Monday, 28 October 2019

(10.00 am)

SIR BRIAN LANGSTAFF: Our first witnesses this week are Alan and Sarah, are they?

MS RICHARDS: Yes, sir.

SIR BRIAN LANGSTAFF: Alan and Sarah, please.

ALAN BURGESS (sworn)

SARAH ADAMS (affirmed)

Questioned by MS RICHARDS

MS RICHARDS: Alan, you are married to Denise, whom you met when you were both teenagers.

A. Yes.

Q. And you've got three children, Sarah, Laura and Liam.

A. Yes.

Q. Sarah, who sits beside you today, is going to be giving evidence as well, and Laura and Liam have also provided witness statements to the inquiry, as has Denise.

A. Yes.

Q. You have mild haemophilia A.

A. Yes.

Q. Can you tell us how that was diagnosed?

A. That was diagnosed when I was little. I had my tonsils out and I wouldn't stop bleeding. I required some blood transfusions. And then I had a tooth out

a little while after that, the same thing happened, and then they put two and two together, sent me to Addenbrooke's and, yes, I was diagnosed with haemophilia.

Q. And on the occasions after the diagnosis when you required treatment, as far as you can recall it was mostly cryoprecipitate that you received.

A. Yes, it was.

Q. You're unsure, I think, about whether in 1976, when you had a dental extraction, you received Factor VIII or cryoprecipitate.

A. I thought it was Factor VIII, but it's in the notes as cryo, but that's a bit of confusion there. Even on the UKCDHO it says unsure.

Q. We'll look at those in a moment.

You didn't, I think, as a mild haemophiliac, need treatment very often.

A. Not every week or anything like that, no.

Q. So you and Denise got married and started a family, and your wife says in her statement that you lived a very normal life, you loved playing football.

A. Yes.

Q. And you didn't let your haemophilia hold you back.

A. No, not at all.

Q. You set up in business as a painter and decorator.

A. Yes, had my own business, employed a couple of blokes, so yeah.

Q. In December of 1982 you had a bleed to your left calf following a football injury. Can you tell us what happened?

A. That was in the days when you had to present to casualty, you know, I wasn't on home treatment then. I knew it was a bleed, but believe it or not, they wouldn't take it as a bleed. They said, "No, no, you're just badly bruised" and strapped it up and sent me home. I should've -- looking back, I should've, you know, put my foot down, or good foot down, and said, "No, treat me". But in those days you took everything a doctor said, you know.

But it got worse, it got bigger. Went back again, but they still refused to treat it. They just gave me some painkillers. In the end I had to go into hospital because it started to swell, it was all colours of the rainbow. Went in there for a few days and then they needed the bed so they sent me back out again, didn't send the ambulance to come and get me the following day, so I was in agony by that time, and they sent me to Addenbrooke's because they couldn't stop the bleeding in the end. So that's when they gave me the Factor VIII that we think infected me.

Q. And we'll look at one document, it should come up on the screen in front of you. Henry, it is 1122006, please.

It's a letter dated 17 December 1982, and it's from Addenbrooke's Hospital, Dr Clark, a registrar in the haematology department, to your GP, and it says this:

"This 24-year-old man known to this department to have mild haemophilia was admitted on the above date [10 December 1982]."

It refers to your problems having begun 5 days previously, when you sustained a blow over the left tibia.

"Initially treated with a compression bandage but no specific anti-haemophiliac treatment was given. The calf subsequently began to swell. 48 hours after injury he was given come cryoprecipitate. He was evidently given instructions to rest this limb and it gradually began to improve, although on the day prior to admission there had been some deterioration with further swelling of the affected calf."

That's the point at which you were sent to Addenbrooke's.

A. Yes.

Q. Which was the local haemophilia unit.

A. Yes, it was, even though it was 50 miles away, but it was the local one.

Q. Local to you.

A. Yes.

Q. And then it refers in the next paragraph:

"In the past he has had Factor VIII cover for dental extractions in 1976."

A. Yes.

Q. That's the one you're not clear whether that's right or wrong.

A. Yes, I thought I was given -- because with cryo, you always knew you had cryo because it was cold, you know, but this particular time it wasn't and I -- I'm sure they said that was Factor VIII. But in some notes it says Factor VIII and in some notes it says cryo, so I've no idea really.

Q. Then it refers to an episode of left shoulder stiffness responding to cryoprecipitate two years later, that would've been 1978. There had been no other problems.

Then if we go down to the last paragraph on that page, it talks about you appearing well but the most striking abnormality is the presence of an egg-sized lump overlying the mid-left tibia, and it refers to swelling of the muscles.

If we go on to page 3, please, Henry.

The next page is blank.

So it's not very well copied, and this is the only copy you have, as I understand it, in your records, so we lose the last bit of it, but we can see there reference to you being given "enough Factor VIII concentrate to [something] actual levels up to greater than 50 per cent for 48 hours".

A. Yes.

Q. And then it refers to you being gradually mobilised and discharged and able to weight-bear on the affected limb without too much difficulty.

So those are the circumstances in which you were given in December 1982 a Factor VIII product.

A. Yes.

Q. Either for the first time or possibly for the second time if you'd had one in 1976.

A. Yes.

Q. Were you, on this occasion or any previous occasion, given any information, warnings or advice about any risks of infection associated with the product?

A. No, none whatsoever.

Q. Very shortly after you were given Factor VIII on this occasion, you began to feel unwell. What can you remember about that?

A. It was -- well, I remember it was New Year's Eve. There was a party I couldn't go to, a neighbour's one, because I was -- I had shivers, you know, shaking. It was like flu, really, a really bad dose of flu, but felt worse, and -- yeah, that more or less I would've thought coincided with that bad dose that I had, but I didn't realise that at the time, just thought I'd caught a chill and it got worse.

Q. Then between that date in December 1982 and 1985 --

A. Yes.

Q. -- you had several treatments for small injuries, but they were all with cryoprecipitate.

A. Yes.

Q. We have got individual treatment records, but we'll just go in fact to the UKHCDO record. It is 1122002, please, Henry.

If we look at the bottom of the page, we can see for 1976 the entry is just "Error", hence you're not sure what you received then.

A. Yes.

Q. 1978, cryoprecipitate. Then 1982, which is the occasion we've just been discussing, BPL Factor VIII.

A. Yes.

Q. In the following years, 1984 and 1985, cryoprecipitate.

A. Yes.

Q. You're not recorded as receiving Factor VIII again until 1988.

A. That's right.

Q. Now, in 1985, probably August/September of 1985, you received a phone call --

A. Yes.

Q. -- saying that you would have to be tested for the AIDS virus.

A. Yes.

Q. What can you recall about that?

A. Well, I was -- I knew about it, I had seen a Panorama programme, but, I'll be honest with you, didn't think it affected me, because the Panorama programme really went to San Francisco and obviously gay men were presenting there, and didn't realise there was a problem, you know. And then they said, "Well, there could possibly be a small risk, you know, that some of the Factor you've had in the past might have been contaminated but we don't think so", because the reason they gave is, "You've had British products, but we're going to test you anyway". So went for a test, and -- well, you know the rest, don't you?

Q. Well, I do, and you do, and others will soon hear.

You said in your statement you put it to the back of your mind because, when you received that phone call asking you to come for testing, you were essentially told that there really wasn't likely to be anything to worry about, it had been British product, and you yourself knew you'd received very little.

A. Yes, yes.

Q. So you put it to the back of your mind. But then, late in September of 1985, you received a letter.

A. Yes.

Q. Now, we're going to look at the letter in a moment, but first of all, what can you remember about receiving that letter?

A. Well, that was in the days when the postman called early, you know, twice a day sometimes. I was in bed about 7.30, getting, you know, my cup of tea, going to get up for work, and Denise was up with the kids at that time, and she had the post. Right, lovely. A cup of tea there and this brown envelope. Opened it up and told me I've got the AIDS virus. And I -- well, you know, I was -- I thought: what? You know. It was -- you had to go downstairs and act normal in front of the kids and go to work, and -- but didn't really have a chance to even talk to my wife, you know, we just -- "Right, okay", and that was it.

Q. And we'll have a look at the letter.

A. Yes.

Q. You kept a copy of the letter.

A. I did, luckily enough.

Q. And you say "luckily enough" why?

A. Well, because it's not in my notes.

Q. And it's 1122004.

We can see it's from Ipswich Hospital department of haematology, dated 25 September 1985, from Dr Edwards, consultant haematologist, to you. It says this:

"Dear Mr Burgess,

"We have at last had the result of your test, and I am extremely sorry to say that it has proved to be positive for the AIDS-associated virus. This obviously will be of some concern to you and your wife. I would like to suggest that if you give me a ring we could arrange an appointment for you to come and talk to me and my colleague, Dr Philip Jones, about it and its implications and to try and put your mind at rest."

A. Yeah, there you go.

Q. You are very critical in your statement of how this news was broken to you.

A. Yes.

Q. You've described it as entirely thoughtless and inappropriate.

A. Well, if the letter had gone to a neighbour, if it hadn't been delivered, if it had gone missing, the connotations are horrific just to even think about it, because at the time -- I mean, the stigma is still about now, but the stigma then was pretty awful. You can only imagine what would've happened. Yeah, it -- I thought it was shocking. But that was indicative of the way we used to get treated, you know, by the medical profession, to be fair.

Q. Can I ask you, what do you think would've been a right way or better way to inform you of the positive test result?

A. Called us in, said, you know, "I'd like to meet you and your wife, important that you come in for an appointment", and you come in face-to-face, how it should be done, really. Common courtesy for a start. It's just -- just thinking about it now is shocking, you know. The shock never went away really.

