is Goldman's.	21	have realised, once Goldman had spoken to you and
22	MS RICHARDS: Yes, I'm sorry, I meant to highlight that.	22	shown you or told you of the article, that someone had
23	Yes, he is one of the authors.	23	been in possession of the knowledge that your husband
24	A. It is a she, I think.	24	had been infected with HIV and that HIV might very
25	MS RICHARDS: Yes, but Professor Goldman himself is one of	25	well be the cause of his death
20	185	20	
	100		186
1	A. Uh-huh.	1	things I had to put up with. But everything that was
2	SIR BRIAN LANGSTAFF: back in 1983. Did that knowledge	2	put in my way "Oh, you can't get on because you
3	do any further damage to you?	3	haven't got a degree", because when I started off, you
4	A. Perhaps it was the frustration for me that he died	4	didn't need a degree. I went to [redacted] and I did
5	unnecessarily, I felt, because of being contaminated	5	it that way. So then when my children were quite
6	by HIV when the transplant had worked and he didn't	6	young, I went off and did an OU degree at home.
7	have leukaemia anymore.	7	Everything they put in my way, I batted out of the
8	SIR BRIAN LANGSTAFF: So it gave you that additional	8	way, you know, because I'm a bit determined, and
9	worry?	9	I worked up the [redacted] ladder, and I became
10	•	•	
11	A. Yes ves	10	
	A. Yes, yes.  SIR BRIAN LANGSTAFF: Thank you.	10 11	[redacted] by the time I finished, because I wanted
12	A. Yes, yes.  SIR BRIAN LANGSTAFF: Thank you.	11	[redacted] by the time I finished, because I wanted I had to keep doing that to compensate for those years
12 13	SIR BRIAN LANGSTAFF: Thank you.	11 12	[redacted] by the time I finished, because I wanted I had to keep doing that to compensate for those years where I had pulled out my pension in those very early
13	SIR BRIAN LANGSTAFF: Thank you.  A. And, you know, it does impact on your life, but	11 12 13	[redacted] by the time I finished, because I wanted I had to keep doing that to compensate for those years where I had pulled out my pension in those very early years for what we planned to do as a couple.
13 14	A. And, you know, it does impact on your life, but because I had those eight/nine years where I didn't	11 12 13 14	[redacted] by the time I finished, because I wanted I had to keep doing that to compensate for those years where I had pulled out my pension in those very early years for what we planned to do as a couple. So there were loads of other issues, but we had
13 14 15	A. And, you know, it does impact on your life, but because I had those eight/nine years where I didn't know, I sort of tried to move on and provide stability  Output  Description:	11 12 13 14 15	[redacted] by the time I finished, because I wanted I had to keep doing that to compensate for those years where I had pulled out my pension in those very early years for what we planned to do as a couple.  So there were loads of other issues, but we had to get on with it. Nobody there to help us. I had to
13 14 15 16	A. And, you know, it does impact on your life, but because I had those eight/nine years where I didn't know, I sort of tried to move on and provide stability for the children and trying to develop my career,	11 12 13 14 15	[redacted] by the time I finished, because I wanted I had to keep doing that to compensate for those years where I had pulled out my pension in those very early years for what we planned to do as a couple.  So there were loads of other issues, but we had to get on with it. Nobody there to help us. I had to get on and do it. Except my mum.
13 14 15 16 17	A. And, you know, it does impact on your life, but because I had those eight/nine years where I didn't know, I sort of tried to move on and provide stability for the children and trying to develop my career, which I had to do to earn I had to up my pension	11 12 13 14 15 16	[redacted] by the time I finished, because I wanted I had to keep doing that to compensate for those years where I had pulled out my pension in those very early years for what we planned to do as a couple. So there were loads of other issues, but we had to get on with it. Nobody there to help us. I had to get on and do it. Except my mum.  SIR BRIAN LANGSTAFF: Well, thank you very much for your