Q. You went to Ipswich Hospital and saw the doctor.

A. Yes.

Q. What's your recollection of that meeting and what you were or were not told?

A. It was poor. Very, very poor. And the advice -- well, they didn't really give us any advice. They told us to keep it quiet, best not to tell anybody. But they -- they didn't have a clue what was going to happen to me. They said, "Oh, the prognosis might not be good, but at the end of the day we don't really know", and we went away as confused -- more confused, probably, than we went in, and that's why we weren't very happy.

So I then went to see Dr Seaman at Addenbrooke's because she was the -- really she was the head of the East Anglian haemophilia unit, but that was a massive mistake. We walked in her office and she -- she was very angry with us. She wasn't nice to us. She wasn't comforting or consoling. She said, "What are you here for? You're wasting my time, you've wasted Dr Edward's time, and you've wasted your time being here. You've had all the information from Dr Edwards. She's phoned me up and she's very angry." My wife was in tears and -- well, that was how we were treated.

Q. Just going back to the first meeting with the doctors in Ipswich.

A. Yes.

Q. You've said in your statement that the transmission of the virus wasn't discussed with you.

A. No.

Q. And you weren't warned about the risk of unprotected sex or of considering further adding to your family.

A. Like I said, there was no advice really at all.

Q. There's one letter in your records which relates to that meeting, and we'll just look at that for the sake of completeness, Alan.

A. Yes, sure.

Q. It's 1122007. We can see it's a letter -- it's from Dr Edwards to your GP, dated 3 October 1985, and it says this:

"With the recent publicity about AIDS, it has been recommended nationally that we should check all our haemophiliac patients for the AIDS-associated virus HTLV III. In accordance with this, we have tested Alan Burgess, having explained everything fully to him and doing it with his agreement."

Pausing there, you accept, I think, the test was with your agreement --

A. Yes.

Q. -- in response to the phone call.

A. Yes.

Q. "We had been hopeful that he would be negative because he has not had a great deal of commercial dried Factor VIII products. Unfortunately, the result has come back proving him to be HTLV III positive and

therefore a high-risk patient. This obviously has been of some concern to Mr Burgess and his wife. He has been informed and Dr Philip Jones and I had a talk to him and his wife yesterday to try and explain things fully to him and to answer any of their questions."

Then the letter continues saying:

"The most important point of course that we put to him was the absolute confidentiality of this information, and I have stressed this at all points."

Pausing there, that I think does reflect your recollection, Alan, that you were told you shouldn't tell anybody.

A. That's right. That's right, yeah. Yeah, that's the information.

Q. The letter goes on to talk about what arrangements might be made within the hospital in terms of notifying people if you needed treatment.

Then if we go to the next page, please, Henry, we can see it talks about the second point raised particularly was the problem of children -- raised by your wife was the problem of children and whether your wife herself was infected.

A. Yes.

Q. And I think it's right, and Denise has said this

herself in her statement, Denise had to be tested.

A. Yes.

Q. And you've described, I think in your evidence to Archer, the awfulness of the wait to find out the result.

A. Yes.

Q. Which thankfully was negative.

A. Yes, but she's also been tested various times since and every time is -- every time was awful, really, you know. It's something that Denise didn't sign up for and -- yeah, it's not nice.

Q. But you don't recall there being any discussion in any detail about risks to Denise or about planning future pregnancies.

A. No, that came later, but not at that particular time. It was very poor, as I say.

Q. You therefore went to Addenbrooke's hospital, as you've described, to see Dr Seaman.

SIR BRIAN LANGSTAFF: Can I, just before you do that, just go back to the first page of that letter. This is 007. About six lines down:

"We had been hopeful that he would be negative because he has not had a great deal of commercial dried Factor VIII products."

From 002, the UKHCDO records, he had had none,

had he?

MS RICHARDS: The records suggest he had had none, and Alan's only recollection with any clarity is of December 1982, when the records suggest BPL. But in fact there is an issue that Alan has, or a concern Alan has, about the accuracy of the UKHCDO records as a whole, and there is one further document in that regard, perhaps we can deal with it now.

SIR BRIAN LANGSTAFF: Because certainly there seems to be some doubt in the mind of the writer of this, as to what he had had.

MS RICHARDS: Yes. Yes, and we don't know what that was based upon.

There is one further UKHCDO database document, which is 1122018, please, Henry.

Alan, you've flagged this to our attention. Can you explain or point out the discrepancy which concerns you?

A. Well, it says, "Date first positive" on there and it says 15 January 1985. And ... I was -- obviously had the testing in August, I think it was, that year, so I don't know how that can possibly be right.

Q. The sample date is given as 15 September 1985.

A. Yes.

Q. But as you say, date first positive, 15 January 1985.

You don't know whether that's a transcription error or tests of which you're not aware.

A. That just doesn't make any sense, but what does? But there you go.

Q. And I think, as we've already covered, you don't know for certain one way or another whether you were given Factor VIII at any earlier point in 1976.

A. Yes.

Q. And if so, what that Factor VIII might have been.

A. Yes.

Q. And the UKHCDO records don't tell us.

A. No.

SIR BRIAN LANGSTAFF: But the chances of there being the AIDS virus transmitted in 1976 seems vanishingly small.

MS RICHARDS: It does, but whether that was the basis for the statement in the doctor's letter or not, we simply don't know. There's nothing else in the records that provides any assistance in answering that.

SIR BRIAN LANGSTAFF: Thank you.

MS RICHARDS: You've told us about meeting Dr Seaman at Addenbrooke's.

A. Yes.

Q. And I should say we have invited Dr Seaman to respond to your criticisms, and if we receive a statement,

that will be published on the website.

Is there anything further you can recall about that encounter?

A. No, just apart from the -- the sheer horror of it, really. She wasn't understanding, as I say, she wasn't -- she didn't have any empathy for us. We don't want sympathy, but there was nothing -- she was angry. She was angry because we were there, and I couldn't understand why. And like I say, Denise ended up crying and I -- well, it was a horrible -- it was a nightmare experience. That's all I can say, really.

Q. At that stage, were you or Denise offered any form of counselling or practical support?

A. No.

Q. Or psychological support?

A. None whatsoever.

Q. You said this in your evidence to the Archer Inquiry:

"We were basically left on our own, a very bewildered couple."

A. Yes, describes it well.

Q. Now, within a few months of your diagnosis, Denise was pregnant.

A. Yes.

Q. And what can you recall about going to doctors for any advice or assistance in relation to what you should do?

A. Nobody -- nobody could give us any concrete advice. Obviously Denise was tested, she was negative, but they said at the time that the test could take a while to come through and if she was positive, there's a good chance the baby would've been and all this, and we had to think about whether abortion, you know -- but we didn't get any actual real advice and so we ended up going to a GP in the end and saying, "Look, what do we do?" And all he could say to us was -- he said, "I believe in God, the only thing I can tell you is put it in God's hands." That was the advice we were given.

We went ahead with the pregnancy. Luckily enough, everything turned out okay, you know. Denise wasn't infected, nor was *[redacted]*, and -- but at the time there was very, very little advice what to do.

Q. What can you recall about the circumstances of Denise's admission to hospital when she was giving birth?

A. That was -- what should've been a happy time, because of the hospital staff, wasn't a happy time at all. Denise was put right at the bottom of the corridor in a room on her own, there was -- she had -- even though

she wasn't infected she had biohazard stickers and everything there, and the staff took me to one side and said, "Do not -- do not tell anybody up here what you've got because it will clear the ward out as quick as anything. Nobody will want to be up here."

So it was almost -- everything was done covertly and -- yeah, we were made to feel like lepers, basically, and -- yeah, that was how it was at the time. Denise remembers that and -- yeah, it wasn't pleasant. What should've been a pleasant experience was not.

Q. After Liam's birth there were I think a few years when you remained reasonably well.

A. Yes, yeah, I did.

Q. You've said in your statement you tried to put your diagnosis to the back of your mind and get on with life.

A. Yes.

Q. You built up your business.

A. Yes.

Q. But you were very careful not to tell anyone --

A. Yes.

Q. -- of your diagnosis --

A. Very careful, yes.

Q. -- because of the stigma attached to HIV and AIDS which you were very well aware of from the media and TV.

A. Yes, it was awful.

There was a time -- when Denise -- obviously even if there had have been, but there was no such thing as paternity leave and I was self-employed so I had to go straight back to work. But luckily enough my neighbour, that was rented out to American personnel who used to work at the local base, well, they wanted me to paint the outside of the house and I said I will do that and I can keep popping back to see Denise and the babe. Anyway, we were out in the garden and we used to have the radio on, me and the chap who was working for me, and at the time there was a lot on the news, on the radio news, and there was an AIDS story. I forget, somebody that died, might have been Rock Hudson, I can't remember. But Denise was out in the garden, I think she was -- I don't know what you'd -- hanging washing out -- anyway, he says, "You know what I'd do with the bloody lot of them? I'd put them all against the wall and shoot the lot of them. Either that or put them on an island, dirty bastards." And I thought, "Oh no". Of course, Denise heard. She had a go -- I couldn't have a go because I didn't want to draw attention to myself, you know?

I thought, "Ah, he protests too much" type thing, you know. But that was the sort of attitude you got, and this was a chap who was working for me, you know, and I didn't realise he thought like that.

And, yeah, that was why you couldn't -- you couldn't possibly come out with anything, because can you imagine if I had, being a self-employed painter, nobody would've had me in their house. Nobody would've employed me. My business would've gone down the drain straight away. So I had to -- everything had to be kept quiet.

Q. Now, you then started to feel the physical effects of your infection.

A. Yes.

Q. You started to suffer from recurrent chest infections.

A. Yes.

Q. And on at least one occasion I think you had pneumonia.

A. Yes, I did, very ill.

Q. In 1991 you were involved in the HIV litigation.

A. Yes.

Q. We'll come back to the circumstances of that litigation at a later stage of your evidence, but you describe the mere fact of involvement as being very stressful and, again, something you couldn't talk to people about.

A. No. Just had to keep it in the family, you know. We had a family. Obviously the kids didn't know because they were too young to know then. Me and Denise had to keep it to ourselves. And it was -- people -- it was very difficult because people could see I was off work and back to work, off work, back to work. These are people who are close, you know. If it had been cancer or something like that, you could talk about it, but you couldn't talk about this because the stigma was too much. So you had to keep everything -- you couldn't talk about the court -- nothing, you couldn't discuss anything. Didn't even tell people I was a haemophiliac.

Q. If we have up on screen, please, Henry 1122008.

This a letter dated 4 July 1991 to a clinical psychologist, and we can see that it refers in the fourth paragraph to you having requested counselling and wishing to commence urgently, and it talks about there being a number of concerns:

"Certainly the question of how his children are to be told and how to handle that is one matter which I think he needs to address."

And then if we have up on screen, please, Henry, 1122009, we can see this is a letter back from

a chartered clinical psychologist in November of that year. It refers to him having met with you in July, and seeing you twice then on an outpatient basis, and then says this:

"Each time we have met he has wanted to unload the strong feelings that have built up. There are four people in his life who know of the HIV infection. He is generally reluctant to tell them when he is feeling downcast out of fear that it might worry them. The one friend he could talk to died last month from an AIDS-related problem, thus leaving him even more on his own. Alan appears to be a resilient person and one who draws strength from the love of his family. Nevertheless, he is facing stresses of major intensity and he does experience feelings of depression."

And then it talks about tackling the issue related to telling your children.

So by the middle of 1991 things have come to such a head that you wanted counselling.

A. Yes, I -- I know I needed -- I mean, it was -- I think Denise was the one who pointed it out. She said, you know, "You need to speak to somebody", and also my friend dying, you know, we were very close, even though he lived up in the north-east, but we met each other at a Haemophilia Society do, but still in touch with his daughter now, strangely enough.

And it was -- yeah, that year it was the -- yeah, it was tough. And also getting ill as well, myself, and -- even though I was back at work again. But when I visited him, or when we went up to visit him, his wife said, "You mustn't -- you mustn't tell him", because she phoned us up and said, "Look, Jeff's only got a couple of weeks", and I said, "Okay". And we -- we went up there but she said, "You mustn't tell him that he's dying because he will, he'll just go ever so quickly, so you've got to make out you was up here in the lakes and you've just popped in on the off-chance", so we did. That was awful. I couldn't say goodbye to him. I had to say, "See you again, come down, have a bit of Suffolk air, that'll do you the world of good". I knew that was the last time I was going to see him. We were very close, as I said. Yeah, yeah, he did, he died a week or so later. And, yeah, I felt awful then because I could see myself laying there, when I was visiting him. You know, I thought, right, that's going to be me, I suppose, you know, and it was not nice. It was a horrible time. Yeah.

Q. So you took the initiative to ask for counselling.

A. Yes.

Q. It hadn't been suggested to you.

A. Yes.

Q. I don't think the medical records tell us how long it lasts other than the documents we've looked at. Can you recall how many times you were able to see a counsellor at that stage?

A. I saw him two or three times only -- I used to come back and Denise would say, "How did it go?" I said, "Well, crap really". He didn't have a clue, you see. I mean, he's probably very good in his field, but his field was not HIV/AIDS or anything like that, and he -- I felt worse after coming away from him because he'd sort of sit there and go, "Oh, really? That's happened?" He was very -- ah, yeah, I felt as though he was off-loading more to me sometimes. So that finished.

I saw a nurse who was -- because I used to go in every month for sandoglobulin infusions, and a nurse there was very interested in psychology, but I just saw her now and again. But apart from that, there was nothing, you know, nothing.

Q. You had refused to go on a trial of AZT in 1989.

A. Yes.

Q. But there came a point subsequently when you did start AZT.

A. Yes.

Q. How was that? What side-effects did you experience?

A. Oh, it was horrendous. Because I was trying to carry on work at the same time. I -- it -- it was -- I could -- there was -- I could hardly hold a paintbrush, you know? Your whole body was affected. It was -- it was a -- it was a horrible, horrible thing to have. You had headaches, you had sickness. It was -- it was horrible.

When I phoned the doctor up who prescribed it he said, "Well, yeah, that's normal, that will pass, keep with it." But it never did really pass. And I was, as I say, trying to work, but I was going to sleep in my dinner break, that's how bad I felt. Then you had to come home, you had to then go out and price jobs -- it was -- it was horrible, because it just affected -- affected the way you lived, the way you slept, very fitfully, you know. It was a horrible -- but you were told at the time, "That's the only thing for you. If you don't take it -- well, you'll probably die anyway, but if you don't take it you'll die quicker", so in the end you take it because you've got a young family and you want to keep alive for them. But, yeah, not nice. Not nice.

Q. By 1994, your physical health was very poor.

A. Yes, yes.

Q. You were advised to take a break from work --

A. Yes.

Q. -- which, because you were self-employed running your own business, meant you no longer had any income.

A. That's right, yeah.

I can remember -- because I had to let the chap go -- no, I didn't, actually, Denise was taking him to work, weren't you? Because he couldn't drive. I was at home and couldn't even tell him what was the matter with him, you see. I couldn't pay the wages in the end so we had to let him go. And I couldn't go out and price a job, so the jobs dried up, and I remember Denise sitting in the garden one afternoon in tears because we didn't know if we're going to be able to pay the mortgage, you know, and the bills were piling up, and it was tough. It was a tough time. It was a very tough time.

Q. You got a Motabilitycar, but what happened to it?

A. Well, because we lived in a little close, the rumours were circulating about me. I didn't realise at the time until later that my children told me there was rumours at school and I was -- they said, "Oh, is he a drug runner? Where is all his money coming from?" They knew I was a haemophiliac. We didn't know if people were putting two and two together or what was happening, but one or two people stopped talking to us, and we got the car and within two days it had been vandalised.

So, yeah, someone put a brick to it, so that had to go and be repaired and come back and the same thing happened again. We reported it to the police. The police took it so seriously they put a camera in your bedroom, didn't they, a surveillance camera to -- to -- but the only thing that happened after that was the aerial was broke -- the pictures were so bad they couldn't see who done it, so yeah.

Q. You describe in your statement one occasion when you went away, you returned from holiday, and the window frames on your house had been vandalised.

A. That's right, they had. Somebody had thrown -- well, I don't know, some -- something over them. I don't know whether it was acid or -- I don't know. But -- that's then I said, "That's it, we're going to move. We're going to have to move."

It took us a while to find somewhere, but we did, we moved.

Q. You said you didn't have the energy anymore to fight your illness and to continue working.

A. No -- well, that was what I was told by the doctor --

they said, look -- I was having reoccurring infections monthly, really, and some of them were -- were laying me low. And -- and she said, "Look, you can't -- your body's only got so much energy, you can't do both, you can't work and fight the virus at the same -- because you're going to be dead within six months. Prognosis is not good anyway, but you're going to have to stop because your body can't physically do it." So I had to stop, and stop I did, and there you go.

Q. It was around this time, I think, that you made a will.

A. Yeah, we were told to put our affairs in order, "Go and make your will", which we did, and sort of like sit back, prepare to die, basically.

Q. In April of 1995 you discovered that you had been infected also with hepatitis C.

A. That's right.

Q. How did you learn that information?

A. Oh, once again, I didn't even know I'd been -- I didn't even know I'd been tested for a start. But what I used to do -- I mean, in the early days they used to try anything to try and improve your immune system, keep you alive, and one of the things that they'd done, they'd -- I had to go in hospital once a month for what was called sandoglobulin infusion,

they give you about 8 pints of sandoglobulin, and they thought it would boost your immune system. There wasn't any concrete medical evidence, but they thought it would help, and so I did. I went in every month for two or three years. We used to call it my petrol, didn't we? "You're going in for your petrol."

When I was in there, like I say, as an inpatient, you then had to at the end of it go and sit in the sister's office to make the next month's appointment, you know, make sure there was a bed. And I was sitting there and my notes were on the table, you know, and there was elastic band around them, but underneath the elastic band was a little form from the lab, you know, one of these lab forms. I just looked at it, it said: hepatitis C positive. I thought what? You know.

Anyway, sister came in and I said, "What's this?" She said, "Oh, you shouldn't have seen that." I said, "Obviously", I said, you know. She said, "I think *[redacted]* wants to talk to you about that." I said, "Yeah, I want to talk to her."

And so I did, I saw *[redacted]*. *[redacted]* was my haematologist, and I said, "Why didn't you tell me I've been" -- "Oh," she said, "but you know you have a full blood count and things like this." I thought,

well, that doesn't cover it, not really. I said, "Me finding out like this?" "Oh," she said, "I've told you, you know, you're quite resilient." I said, "I'm pretty bloody angry, you know." I said, "I found out, you know, I had AIDS from a bloody letter, and now this?" I said, "Can't you get anything right?"

Then she writes -- luckily enough, because once again the lab note is not in my notes, strangely enough, but luckily enough -- well, this is what you're going to come onto next.

Q. It is. 1122012, please.

We can see this is an entry in your notes from 13 April 1995. It says:

"The hep C serology is back and he is hep C AB positive. Unfortunately he had seen the form on the front of his notes. He says he feels all right about it as he expected it to be positive anyway."

You take issue with that, I think.

A. I couldn't expect it to be -- I didn't know I'd been tested, so how could I expect -- how possibly could I have known? And I was angry really because I thought *[redacted]* at the time was okay, and -- but looking back on my notes -- because you never saw your notes in those days, you didn't know what was written about you, and that's -- I hate to say it, but bullshit basically, and a lot of it is, and they -- what I found with doctors is they'll write the notes to suit what they think, not the actual -- you know, the facts of the time. And that -- I was not all right with it. I didn't even know I'd been tested. I mean, Denise would've known. That's bull -- that's rubbish.