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1 lot of support here over the two days and prior to This order remains in force for the duration of 2 2 this with people e-mailing me. I mean, I have had the Inquiry and at all times thereafter unless 3 3 lots of support from your team, whoever they are, all otherwise ordered, and I may vary or revoke the order 4 of you. It's been excellent, so thank you. 4 by making a further order during the course of the 5 SIR BRIAN LANGSTAFF: Thank you very much. 5 Inquiry. 6 6 With that protection, Mrs AP, please come (Witness withdrew) 7 MS RICHARDS: Sir, if we could just have two or 7 forward. 8 8 three minutes, we need to sort out the live stream MRS AP (affirmed) 9 9 Questions by MS RICHARDS 10 SIR BRIAN LANGSTAFF: Let's take five minutes and then be 10 MS RICHARDS: You have a bleeding disorder known as 11 back for our final witness for the day. 11 Factor XI deficiency. 12 12 A. Yes, that's true. (4.24 pm) 13 13 Q. And that's sometimes also known as Rosenthal syndrome (Short break) 14 (4.31 pm) 14 or haemophilia C. 15 SIR BRIAN LANGSTAFF: Now, our final witness for the day 15 A. Yes. 16 is anonymous and will be known as Mrs AP. In her case 16 Q. It is a rare clotting disorder. 17 17 the order is as follows A. Yes, very rare. 18 The name and address of witness W1011" -- that's 18 Q. You say in your statement that the beginning of your 19 Mrs AP to you and me -- and any identifying 19 difficulties was 1978. 20 information, such as the witness's image or 20 A. That's right, yes. 21 any description of their appearance cannot be 21 Q. You were diagnosed with ulcerative colitis and 22 22 disclosed or published in any form unless express admitted to the London Homeopathic Hospital. 23 permission is given by me or by the Solicitor to the 23 A. That's right. 24 Inquiry on my behalf. Witness W1011 must be referred 24 Q. In the course of the treatment you received there, you 25 to only as "Mrs AP". 25 received blood transfusions and fresh frozen plasma. 189 190 A. Yes. 1 1 young man. So I knew about it. 2 Q. It was then in September of 1980 that you required 2 Q. Your recollection is there was significant volumes, as 3 a further admission to hospital for surgery. 3 you put it, of blood and blood products administered 4 4 A. That's right, yes. to you in the course of that admission to hospital. 5 Q. What happened then? 5 A. Yes. 6 A. During the surgery -- the surgery went well, but after 6 Q. You then describe being given subsequently, not during 7 7 the surgery I started to bleed profusely. There was that admission but later on, fresh frozen plasma in 8 8 drains and blood was just coming out. I obviously was anticipation of surgery for an abscess. 9 9 seriously ill at that point and I woke up in dreadful A. Yes. 10 pain to the consultant, the surgeon pumping blood into 10 Q. The surgery itself did not proceed. my arms and telling me that I was bleeding, and it was 11 11 A. That's right. 12 extremely painful, because it was just literally being 12 But you had had the fresh frozen plasma. Can you 13 pumped in. They told me that they thought there was 13 recall which year that was? something wrong with my clotting. No-one knew at that 14 A. That would have been probably -- well, it was soon 14 15 time what it was. 15 after, within weeks of my surgery. It was because of 16 16 Q. You say in your statement you required units of blood the bleeding that I had had, it had all been into the 17 and you also received either Factor VIII concentrate 17 pelvic cavity and so it had caused this abscess, and 18 or cryoprecipitate. You are not sure which. 18 in order to cure it they wanted to operate, but they