Q. Just for the sake of completeness, it continues:

"However I apologised as I would like to have told him myself."

A. Yeah, that's -- yeah. Apologise. Bit late, but there you go.

Q. By 1996, so the following year, you were finding life very difficult.

A. Yeah, I was. I had gone on to some other drugs, antiretrovirals, and they were just as bad as the AZT, and I was -- every day was -- yeah, it felt -- you felt rotten everyday, really. Sickness and diarrhoea was awful and -- and obviously -- I swear they played with your mental health as well, I think.

Q. You had night terrors.

A. Yes, I had terrible night terrors. Denise -- I used to have -- yeah, horrible -- I think it might have been -- because I was on something called efavirenz at the time, and a lot of people have said that affected

them that way. But I was on other -- I think I was on the triple combination at the time.

But the drugs were horrible, and I'd lost my business, obviously, and I'd become part of a group called the Birchgrove Group. And that was a group set up by haemophiliacs for haemophiliacs because we found that we didn't have anywhere to go, you know, there wasn't any support group for us. There was for drug addicts, you know, for gay men and -- but not really for -- so that was set up, and I became a member of that, and that was fantastic, but it had a downside because you -- people used to say, "Well, you're a grown man, why do you hug each other at the end?" Well, we didn't know if we were going to see each other again. We were dying at quite an alarming rate, and I did lose some friends, and I had lost -- lost a couple of close friends then, and the drugs and -- I just didn't see a future, really, and I didn't like what I saw in the future. And I -- yeah, I had a breakdown, basically.

Q. You've said in your statement you were not a nice person to live with for your family.

A. No, I wasn't. I -- my daughter will tell you and my wife will, because you take it out on your nearest and dearest, don't you? You know, I wasn't -- it wasn't

their fault, but life was horrible, it wasn't nice, and it just seemed to get worse, not better.

Even though they put you on a new drug, you think, "Oh well", but you just feel as though -- it's almost like being on -- it was like chemotherapy every day, you know, whereas chemotherapy people have it for six months, and, yes, the effects of chemo is horrible, but they know there's going to be an end to it. But with this there didn't seem to ever, ever be an end. Yeah, it wasn't pleasant.

Q. And there came a point where you decided that you were going to kill yourself.

A. Yeah, I did, yeah I ... I used to go on what they used to call walkabouts. I'd take myself off. They wouldn't know where I'd been. I thought, "Right, this is it, I'm going to do it", and I -- they couldn't understand why I took a load of socks. That was because I'd read, you put the hosepipe in the exhaust, you've got to make sure there's no gaps and everything. That was -- that was what I was going to do. But I got out to the countryside and ... I don't know really what stopped me.

I was thinking about it, and then my sister found me, funnily enough. I think the police were informed and all this because I was on drugs and

whatever. But it was my sister who eventually found me, and I didn't do it, obviously, because I'm here. But I was then admitted into hospital.

Q. You were admitted to St Clement's Psychiatric Hospital.

A. Yes.

Q. And you described yourself as having had a complete physical and mental breakdown by that point.

A. Yeah, it was -- that was a horrible period. It was not nice.

Q. And your wife talks about having an additional secret to keep because now she had to keep secret the fact that you were in a psychiatric hospital.

A. Yes, because obviously then -- I mean, you can talk about mental health issues now, and people will have empathy, but then it was just -- no, that was a definite no-no, you couldn't talk about it then at all.

Q. You stayed in hospital for some 4 to 5 weeks, I think.

A. Yes.

Q. After you were discharged you saw a psychiatrist, but did that help? Did things improve?

A. No, no, not really. Well, actually, they discharged me and I didn't see anybody for a while. That was only because I had made my own arrangements to try and find somebody, and I found somebody in Norwich, but Norwich is about 45 miles away so -- that was the nearest, and it was always down to me to try and do it, you know, there was no real help. But I recognised I needed the help, but it was almost impossible to find, if you get my drift. Once you were let out of hospital then, that was it. They -- they'd think, "Well, you know, we've done our job, on your way", so ...

Q. It was at this time that you and Denise separated.

A. Yes, yes, it was, yes. Could you pass us a tissue?

Yeah, it was. What had happened was I -- I was just as bad, I got bad again, because the help wasn't there, really, and I was regressing again and I -- I knew, I knew I wasn't a good person to live with. I didn't even like myself, if you know what I mean. And we were rowing a lot in front of the kids, and -- yeah, it was -- it was a tough time. So we did, we separated.

MS RICHARDS: Sarah, can I ask you before I ask you about your recollection of the time when your parents were separated, can I ask you first of all about your recollection of how you were told and when you were told that your dad was HIV positive?

MS ADAMS: It was 1991. I was 11 years old. I was

helping Dad paint the kitchen ceiling, bizarrely, and I think something had been on the radio, and we stopped what we were doing, and it was at that point I was told that he was HIV positive, that he had been given some "bad blood", and we didn't -- we didn't know what was going to happen. We knew he was, you know, very poorly. We'd seen him come home from work and disappear up to his bedroom and we wouldn't see him for the rest of the evening. And as children -- well, me at that age, we always wondered why, and obviously that was then the explanation as to why he was so ill.

Of course, the first thing that goes through your mind at that age is, well, you know, Dad's going to die, and he's going to die soon, because that's all you ever saw in the press, and everything else was, yes, there were people out there with AIDS, but they would be dead before you knew it. And so that's naturally how, you know, we led our lives, thinking that, you know, this was going to be it.

Q. And you -- you're the eldest?

A. Yes.

Q. You weren't able to talk to your siblings because they were younger and didn't yet know.

A. Absolutely.

Q. You were sworn to secrecy?

A. Yes. Because of the stigma that was out there, it was for our protection, really. I can understand why I was sworn to secrecy. But, yeah, I wasn't allowed to tell a soul, so the only person or people I did have to speak to was either Mum or Dad, and I didn't want to go and speak to Dad, so Mum was obviously there for me at the time, and, you know, sleepless nights and tears. I mean, I'm exceptionally close to my dad, always have been, and so -- yeah, it was -- yeah, it was awful.

Q. When you were about 13 you asked your parents for permission to tell your best friend at school so that you could have someone to talk to.

A. Mm.

Q. What happened?

A. Rumours started flying around, unfortunately. I mean, not blaming anybody, but that's what kids do. It didn't take long before the wrong people in the school knew, started casting their own opinions about how Dad may have become infected and, you know, where we were getting money from, because not long after that we went on holiday, a holiday of a lifetime to Florida, and yet Dad wasn't working, and how on earth did we have this brand new car? How were we going on

holiday? You know, he was known at school as the local drug dealer.

Q. The car in fact was a Motability vehicle.

A. Yeah.

Q. The holiday was paid for out of the money from the HIV litigation settlement.

A. Indeed, indeed, but as children they don't obviously see that. It didn't take long before people would stop coming round, and after this had happened as well, Mum and Dad being on benefits that they were, we were then entitled to free school meals. Well, at our school you had to queue up separately for your meal ticket if you were on free school meals, so that in itself brought a huge amount of stigma as to why is this happening, so it was easier for us just not to get the free ticket and not to eat our meal. So we wouldn't eat during the day, it was just easier that way. The taunting, the name-calling, the bullying, and -- yeah, not pleasant.

Q. Your dad told you of his hepatitis C diagnosis about the time he found out himself.

A. Pretty much as soon as he knew, he told us. I know it sounds crazy, but when you're going through your mind, oh, your dad's got AIDS, to then be hold he's got hepatitis C, you're a bit like, "And?" It was almost dealt with like a secondary illness, even though it's not, it's equally as important and sometimes can be worse. But no, we didn't -- we didn't see it as an equal. It was almost shrugged off in the family as well, "Okay."

Q. Your dad's described the breakdown he had. What can you recall about that time?

A. Oh, it was awful. So like he said, Mum and Dad were rowing constantly, always fighting. Dad was like Jekyll and Hyde, you know. One minute he'd go into one room, be pleasant and joking, the next minute he'd be ripping your head off for putting the toilet roll round the wrong way. Little things like that. It was that intense at home.

He would go missing for hours. Sometimes longer. We wouldn't know where he was.

He just wasn't a very nice person, to be perfectly honest.

Q. You've described in your statement pupils at school making AIDS jokes and jokes about psychiatric hospitals.

A. Indeed, yes.

Q. You had to just put up with that?

A. That's right. Our local psychiatric hospital was always the butt of jokes with kids, you know, "You'll

end up in St Clement's", and this, that and the other. Well, that's where he was and had been. So all you heard was the AIDS jokes, you know. Mental health isn't the way it is now, you know, it was the butt of all jokes back then, and so I'd just have to go along with it, really. It was easier that way than fighting what they were saying.

Q. And your parents then, as we've heard from your dad, separated for a period.

A. Mm.

Q. What was that like for you and your siblings?

A. It was awful. I think I must have been about 19 or 20, I think, when they separated. We were torn completely. Mum wanted us with her to look after us, of course, but in all honestly this whole thing hadn't made her a nice person either. Dad wanted us with him, but we couldn't do that either. Fortunately, the job I had at the time led me away, so I managed to escape a lot of it. I was flying around the world, so that's what I did. I just didn't want to be at home. I couldn't be anywhere near either of them. To be honest with you, they were both vile.

Q. Your sister and brother have both made statements, but your sister's made one that, because she can't be here today, she would like to have me read out about her

experiences at this time, so I'm just going to do that.

A. Yes, thank you.

Q. This is from Laura, and it says this:

"I was 11 years old when my parents sat me down and told me, 'Your dad's not well, he has something called HIV.' As you can imagine, as an 11-year-old, I was petrified, confused and upset. I knew something wasn't right as my dad was always ill and he always went to bed after work, so we barely saw him.

"I had seen the AIDS adverts on TV and so had my friends at school, and they always joked about the 'gay plague'. I couldn't tell anyone, sworn to secrecy. It made me feel isolated and alone. I even went to the extremes of not getting my ticket for a free school meal at lunchtime so no one would ask me why I get them. It was easier not to eat than to have to lie.

"Eventually my dad had to give up work because he became so ill. This then meant that any time my family had anything nice or went on any holidays, it would go around the school that my dad must be a drug dealer, as that was the only plausible explanation as to how he could afford things. This was humiliating and embarrassing.

"Home life was hard. My mum and dad argued a lot. My dad had developed a terrible temper, to the point of even if you put the toilet roll on the way he didn't like, it made him uncontrollably angry. Things got so tough that my dad had a nervous breakdown, and this was horrific to watch. He was put in a mental hospital for a few weeks to recover. He has since had two other nervous breakdowns, one only just recently.

"When my dad got out, I remember he used to disappear for days on end, and no one would know where he was. It was terrifying. Every time my dad would get ill, we all used to worry that this was it. It was like living a rollercoaster of emotions all the time.

"My dad's drugs to treat the HIV were highly toxic, so seeing him in so much pain and bedridden while his body got used to them tore me apart. Even if he did get used to them, there were never any guarantees that they would work as my dad had become immune to so many drugs. This was always a worry as we never knew if they would eventually run out of options to treat my dad.

"As a teenager, living this nightmare was horrific. My family fell apart and eventually my parents separated, although they did reconcile a few years later.

"For me, my dad's illness has had a massive impact on my life. I have been basically robbed of any sort of normal life. It has had an effect on who I am as a person, one who struggles to deal with life's pressures. It has had an effect on all of my friendships and relationships. I have suffered with depression since the age of 14, seeing endless counsellors and taking a variety of different medications.

"At 19 I began taking drugs and self-harming, eventually leading to a suicide attempt where I was hospitalised. I just didn't want to be here anymore. I am still suffering from severe depression now, and I have debilitating anxiety. I am under the NHS for my mental health and I am awaiting a psychologist appointment, which I have been waiting two years for. My mental health has again reached a very low critical point.

"I have never come to terms with my dad's illness and the way in which he contracted it, and it feels as though my family and I have been living a 30-plus-year death sentence. The rollercoaster that we have lived through with all the inquiries and promises has been heartbreaking, and I simply do not

think our community can take another knock-back."

That's Laura.

A. Mm.

MS RICHARDS: Alan, I think you didn't know the full extent of Laura's struggles until the Archer Inquiry.

MR BURGESS: No. No.

We were both invited to give evidence at that, and I gave mine, but Laura started to give hers, but she broke down, and I had a close friend, Gareth Lewis, he took over and he read Laura's statement for her, and then I was -- I didn't know but -- I didn't know just how bad it was, you know, ,regarding the suicide. So, yeah, that -- yeah, that -- that hit us -- hit me.

I think my wife knew more, but she didn't tell me because she didn't want -- she thought I had enough on my plate, really. But it was a shock, and -- it's -- even though I was the one got infected, it didn't just happen to me; it happened to the whole family, and it is still happening to the whole family. And -- yeah. Yeah. That's why I have sometimes these -- these feelings of guilt because, you know, it's me that has -- that's -- I'm the reason why, you know, the family's like they are, and that's hard to -- you know, to come to terms with that sometimes.

And I know what happened to me wasn't my fault, but you know -- you know that it's not how a family should be, really, and it will never be right. But there you go.

Q. You and Denise were separated for three/three and a half years.

A. Yes.

Q. But you had stayed friends.

A. Yeah, yeah.

Q. And you reconciled.

A. Yeah, I got -- I recognised -- I recognised the problems in me again and I did, that's when I got help, and I had an organisation in *[redacted]* that helped me. I forget what they were called. It was an AIDS organisation. And they told me this woman up in Norwich, and she helped, and I went up there quite a few times and she -- I could feel, you know, the -- what she put in place for me was working and helping me, and, yeah, I think Denise could see the change in me and the kids, and we did, we started courting again, you know, and we -- and then eventually we reconciled which was nice. And we're still together, just!

But she has been a rock, you know. She didn't sign up for this. She didn't -- yeah, it's -- yeah,

it -- we're back together, but the problems are still there, but it's how you deal with them, isn't it?

Q. Although at this stage your mental health was improving, your physical health was declining.

A. Yeah, yeah.

Q. By January of 2002 you were resistant to the drugs that you were being given for HIV.

A. Yes, I was on what was called salvage treatment. At the Chelsea and Westminster Hospital. But I got so ill. My viral load was off the chart, more or less, and I'd got very, very -- very few cells, CD4.

I remember I went into hospital because -- Macaulay Ward there, and Professor Gazzard, who I was under, sat on the bed and he said, "Right, we've got one more set of drugs", and he said, "You're in the last-chance saloon. I hate to put it that way, but this is the last-chance saloon." And luckily enough -- well, it took a while, I was in there a few weeks, but they did, they -- they luckily enough worked. But once again the side-effects weren't that great, but I was in hospital to deal with them, so it wasn't quite so bad as being at home.

Q. You have over the years suffered numerous significant physical health difficulties, either as a result of the infection directly or the treatment you have received for it.

A. Yes, yes.

Q. You've had mouth ulcers.

A. Yes.

Q. Skin infections.

A. Yes, and candida, you know, throat and -- yeah, yeast infections, all sorts. Chest infections are the worst. It seems to go to my chest.

Q. You've had cardiovascular difficulties.

A. Cardiovascular problems have shown up. Bone thinning has shown up. Sorry? -- oh, yeah, pancreatitis from the drugs. Kidney -- I have had stage 3 kidney disease because of the drugs and the HIV.

Q. And --

A. So that's had an effect on my body.

Q. And it's relatively recently that, again, you've had to change drugs again --

A. Yes.

Q. -- because of the kidney implications.

A. That's right. I was on a drug called Truvada, and my results weren't very good kidney-wise, so -- it weren't just me, actually, quite a few haemophiliacs, might be people in general, were taken off Truvada straight away because they realised it was damaging the kidneys.

Because I'm under Professor Nelson now, but as I was explained by him, the trouble is we're at the forefront. There's nobody in front of us, you know, because we're the first generation, so to speak. We're long-term survivors, and there's nobody else in front to gauge these drugs to. I mean, they're on the market pretty quick as it is, and sometimes you're on named patient basis only. But that is the problem.

So, yeah, who knows what's in the pipeline next really, what's going to affect us.

Q. You've put it this way, Alan:

"HIV/AIDS medication has played a massive role in my health over the years, both physically and psychologically ..."

And will continue to do so because you are on medication for life.

A. Yeah, that's it. You're on it for life, and, you know -- unless they come up with a miracle cure, which I don't think they will because there's too much money in the drugs themselves, so I doubt there will be a cure. So, yeah, that's -- that's until I die.

Q. At some stage you were told also of the risk of exposure to vCJD.

A. Yes.

Q. What can you recall about that?

A. That was my haematologist just said that in all probability one of the batches or whatever it was -- they recognised that there was a risk, "But you're not going to get it, because the only way that we can test you is if you're dead and" -- I don't know, the brain or the tonsils, "But you're at risk, we have to tell -- you have to tell either dentists -- and obviously they will take note of that -- any future operations", which they do. I'm always last going in because they have to do a deep clean and what have you. So, yeah, that was -- I didn't really take too much notice of that, really, to be honest, because as Sarah said, that's just something you've just got to -- you know, you've got enough on your plate. If that was on its own, then yes, you'd probably think, "Oh, blimey", you know. But because you've got so much else, it tends to get put to the back of your mind and you don't think about it too much, until you do go in hospital, then you realise you've got it because then we've got to have special equipment and all this sort of thing. But that's what happens.

Q. You've not had any treatment for hepatitis C.

A. I had a liver biopsy in the 1990s, I can't remember what year it was, but that showed everything was fine.

The problem is, what I was explained, I could've

gone on interferon and -- what's it called? Pegylated -- anyway, they said the trouble is because of your HIV and because it's -- you know, the drugs go through the liver, sometimes it can upset your HIV, make it worse, so if it's not broke, don't fix it, and that's the advice I've been given. So, no, I've not had any treatment for that.

Q. Your statement says you do have some ongoing monitoring of your liver. What does that comprise?

A. Yes, Professor Nelson at the Chelsea and Westminster -- I used to go to Addenbrookes for it, but he said, "Look, I can do that here, save you a trip", so they look after me there. So he monitors everything and does my liver function tests and everything, so yeah.

Q. In terms of your physical health at the moment, Denise in her statement says you continue to get extremely tired.

A. Yeah, that's fatigue, really. I mean, obviously I'm not getting any younger anyway, but, yeah, it's -- it's fatigue. It's -- come the afternoon, that's it, I'm like an old man sometimes, you know, have to have a sleep and -- yeah, I do get fatigued very quickly, very quickly.

Q. In terms of your mental health you've told us about what happened and the events that led to your first inpatient admission.

A. Yes.

Q. But you've continued to struggle with your mental health.

A. Yeah, I do. I think I will probably until the day I die. But it's not helped by -- over the years, we've -- obviously you give up your job, you give up your livelihood and the business you've been building and what have you, and to -- for a man, you know, to -- you know, it's not right, you feel emasculated, and to have to rely on charity and benefits, I mean, that's a daily thing and you don't want that. All we've ever asked for is financial dignity, but we've never got that. And that affects you.