Factor VIII because I grew up with a haemophiliac 25

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couldn't get my bloods correct.

frozen plasma.

A. Yes.

Q. This had taken place at University College Hospital.

Q. Then you developed an allergic reaction to the fresh

Itchiness, swollen eyes and then anaphylactic shock.

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A. Yes. They told me that I needed Factor VIII and that

because it was some kind of bleeding disorder,

clotting disorder, but they didn't know what it was,

that Factor VIII should stop the bleeding, so they

would give me that. I heard about Factor VIII before.

I didn't think I was a haemophiliac, but I knew about

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A. Yes, but that wasn't because of the abscess. They were trying to cure this abscess but they couldn't get rid of it because my bloods weren't right. What they said was, "What we need to do now is to bring you in and we'll start to see what we can do to make your bloods -- you know, your" -- homeostasis? -- "to achieve homeostasis".

> By then I was well. The abscess actually was managed to be cured by antibiotics and some alternative therapies, but I was called in as a day patient and given FFP. I think it was mostly that. Then they were monitoring my bloods. During that time I had anaphylactic shock.

- 14 Q. You were transferred -- I am not sure of the exact year, but maybe it doesn't matter -- to the Royal Free 15 16 Hospital.
- 17 A. That's right, yes.

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- Q. You came under the care of Dr Kernoff. 18
- 19 A. That's right, ves.
- Q. That was because of the unusual and rare blood 20 21 clotting disorder you had, the Factor XI deficiency.
- 22 A. That's right.
- 23 Q. In 1987, by which time you were married and hoping to 24 start a family, you were referred, still within the 25 Royal Free, for IVF treatment.

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up and have your hormones done. It was a junior doctor said to me just very casually, "Oh, you have had a lot of blood products in your life, haven't you? Have you thought about getting tested because there's a lot of viruses and infections out there, and maybe -- you know, you are trying for a baby, you ought to be tested. Why don't you go along to the Royal Free", because I was under the haematologist there, "and ask to be tested?"

I didn't think much of it at the time, so I went on the next routine appointment to the Royal Free and asked and they said okay. I didn't really hear much more about it until probably my next followup appointment, probably a year later, that I then found out I had hepatitis C.

- Q. Prior to that casual comment from the doctor during one of your IVF cycles, had anyone ever given you advice or warning about risks of infection associated with blood or blood products?
- 20 A. No, and I think had they, particularly when I was 21 going through the, "We will try to see what we can do 22 to improve your homeostasis", if they had told me, 23 I wouldn't have had it because I was well by then. 24 The illness I had had been cured and there was no 25 reason for me really to start worrying about what if,

A. That's right.

Q. In fact, I think you decided you wanted to undertake the treatment elsewhere under Professor Winston.

- 4 A. That came afterwards. We had had a couple of cycles 5 at the Royal Free that weren't successful and they 6 were a bit complicated. I had hyperstimulation of my 7 ovaries and became quite unwell. It was the very 8 early days of IVF at that time and I just wanted to go 9 to the best place. It wasn't NHS treatment, we were 10 paying, so I didn't want to keep going through 11 treatment unnecessarily, so I opted to go to the 12 Hammersmith Hospital, where Professor Winston was 13 working.
  - Q. In total you underwent eight or more IVF attempts.
- 15 A. That's right, yes.
- 16 Q. You say in your statement that all of the IVF cycles 17 that you underwent required clotting treatments.
- 18 A.
- 19 Q. By that time, with Factor concentrate.
- 20 Yes. Factor XI concentrate.
- 21 Q. Factor XI concentrate. It was after around seven of 22 those IVF cycles that a casual comment was made to you 23 by a doctor. Can you recall what that comment was?
- 24 A. Yes, I was up there for just some blood tests in the 25 morning. Every morning for IVF you used to have to go

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Royal Free, who by then was Dr Christine Lee.

- 1 what if, what if. I was a 20-year-old woman and I was 2 told I was cured, so I wouldn't have gone through it. 3 Q. Now, you describe in your statement in 1995 a routine 4 consultation with your consultant haematologist at the
  - A. Yes.

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- Q. What can you tell us about that consultation?
- 7 8 A. I went in and we were just talking about the Factor XI 9 deficiency and had I had any bleeds or had I had any 10 problems, which I hadn't, because I never knew about 11 it until I was 20. I don't spontaneously bleed. 12 I don't have any problems with it. She said, "By the 13 way, you do know you have got hepatitis C, don't you?" And I didn't know I had hepatitis C. She said, "Oh, 14 15 yes, yes, it is a very serious illness. I can give 16 you a leaflet on it and you can go away and you can 17 think about it". I said to her, "I can't have 18 anything like that". I think this was about 15 years
- 19 later, 13, 15 years later. "That can't happen. 20
- I feel okay. I feel all right". I remember her
- 21 saying this specifically, "Oh, you could be walking 22
- around with half a liver and not know about it. At
- 23 this point we don't know if you are ill or not. You
- 24 need to have some tests". So I had some tests and had 25

to wait.