Also, because we were -- I mean, we were lucky to get a mortgage, but the only mortgage we could get, because we couldn't get life insurance, was one that you had to -- you just paid the interest off each month and you had to pay the capital amount off at the end. Well, that meant that you had to save up for the capital amount. But the trouble is when you're on benefits, it then flags up once you go over certain savings. And I've had awful letters come saying, "Right, you know, we're going to interview you under

caution" and all this. And, "We think, you know, you're guilty of fraud". That's how it used to be when it first started off. Then we explained it and we thought, "Right, lovely, they won't investigate us again" -- because any money that came from the Macfarlane Trust was -- you didn't have to declare for benefits or for tax purposes, that was one of the things they put in place, which was good. But every year or twice, three times a year, you get these letters saying, "Right, we're going to come and visit you, we want to see all your banks books, we want to see this, that and the other", and you'd explain and say, "Can't you just put a note in my file?"

They used to come round. Denise would cry sometimes, because sometimes they'd be quite nice, sometimes they'd be horrible. When my son was living there, they went through his bank books and everything. Can you imagine how I felt, asking my son -- anyway. That was ongoing.

Then eventually, because when I was self-employed I put money in pension pots and everything, the law has changed now, you can get hold of your pension now, so when I was 60 I said, "Right, that's it", that money -- we were going to use it for, I don't know, holidays and goodness knows what else,

but I said, "Pay the mortgage off, I've had enough of this now. Every bloody year, two or three times, they'll come in and investigate you."

Lo and behold, we had done that, but this year, twice within four months, I get the first one, that was DLA to PIP, so you have all these forms to fill in again, you have to get -- you have to prove how ill you are still, and then two months later I get the other one and that's for ... and that's for care allowance and what have you, and you have to fill the same forms in again. That's another layer of your dignity stripped away from you every time you fill these bloody forms in, every time you have to write a letter to Macfarlane Trust, you know, or whatever, EIBSS. You feel like you're begging. And that has an effect on anybody, let alone a man, but a man, you feel like you should be providing for your family.

So it affected me mentally. I'm trying to say this -- this is ongoing, and I haven't heard back from the DLA thing, and funnily enough the other form I sent Saturday, but this is -- and you have to prove -- I think, "You buggers give this to me, yet you're making me jump through hoops, making me prove how ill I am, how ill you've made me?" And that's almost like they get some perverse enjoyment out of

doing it, and that's not -- we've been asking for years for this to stop, to be passported or whatever, but no, it's not happened. And that's another thing that you have to deal with, you know.

I don't know if there's a name for fear of brown envelopes, but I fear brown envelopes now, you know. I do, I fear them. But there you go.

Q. And what you've described as one of the factors that precipitated a breakdown of some kind this year.

A. Yes, yeah, I had a few family problems as well, to be honest. These two investigations, assessments whatever you want to call them. And then obviously -- I mean, it's great having the inquiry, it's brilliant, we've been calling for it for years. But I had to go through a lot of my old stuff, because I did keep a lot of old stuff, much to my wife's annoyance, she always thinks I clutter the place, but I went through things, that brings back memories, things that you lost, things that happened to you. And -- yeah, and that all -- yeah, perfect storm.

Then what happened was I ... yeah, I -- I did, I had a break -- I knew -- I knew I was heading for it, but when it happened, I thought: no, I've had enough now. I really did, I said: that's it, I'm -- I can't ... I can't put up with life anymore, you know. I'm just fed up with these bloody intrusions -- you just want to get on with your life as much as you can, but it's intrusion upon intrusion upon intrusion.

And I was -- I was going to -- yeah, I thought I'm going to -- but this time I decided to do it in a slower way. I decided to stop taking all my meds, all my medication, because I had a friend, a very close friend, he -- his first marriage failed because his wife couldn't deal with the AIDS aspect of it. He thought he'd met his soulmate, he had, but she died and he was devastated, so he decided to stop taking his medication and 18 months later he was dead.

I thought: right, that sounds good, I'll do that because the only person I'm hurting is myself. So I did, I stopped taking them for over a month, but I started to get ill. Because my wife sorts out my drugs, she knew, but I said, "I'm not going on them. I've had enough, Denise, I just want to" -- you know.

And -- but in the end I -- I went -- I was in a bad place, weren't I? I just had a complete breakdown and Sarah, bless her, she -- she lives in *[redacted]*. She drove from *[redacted]* to *[redacted]*, and I didn't know -- because I was just -- I was -- I was just a shell, really, I was crying and -- that was horrible. And you took me up to hospital, didn't

you? I saw a psychiatrist up there, and she admitted me and I came out a couple of weeks ago, so here I am. But, you know, I'm -- I'm not recovered, I don't think you can ever recover, but I've got help this time and I'm putting things in place. And -- yeah.

But that's what this has done to me, you know. This is -- this is -- anybody knows me think, "Oh, he's Jack the lad" and everything, but that's tears of a clown type thing, it's something that's affected me and the whole family, and trying to deal with it better this time, though, and hopefully I will.

MS RICHARDS: Sarah, you were closely involved in relation to your dad's recent admission.

MS ADAMS: Yes.

MS RICHARDS: Is there anything further you'd like to say about that?

MS ADAMS: Yes. When you see your dad going downhill psychologically over a course of months, it's hard to take anyway. But then when you see him almost a shell of a man saying he wants to take his own life -- -- you know, he told us how he had prepared for it, he knew exactly what he was going to do and the day he was going to do it. Fortunately there was something that he saw that stopped him.

MR BURGESS: I saw -- I was going to do it on this day

that my wife had gone to *[redacted]*. I couldn't go with her. I said, "I can't face anybody", and I thought: right, today is the day, I'll do it.

And I was going to -- I had all my drugs there, but I was closing down my laptop and -- whether this is fate or not, I don't know -- but as I was closing down the windows, it was a Facebook, and there's a picture of Sarah and Mark, Mark my son-in-law, at their wedding, and I thought: what on earth is that on there? It was their wedding anniversary. And I thought: I can't do that on their wedding anniversary. So obviously I didn't -- because I seriously was -- and so I didn't. And there you go. But, as I say, I stopped taking my drugs anyway so -- sorry.

MS ADAMS: No, that's fine.

And, yeah, so obviously we learnt about this, which breaks your heart anyway, of course. Just seeing him rapidly decline quicker and quicker, and the drinking had become an issue as well because it was almost like a sticking plaster over the pain that he was going through, so he would drink and drink and drink and drink, and -- and then he decided, like Dad said, about the medication strike. So every time we would mention it, it would be, "I'm another day closer

now, I'm another day closer."

When we had to have him admitted that day in *[redacted]*, I'd driven down. They didn't know I was coming because unfortunately the doctor should've arrived at Mum and Dad's house the day before to assess him, and the doctor had gone to the wrong address.

In hindsight, it's actually a good thing, because I think had the doctor have gone to Dad's address, I'm not sure he would've been admitted on that very day. But fortunately when I arrived in *[redacted]*, Mum and I managed to get him an appointment to be seen that lunchtime, and the psychiatrist wanted him in there and then.

To take him up to the ward, it was so painful, to -- the look of a 3-year-old innocent child just looking at you with wanting and, you know, "Why are you leaving me here?" That is how it was. He was a child, on that day. I was the parent, he was the child. Something I never, ever want to do ever again. That was one of the hardest days of my life, having to do that to him.

He was on suicide watch in the hospital as well, wasn't allowed any cables, leads, anything like that in his room. And he was still adamant, even when in the hospital, "I'm not taking my medication, I want to die, I have to die." He'd wake up angry every morning at the fact that he'd just woken up. He didn't want to be here anymore.

Fortunately the care within the hospital was outstanding. He's not better, I don't think he'll ever be better, but with help, you know -- we're going to get you there.

MR BURGESS: We'll get there, we'll get there.

MS RICHARDS: Sarah, can I ask a little about the longer term effects of everything that we've heard from you and your dad on you.

MS ADAMS: Mm. Well, I'm currently signed off work at the moment through depression. I'm on antidepressants myself. You just have to be strong, but you can't always be, you know. Seeing Dad go through what he goes through, it does have an impact on us all. Even goes as far as my children. I've got a 13-year-old daughter who has known for a couple of years now and she struggles a great deal with all of this. And because of the inquiry I've just recently had to tell my 11-year-old daughter as well, something that you don't want to sit down, you know, and tell your children that their beloved grandad has got what he's got and why he's got it, you know. I've got another

son to have to deal with when that time comes too.

I worry constantly, obviously. I live 130 miles away from Mum and Dad, so the constant worry of can I get there on time, if anything were to happen, you know, things like that really. It's -- I struggle.

MS RICHARDS: And I wanted to ask you next, if I may, about some of the financial and employment affects of your infection and treatment?

MR BURGESS: Yes.

Q. Then I'm going to ask you more broadly about your involvement with the Macfarlane Trust and the Haemophilia Society?

A. Yes, yes.

Q. As you've told us, you had to give up your employment.

A. Yes.

Q. Your job. You had to move home. You could only then get the interest-only mortgage.

You were involved in the HIV litigation in 1991.

A. Yes, yes.

Q. What can you recall about the way in which that ended?

A. Well, it ended quite abruptly, really. Because we thought it was going to court, Justice Ognall at the time was presiding over the case, and we were all ready for our day in court, really, and I wish we'd had it, to be honest. We might not be here now,

because I think the facts would've come out and we'd have been in a better place.

But Margaret Thatcher left and John Major came in, and the next thing you knew they -- I wouldn't say offered, they didn't offer the money, we were told the money was going to go to the Macfarlane Trust and then it was going to be distributed to us, but we'd all have to agree to have this money. Because it was in the days before social media, so you didn't really know anybody else going through it. I certainly didn't. So when you go and see your solicitor and the solicitor says, "Yeah, good news" -- well, they thought it was good news. And I must admit, at the time, prognosis wasn't that good, and you think, well, they offer you this money, you have to -- you have to accept or nobody gets it.

Also, there was one other -- there was one other caveat that they put in place, and that was that you had to sign the waiver, that you wouldn't take the government to court on any other blood-borne viruses in the future. I discussed it with Denise.
I thought: I ain't got that long anyway. I said, "Is there anything in the house you need?" I thought I'd try and get the house in order before I do stuff it, so to speak, and had an extension done and I took the

family away, and that was that.

But we signed the waiver and I didn't think any more of it, to be honest, but now I realise we were coerced into it. That was sort of like moral blackmail, really, and there you go.

Q. At that time you didn't know that you had been infected with hepatitis.

A. No.

Q. Because you only discovered that in the way you described in April of 1995.

A. Yes.

Q. Were you also told that your Legal Aid would cease to be available if you didn't take the offer?

A. Yes, we sat in the office and they said if you refuse the offer, because you're on Legal Aid, that -- that that will stop. You'll then have to fight the case on your -- well, couldn't do that, so we -- like I say, blackmailed into it, really. You had to. You had no choice. That was how it was put to me.

I mean, solicitors' role in all this, I don't know what it was, but we didn't get the best advice, not really, at the time.

Q. In 1995, shortly after you learnt of your hepatitis C diagnosis, you wrote to your MP --

A. Yes.

Q. -- about what was then a campaign by the Haemophilia Society for those infected with hepatitis C. We'll just look at the response, Alan. It's 1122011. This is the Department of Health's response to your MP.

You'll see it says this. It's dated 19 May 1995:

"Thank you for your letter of 1 May to Virginia Bottomley enclosing one from your constituent, Mr A Burgess, about the Haemophilia Society's campaign on behalf of those patients with haemophilia who have been infected with hepatitis C. I am sorry to read that Mr Burgess has contracted the HIV and hepatitis C viruses.

"We have great sympathy with those patients who may have become infected with hepatitis C through blood transfusions or blood products. Most haemophilia patients were infected with hepatitis C before blood products were treated to destroy viruses. These patients received the best treatment available in the light of medical knowledge at the time.

"The health departments are considering a range of potential initiatives to improve the understanding, treatment and management of hepatitis C. This could include encouragement of research into the condition and guidance to the NHS on best practice where there

is a clinical consensus.

"The government does not, however, accept that there has been negligence and we have no plans to make payments to such patients."

Then the letter talks about not accepting the case for no-fault compensation.

And then if we go to the next page, please, Henry, the letter continues as follows:

"It is the government's view that the most effective use of resources is to seek to improve the understanding, management and treatment of the condition. Only in this way can the impact of the disease on individual patients and their families be effectively minimised. This department is supporting an initiative by the Haemophilia Society to undertake a study into the best way to support its members who are infected with the virus."

Then the letter ends as follows:

"I hope that this will reassure you that the government will do all it can to care for those affected."

A. That's a joke, absolute joke, but there you go. Everybody in this room knows it's a joke, but there you go.

Q. And that was the response that your letter got.

A. Yes, yes.

You've got to remember, I mean, I've been campaigning -- the first Prime Minister I wrote to was Thatcher, so good few years, but this was just -- really this was the sort of reply you always got, whether it was HIV, hepatitis C. They always thought that they'd done everything for us and continued to do everything for you, and -- yeah, brilliant, the government, superb.

Q. You've said in your statement that the monthly payments that you now receive from the EIBSS in relation to hepatitis C is the first time you've ever been able to put any money aside.

A. Yes, yes, the first time -- first time ever, yeah.

But you're playing catch-up, obviously, because funds over the years have been so -- so poor, you know. But, yeah, now it's -- yeah. I wouldn't say we're comfortable, but at the end of the day it's a lot better than what it was under the Mac Trust. Although I haven't got any time for EIBSS, don't get me wrong, but at least they've recognised now -- because even with the -- you couldn't even -- even though I had hepatitis C, you couldn't claim off the Caxton, you see, Caxton was set up just for mono-infected hepatitis C, so we wouldn't claim --

even though we had HIV and hepatitis C, we couldn't claim off them. So the fact you had hepatitis C was never really recognised by the government, as such, apart from the Skipton Fund, but that was a one-off.

Q. You've explained in your statement that you fell ill on a holiday and had to pay medical bills of £220.

A. Yes.

Q. And when you sought reimbursement from the EIBSS, what was the response?

A. They said they don't pay for HIV and only pay for hepatitis. So I said, "What? But you're there" -- said, "You could get that -- you've got hepatitis stage 1, but if you had stage 2 we'd be able to pay", and the same thing happened to me with -- because I asked for a funeral grant, told I couldn't get it. So I just find the whole set-up crazy, because they carried on what the Macfarlane Trust done, but -- I think I may have got the money off the Macfarlane Trust, but for some reason they're not recognising the fact that I'm co-infected, which is strange.

Q. What you said in your statement is health-related costs for those who are HIV infected, EIBSS has told you they would not be meeting those.

A. No, they wouldn't.

Q. You've suggested in your statement that it's part of what you regard as the suggestion that HIV should be downgraded because it's now considered a treatable illness.

A. Yes, well, as -- that's a ploy by the government to do that. I mean, they've peddled this myth -- I mean, yes, it's -- if you're diagnosed now, right, as awful as it sounds, but if you get in there quick, your immune system has not been damaged and you go on the medication, you can have a reasonably normal life, now. But people in here who, you know, are long-term survivors, the damage has been done to our bodies, you know, over the years. The immune system has been damaged, your kidneys, cardiovascular problems, mental health problems, yet the government want to band us all in together: no problem now, HIV, that's not a problem, you know, it's worse now having diabetes and things like that. Yeah, well, it may be for somebody newly diagnosed, but there's a whole raft of difference between somebody like the rugby player that was diagnosed the other week than us, you know, and that's what we're now fighting to try and prove, even trying to prove it to the organisation that is set up to help you, which is ridiculous really.

Q. And you've already touched on the problems you've had with the DWP.

A. Yes.

Q. As I understand it, it's the repeated requests to demonstrate that you are ill.

A. Yes.

Q. To fill in further forms.

A. Yes.

Q. To undergo further assessments.

A. More doctor's notes -- waste of my doctor's time as well, having to keep filling these bloody forms in, because he's as angry as I am, but what choice has he got? I have to do it. That's what they make you do, you know. You've got to remember, in the early days we were given this for life. They said, "Oh you've got this, we'll" -- but they only thought we were going to live three or four years, so they thought they were on a winner, but we lived a bit longer than they thought so they thought, "Hello, we'd better change the goalposts now", and that's what they done, and now it's worse than ever.

As Mark -- I mean, Mark gave evidence. He -- when he sees a brown envelope, and he's part -- you know, it affects you, it -- it's -- you know, I don't know, I can't really explain it. After a while, it just gets to you and you think, "Oh, for God" -- you know, you've just had enough. And I have had enough.

But what choice have we got though?

Q. You talk about it in your statement as being humiliating and soul destroying.

A. Yes, it is, that is exactly what it is.

Q. And Denise has said this in her statement from her perspective:

"People affected by this scandal should be able to have their own money without having to feel like they are begging for it. I want reassurances that whatever money Alan is receiving will be guaranteed for the rest of his life, without the need for constant check-ups and assessments. We are constantly worried that they could change the money tomorrow and we will be left struggling."

A. Yes, because -- just because we get it from EIBSS at the moment, that's under this government, and yet any future government can change that at a stroke. This is not guaranteed. I mean, we could -- it's like if I was to say to you or anybody in here that's got a job, "Right, you're under permanent risk of redundancy. We don't know if you are going to be made redundant, but you're under the risk." You wouldn't want to live your life like that, would you? Nobody would. Yet that is how you feel. You think -- you know, it's just not right. It's almost like they've

got the hold over you and they don't want this hold to go and -- just financial dignity, that's all we ask for really.

Q. Alan, can I turn to your involvement first of all with the Macfarlane Trust.

A. Yes.

Q. You were a trustee of the Macfarlane Trust --

A. Yes.

Q. -- from about 2008/2009.

A. Yes, yes.

Q. You've described the Macfarlane Trust in your second statement as being reactive rather than proactive, and not making sufficient attempts to get more money from government.

A. That's right, yeah. Definitely right. In fact, they made no effort to get money from the government, really.

Q. One of the committees you sat on was the National Support Services Committee.

A. Mm-hm.

Q. What was the role of that committee?

A. Well, any grant requests that came in each month were dealt with by this committee and we -- that's why I became a trustee, to try and change their way of thinking and to try and do some good, really.

The problem was once you get on to the board, you realise there's, you know, a sanctum of trustees, and the outer ones -- they kept us what we call user trustees on the outside, really. Well, they'd have us on certain committees, but that opened my eyes big time because we had one particular trustee -- and I think it has been -- I don't know if it came up in somebody's evidence, but people would send in photographs of rotten windows, for instance, just to show that the damage was there and they needed a grant, and, yes, of course, you would say yes to it, but there would be one there, he would see a PlayStation, say, and a box of fags, cigarettes, and say, "If you can afford to smoke, if you can afford that, that's a no from me." And, you know, I don't know if I'm allowed to say his name, but he -- yeah.

Q. Perhaps if you tell us his name after your evidence.

A. Yes, I will. But that was what you're up against. I'm not saying all the trustees were like that, they weren't, but this particular one was. And it was -- trying to get changes there was like trying to nail jelly to a wall, basically, you know. It was an organisation that was set up really just to give the government peace of mind. They thought they'd done something for us.

They thought it was a short-term problem, because we'd all be dead, so they'd done a short-term solution, except we all lived longer and they didn't really know how to deal with us. So they had these piecemeal things like -- nobody should have to write in anyway and beg for money, but I just thought if I can join this organisation and try and change it -- well, that was quite naive of me, really. I couldn't change it, really.

Q. You have described a number of initiatives that were started, setting up a partnership to facilitate dialogue between the trust and beneficiaries.