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- 1 Q. Just before we get to the tests, you talk about the
  2 delivery of the diagnosis by Professor Lee initially
  3 being in a very matter-of-fact manner. You questioned
  4 the diagnosis and you got this blunt result was, "You
  5 could have liver damage, people do without knowing
  6 about it".
- 7 A. Yes, and "Here is a leaflet, by the way, here is a
  8 leaflet", that had all about cirrhosis, cancer, what
  9 could happen. It was like receiving a terminal
  10 illness diagnosis just like that, and I was on my own.
- Q. You describe it very vividly in your statement. You
   say it was like taking a sledgehammer to crack a nut
   in terms of the manner in which the diagnosis
   explanation was delivered.
- 15 A. Yes, it felt like that.
- 16 Q. You also say you left in a state of emotional turmoil.
- 17 A. Yes, I did.
- 18 Q. Now, you had tests in relation to your liver.
- 19 A. Yes.
- 20 Q. And what was the upshot of those tests?
- A. I believe that there was very minor changes in my
   liver function, but there was nothing significant. So
   I didn't have half a liver functioning, I was okay.
- 24 I think that the tests came out that it was
- 25 a particular genotype or some kind of particular type

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- I became very thin. I lost weight. I had mouth
   ulcers, a cracking of my skin around my mouth. My
   fingers cracked. It was dry and cracked so I couldn't
   hold on to things. It was just -- I was just in quite
   a mess really with it.
- Q. You also talk about night sweats, aches, pains,disturbed sleep.
- 8 A. Yes.
- 9 Q. And severity of itching.
- 10 A. Yes.

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- Q. And your mood changed; you became intolerant anddepressed at times.
- A. Bad-tempered, moody, yes, very low in spirits, you
   know, really tearful a lot of the time. I felt like
   I was trudging along, trudging through each day and
   couldn't wait for it to finish.

I was told very early on within three months the viral load had come down to virtually nil. So I was motivated to continue, but it was very hard, but there was no stopping. It had to continue for another nine months

Q. What was the outcome of the treatment in terms of thevirus?

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- 24 A. I cleared the virus.
- 25 Q. You've said in your statement you continued to feel

- of hepatitis C that may be susceptible to treatment.
- Q. And you were advised, as I understand your statement, by Professor Lee to embark upon a course of treatment.
- 4 A. Yes.
  - Q. So although there was no serious damage to your liver, she suggested to you that you try the treatment of pegylated interferon and Ribavirin.
- 8 A. Yes
- 9 Q. Did you know what stage that treatment was at, can you10 recall?
- A. Oh, it was a trial. I think it was one of the first
  trials that there was. So, yes, I think I was one of
  the first people to have it. It was a year-long
  treatment. I was told I have to stay on it a year no
  matter what. It was Ribavirin and interferon.
- Q. Can you recall whether you were told about potentialside effects?
- A. I was told I might get flu-like symptoms and to take
   paracetamol the nights I had the injections.
- Q. What, in fact, was that year-long treatment oninterferon and Ribavirin like?
- A. Oh, it was hell. It was absolute hell. It was right
   that I did have flu-like symptoms on the nights of the
   injections, but I was extremely tired throughout the
   whole time. I lost my hair. It went very, very thin.

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- 1 the ill-effects of the treatment --
- 2 A. Yes.
- 3 Q. -- for a prolonged period afterwards?
- 4 A. It took 6 to 12 months for me to get anywhere near to 5 feeling normal, but I would say I have never felt 6 completely normal since. I am much more tired than 7 I remember being and I don't sleep well. The 8 nights -- a year long of not sleeping took its toll. 9 I didn't sleep and I still don't sleep, and I never 10 was really able to resume the activities to a level 11 that I did before.
- Q. We will come on to your work in a moment, but in terms
   of the IVF treatment you have been undergoing,
   Hammersmith Hospital said that it was time to bring
   an end to that.
- 16 A. Yes. It seemed to happen very quickly after the 17 diagnosis, the hepatitis C. Up to that point they 18 were talking about new treatments, new things coming 19 on, "Maybe you will be suitable for this trial of this 20 way of doing IVF" or whatever, and it seemed to be 21 very quickly -- it is a bit woolly, because it was 22 such a period of shock and turmoil -- but very soon 23 after suddenly we were called. We saw a doctor we 24 never met before and he talked very quietly, sort of 25 a whisper almost at me, sort of whispered to me it was

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1		coming to an end and, "We don't think we can help you	1		clear, and nine months to go of treatment, we got the
2		anymore". But no real reason was given.	2		phone call from social services to say, "Oh, lucky
3	Q.	You don't know but you are left with the suspicion	3		you, we have two children aged 2 years old, a brother
4		your diagnosis of hepatitis C might have been a factor	4		and sister but they are both born in the same year,
5		in relation to that.	5		they are not twins but born in the same year, two
6	Α.	Yes.	6		children for you. You have been put forward to be the
7		You had, as well as the IVF process, been going	7		parents for them". We were thinking, "Oh, okay,
8		through the process of being approved as potential	8		great". I mean, it was great, wonderful, but I was
9		adopters.	9		feeling so awful and I had such a long way to go of
10	Α.	Yes.	10		the treatment.
11		When you had the diagnosis of hepatitis C and you knew	11		My husband had to reduce his working hours. He
12		that you were going to be embarking on this treatment,	12		was working in a bank. He reduced down his hours of
13		you decided that you would concentrate your focus and	13		work, with permission, because we knew I wouldn't be
14		your energies on the adoption process.	14		able to do it on my own. Took time off work first and
15	Α	That's right, yes.	15		then went part time. My mum helped. Together we had
16	Q.		16		to work. I was having real problems, because my hands
17	Α.		17		were really sore and just touching nappies was like
18		two children.	18		having electric shocks, the friction. It was likely
19		Yes.	19		electric shocks going on my hands. They gave me
20		But the diagnosis, the infection and the treatment and	20		gloves at the hospital to wear to help.
21	٠.,	its side effects took its toll on your abilities to	21		I had difficulty cuddling the children.
22		practically parent your children in those early years.	22		I couldn't bath the children, so my husband did that.
23		What can you tell us about that?	23		I had to have a lot of practical help, and all the
24	A.		24		time I had to be happy clappy that everything was
25	۸.	difficult, because literally at the three months, all	25		going well, because obviously there was a worry that
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1		social services would come in and take the children	1 2		trial because they couldn't cope with the side
2		social services would come in and take the children away. My focus really was: get through this	2	Δ	trial because they couldn't cope with the side effects.
2 3		social services would come in and take the children away. My focus really was: get through this treatment, get well, don't let them take the children	2		trial because they couldn't cope with the side effects. Yes.
2 3 4	0	social services would come in and take the children away. My focus really was: get through this treatment, get well, don't let them take the children away.	2 3 4	Q.	trial because they couldn't cope with the side effects. Yes. You wonder how many of those people are still alive.
2 3 4 5	Q.	social services would come in and take the children away. My focus really was: get through this treatment, get well, don't let them take the children away.  You describe your life at that time as being on	2 3 4 5	Q.	trial because they couldn't cope with the side effects. Yes. You wonder how many of those people are still alive. Yes. Some of them were very, very sick. I think they
2 3 4 5 6	Q.	social services would come in and take the children away. My focus really was: get through this treatment, get well, don't let them take the children away.  You describe your life at that time as being on a trajectory, but it wasn't an upward trajectory; it	2 3 4 5	Q.	trial because they couldn't cope with the side effects. Yes. You wonder how many of those people are still alive. Yes. Some of them were very, very sick. I think they were very sick to begin with when we went on the
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2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22	A.	social services would come in and take the children away. My focus really was: get through this treatment, get well, don't let them take the children away.  You describe your life at that time as being on a trajectory, but it wasn't an upward trajectory; it was a downward one associated with the treatment concerned.  It was. It was really hard. I don't know how I did it. I felt permanently dizzy. Obviously two young children of 2 years old, it's like two toddlers at the same time, they were running around all over the place, I couldn't run after them, and I was just trying my best. I remember looking forward to Teletubbies coming on, anything to make them stop and watch the television. Or when they wouldn't go to sleep, I would literally stick them in the car and go driving for miles just to try to get them to sleep, because I couldn't cope with them.  I think one of the practicalities was you were going to hospital appointments, hour and a half each way, and you often had to bring the children with you.	2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22	Q. A.	trial because they couldn't cope with the side effects. Yes. You wonder how many of those people are still alive. Yes. Some of them were very, very sick. I think they were very sick to begin with when we went on the trial. Each week in the beginning there was quite a number of us. We all used to turn up on the same day and were monitored. We all went to get our drugs because obviously they were not run-of-the-mill drugs. They were dispensed especially for us. Gradually there was fewer and fewer of us turning up at each appointment. Some people would say to me, "Oh, I have stopped because I am not getting better, nothing is happening for me", and others would say, "I just feel too ill, I can't carry on". I was reasonably young. Some were older than me, but, yes, I think quite a few have probably died. And because of the combined effects of the infection, the treatment, the side effects, and you had to make your priority these two young children you were adopting
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A. Yes.

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to the trial you recall people falling away from the

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- Q. You had run a business with a partner.
- A. Yes.

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- Q. You went first of all part-time, but then your partner
   ended up having to take over effectively full time.
   You ended up having to sell the business for very
   little.
- 7 A. Yes.
- 8 Q. It was an acrimonious end to a business.
  - A. It was. I worked in health, and at the time it was a very innovative way -- it was a time when local authorities were contracting out a lot of their services and we were picking up waiting lists from local authorities and housing associations and the health service, and we had a team of other health care professionals working with us. I was doing assessments. Well, I had been before the treatment, going out doing assessments, employing other people, negotiating contracts, and it was a really busy and flourishing business between the two of us, and it was new and it was innovative, and I also was starting to be asked to be an expert witness in my particular field of expertise. So we were really doing well for the time.

Then once the treatment started, it was clear I couldn't carry on with it. So in the early days of

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offered a partnership in an expert witness company with someone, and that company is still going and that has just been bought out for several million pounds, but I couldn't, because I wasn't well enough.

I couldn't go in with her.

- **Q.** You continue to be under the care of the Royal Free in terms of your blood clotting disorder.
- 8 A. Yes.
- Q. So you have not very often, but I think it is each
   year you either have a telephone appointment or
   an in-person appointment --
- 12 A. Yes.
- Q. -- with a haematologist. But what, if any, ongoingmonitoring of your liver have you been offered?
  - A. No. None at all. When this Inquiry started, it came into my knowledge that people who have cleared the virus are not necessarily cured totally, and that there have been some cases of liver cancer, and I put that to the hospital, the Royal Free, and asked if I could be tested, to which they said, "No, there is no need. You have cleared the virus. Therefore as far as we are concerned you don't need to be followed up and monitored for anything to do hepatitis".

So I went to my GP. I told her. She did some blood tests and actually there is an anomaly with my

the treatment -- this is before the children came -- my business partner took over. I did very little. He took over. It was in the expectation I would go back. Then the children came. There was no way I could go back. So, yes -- well, he basically bought me out.

- Q. You were eventually able to return to part-time work,
   but you say in your statement you never got back to
   where you'd previously been.
  - A. No. I have never gone back to part-time work, partly because of the lack of sleep, the poor sleep pattern.
     I don't think my concentration was ever quite as good.

12 I still was able to work as an expert witness 13 and I did really well as an expert witness, but it 14 wasn't anywhere near to the level my colleagues are 15 doing. I didn't take the number of cases other people 16 were taking. I used to have periods where I would 17 stop taking cases where I would rest and have rest 18 periods before I start again. So I had quite a few 19 career breaks.

- Q. You say in your statement you ended up retiring at 57
   and you directly attribute that to the hepatitis C or
   treatment for the hepatitis C.
- A. I am sure of it. Many of my colleagues are still
   working today. My ex-business partner still has his
   business. After my other business finished, I was

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- Alpha Fetoprotein. It's not mega high, but it is higher than it should be. So I am now having to be monitored, but my GP is doing it, because the Royal Free, even though they know this, have refused to refer me.
  - Q. You now have a lack of trust in doctors.
- 7 **A.** Uh-huh.

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- Q. And that has been compounded, I think, by the factthat many of your medical records have been lost.
- 10 A. Yes.
- 11 Q. What have you been told about your records?
- 12 In the early 1990s I was approached by an American law 13 company after -- I don't know how they got my number or my name, but they did, and said there was a test 14 15 case going on in America about Tainted Blood, did 16 I want to be part of it, to which I said yes, I would. 17 So I tried to get my medical records. Part of that 18 was you had to have your medical records. I wrote to 19 my GP. I wrote to the Royal London Homeopathic 20 Hospital. I wrote to UCH to get my notes.

The Royal London Homeopathic hospital wrote back and said there was no record of me under my maiden name, because I wasn't married when I was treated there, or my married name. There is no record of me at all.

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1		The UCH wrote back to me and said, "All of your	1	been really hard, because for me in particular I have
2		notes have been filed on a digital data system which	2	had to keep a lid on this for years and years and
3		is no longer working and can't be so your notes	3	years. It is only now that we are talking about it.
4		cannot be retrieved and won't be retrieved". I have	4	For me the implication of saying anything about this
5		tried again and it's same answer. My GP I think has	5	could have meant that I would have lost my children.
6		also got a paucity of notes.	6	It meant that I couldn't go on with IVF. It meant
7	Q.	So you are not able to identify which of the various	7	that I couldn't work or job opportunities were denied
8		treatments or products that you received are the	8	to me, because I think it would be very hard for me to
9		products that infected you with hepatitis C.	9	have gone back into the health service if I said I was
10	A.	No, although I have received lists of blood products	10	hepatitis C positive. It has had so many implications
11		from the transfusion service. When the CJD alert came	11	that over the years I just don't talk about it.
12		out, I received a list of blood products which I have	12	I haven't talked about it. I have really just plodded
13		been told by the Royal Free that none of those are on	13	on and tried not to think about it really. This has
14		the affected list.	14	really brought up a lot of stuff for me.
15	Q.	In terms of vCJD?	15	I just hope really I want to thank the
16	A.	Yes, vCJD, but I don't know which ones for the	16	Inquiry for coming forward and doing this because
17		hepatitis.	17	I think hopefully it will give us some closure, give
18	Q.	Those are the questions I have for you. I am just	18	us some answers, hopefully, to what happened. Because
19		going to ask your solicitor whether she has any	19	I can't believe that we were given these products and
20		questions to suggest.	20	we just were ignored for many years. Someone out
21		No, nothing further.	21	there knew what they were doing and what was
22		Is there anything else that you would like to	22	happening, and I went on that 15 years trying for
23		say?	23	a baby, potentially infecting my husband, potentially
24	A.	No. I think from well, one of the things I suppose	24	infecting any babies I might have had, and this was
25		I would like to say is like a lot of people, this has	25	allowed to happen. Who allowed that to happen? It
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1		bugs me. It really bugs me that this has happened	1	A. Thank you.
2		and, you know, now hopefully we can find out. I hope	2	(Witness withdrew)
3		we find out.	3	SIR BRIAN LANGSTAFF: Well, I think last week I said we
4	MS	RICHARDS: Thank you. Sir Brian.	4	would what was happening tomorrow, but I shall not
5		BRIAN LANGSTAFF: Well, thank you. As you've probably	5	say that on this Friday. We have nothing, of course,
6		realised, it is very different being an expert witness	6	next week, because it is half term, but we do start
7		from giving evidence about yourself.	7	again, do we not, on the Monday this time the week
8	Α.	Yes.	8	after?
9		BRIAN LANGSTAFF: And particularly when what you are	9	MS RICHARDS: We do. We start on Monday, 28th October and
10		describing, you are trying to describe and convey, is	10	we are sitting all five days that week to accommodate
11		something which I can very well understand, which is	11	as many witnesses as we are reasonably able to in the
12		how you manage on earth to care for two two-year-old	12	course of the week.
13		children at the same time as having the after effects,	13	SIR BRIAN LANGSTAFF: Can you tell us who we are going to
14		the side effects, of treatment.	14	hear from on Monday?
15	Α.	Yes.	15	MS RICHARDS: I can. We will be hearing from Alan Burgess
16	SIR	BRIAN LANGSTAFF: And a husband who has to be at work	16	and Sarah Adams, Nicola Jones, Stewart Greg and
17		as much as he can be. Plus you added at the end of	17	an anonymous witness on that day.
18		that the fears that you had that everything might	18	SIR BRIAN LANGSTAFF: We will start at 10 o'clock. Thank
19		suddenly be taken away from you, everything that was	19	you for your attendance, and those of you who come,
20		good, if you so much as let it slip that you had the	20	I will see you then.
21		disease.	21	(5.01 pm)
22	A.	Uh-huh.	22	(Adjourned until 10.00 am on Monday, 28th October 2019)
23		BRIAN LANGSTAFF: So I really have to thank you for	23	,
24		coming to talk as much as you have about what happened	24	
25		to you.	25	
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