A. That's right. That was a partnership group. We used to meet. There used to be a bulletin board as well, where just beneficiaries could go on. So they could be themselves, you know, they could be anonymous on there, but it was a way to talk to each other about drug treatments, about anything really. It was a pre-runner almost to Facebook, I suppose, but only to those of us infected.

Q. You also describe initiatives about weekends that were solely for those infected --

A. That's right, yes.

Q. -- who could talk to each other without feeling the constraints of having money around.

A. We had what was called men-only weekends. They weren't stag dos! We found that men would open up more when we were with each other rather than with our partners, this is what we found, and so we said, "Well, I think we need just to have men", you know, and that did work, because we all got together and that was the only time all of us could be ourselves, and we got a lot out of that because we'd have people to give massages there, to give psychological help. We'd just try and put things in place just for the weekend that was a bit of normality, you know. And, yeah, the Macfarlane Trust, they funded that, so that was one of the good things they done.

However, that all stopped, and you want me to come on to that in a minute.

Q. We'll come on to that. But there were also events for families and --

A. Families.

Q. -- for partners.

A. For partners, for widows, for infected. There was -- yeah, we tried to put a raft of weekends so people could meet each other and be themselves and have a little bit of respite from the crappy life that you're leading, really, and it was. For those two days you were with friends, you were with people that actually understood what you're going through, because the only real -- the only people that really understand what I'm talking about now are people that are going through this.

I mean, yes, people do give you empathy and sympathy. That's lovely. But we found that when you're talking about your drug regime, when you're talking about things as basic as going to the toilet, you know, I know it sounds silly, but they are the only people that really get what you're going through, and that was a release and that was good. That was -- we needed it. But, you know -- and we looked forward to it.

Q. But you describe from your perspective as a user trustee observing a change in the trust from about 2012 --

A. Yes.

Q. -- when Roger Evans took over as chair from the previous chair, Christopher Fitzgerald?

A. That's right, yes.

Q. And Jan Barlow took over as chief executive from the previous chief executive, Martin Harvey.

A. Yes, big change.

Q. You're critical in your statement of the direction taken by the Macfarlane Trust under their leadership.

A. Oh, definitely. It was a complete change. He -- between them -- I mean, they got called some pretty awful nicknames. I can't say them here, but they were -- yeah, they weren't seen very favourably by the beneficiaries, and what they done was more or less straight away they stopped the bulletin board, they cut that out, so we couldn't get in touch with each other. Stopped the weekends. Partnership groups stopped. Everything stopped.

When I said, "Why are you doing this?" "This was not what the Macfarlane Trust was set up for. We're going to go back to how it should've been originally" -- well, how it was originally was bloody awful, to be honest. We didn't even have an address for the Macfarlane Trust. All they gave us was a postcode. We didn't know where their offices were, we didn't know anything about the trustees, we didn't know anything about this mysterious organisation, and that all changed. But within months all them changes went by-the-by. They -- "No, this is not what the Macfarlane Trust was set up for. We're not going to go down that route", and they stopped it all.

Q. There was an issue about winter fuel allowance. What can you tell us about that?

A. Well, this was around about the time -- I don't know

if you remember Osborne kept coming out with all these, "Austere times", that was his favourite saying as a chancellor. Roger Evans picked up on that and "The government is in" -- I used to say, "Well, I don't care whether the government are" -- I said, "When the government have got money, they don't give us any more, so don't give me that. Just because the government might be saying these are austere times, people's health still needs addressing. People's health doesn't get better or worse whether the times are austere or not." He used to talk down to you and say, "Look, you don't understand, we'll be lucky to even get what we got last year and we'll be very thankful for it." I said, "But you're joking. We can't -- as trustees, we can't carry out our duties."

And we had a trustee on there, Russell Mishcon, the solicitor, and he looked in and he said, "We can't, we can't discharge our duties as trustees because we're not getting enough money in, we are having to turn down requests that we should be meeting, you know, as a legal stipulation really."

So he --

Q. I'm going to come on to the correspondence and the issue about that.

A. Yes.

Q. But what was the position specifically in relation to the winter fuel allowance?

A. I'm sorry, I got off track.

Q. Don't worry.

A. I had a phone call, right, because this is when the partnership group -- this is just after Roger Evans had become a -- the chair. I had a phone call from him. He said, "Right, you're going to the partnership group" to me, "Yeah, yeah." I had to have two hats on obviously as a beneficiary and a trustee. But I said, "Yeah, I'll go." And he said, "Well, I'm going to propose there that we can't afford the winter allowance this year." I said "What?" He said, "No, no, austere times", and he said "These are -- we can't expect the government to give us money." I said, "You're talking about people's health. People have to have" -- the reason why the winter allowance was given in the first place was because people need -- you know, you've got HIV, you've got medical problems, you need more heat. You know, hepatitis, HIV, you need more heat in the winter, and so that was recognised.

And we did, we put in place this winter allowance, and that was £750, and that would be paid at the start of December. Okay, people spend it on presents, fair enough, but that was for the extra

bills that people were facing, you know, and also, you know, extra clothes and things like that. So that was in place and that was good.

But I said -- as I said, "You can't cut it." He said, "Well, I need you to support me on this as a trustee." I said, "No way." I said, "I'm not supporting you on that at all." And so he said, "Well, I'm very disappointed." "No fair enough."

Funnily enough, I've got a friend sitting there, he was at the same meeting. Unfortunately he'd phoned another trustee up, user trustee up, and he did support him. I can't say his name because you -- but at the meeting people were up in arms about it. They said, "But you can't" -- you know. I think what they used to do is float things to see if there's much opposition. Well, there was opposition. But we had a meeting after that and he said how disappointed he was in me, and he was still determined to try and cut this heating allowance or winter allowance, whatever you want to call it.

Anyway, what they did in the end -- I managed to get a compromise. They cut it to £500. You've got to remember Jan Barlow was also chief executive of the Caxton foundation. They cut their winter allowance at the same time from £500 to £350, I think it was. So they got their way partly. But it was the fact that they were cutting it, you know.

He'd rather not upset the government and not upset the DOH by going for more money. He'd rather the people who were ill, who he's supposed to look after, go without heating, and that is the sort of person you're talking about.

Q. Another decision or disagreement that you describe in your statement was over something that you refer to as discretionary pay.

A. Yeah, discretionary pay. We used to get -- because just after Archer -- they gave us a modest increase after Archer, just a modest one, not much, but they found that they hadn't given us enough because of some formula that they worked out and they didn't work it out properly, so it was agreed -- Gillian Merron was the health minister at the time. She agreed that the Macfarlane Trust could give this discretionary pay and they would fund it. DOH, this is. To just top it up. I think discretionary pay was an extra -- depending on your circumstances, it was up to about £4,000 a year, per annum. Anyway, that used to increase with inflation each year. Whatever the inflation rate was, that went up by that amount.

Well, that year he says, "No, we're not going to

give an increase for discretionary pay." I said, "But that would mean that people" -- I think inflation was about 3 or 4 per cent then. I said, "But in real terms people are going to be 3 or 4 per cent worse off, you can't do that." I said, "In fact, they need more -- they're on the bread line as it is", you know. He was adamant that wasn't going to go up, and it didn't go up. I fought hard against it. But you've got to remember it was -- this was an organisation that's supposed to be looking after you, looking after all -- you know, and they wanted to look after the government's money more than look after us.

Q. Your perspective in your capacity as one of the trustees, a user trustee, was that money was being taken away from beneficiaries, is how you've described it --

A. Yeah.

Q. -- when there were other ways in which you thought the Macfarlane Trust could potentially have saved money, cut down on operating costs and the like.

A. Well, you've got it in all the emails. Luckily enough I kept them. Because I told them, "You're looking at cutting the heating bills, the winter allowance, you're cutting our money each year, and yet you've" -- they took on two -- an operations assistant and

somebody on the finance department, and I said, "You had an operating loss of over £800,000 last year and yet you're taking on these two" -- this is the trustee, I was saying -- "taking on these two extra staff", I said, "You're based in probably the most expensive part of London, you know, SW1." I said -- me and my mate, we went to the Thalidomide Trust to see how they managed to attract government funding, and that was set on an industrial estate in Bedfordshire. Lovely place, but I'm sure they paid a fraction of what the Macfarlane Trust were paying.

So I put it to them, "Why don't you (a) relocate? Why are you taking on these extra staff? Why don't you do as the Haemophilia Society's done?" They relocated, because they were in Hatton Garden, they relocated south of the river, they saved money that way, made redundancies. I said, "Surely you do that, you don't cut money to beneficiaries." But, no, that was their mindset.

Unfortunately, Jan Barlow, she had previous for this. She was at the Fire Brigades Union and she didn't last long there because -- it's all documented, you'll be able to find this -- she was taking on extra staff that they felt they didn't need, and after 10 months she left in mysterious circumstances. Then, lo

and behold, we were gifted her at the Macfarlane Trust. So there you go.

Q. I should say, of course, that if we receive statements in response to Alan's evidence from Roger Evans or Jan Barlow, those will of course be published on the inquiry website.

You and other trustees seem to have become, from your statement, concerned that the trust was not properly discharging its duties as a charity, and was not being run to the advantage of the beneficiaries. Is that a fair encapsulation of your concern?

A. That's right. I mean, if I can just touch on one thing before I forget, Jan Barlow -- I'm going to say this and hope she comes back to it, but the ladies in here -- we are discussing a widow, right? A widow who was infected herself. She had a charge on her house. She got her MP involved and -- in the words of Barlow, he was becoming a nuisance, a big nuisance, and so was she, she said at the meeting, "If it was down to me, this woman wouldn't get another penny." Right? This is the chief executive of a charity. I just wanted to say that, because that is indicative of -- as far as I'm concerned of how she was, and it would be interesting how she replies to that.

Q. Can I clarify, that was a meeting at which you were present?

A. I was present. Unfortunately I haven't got email evidence of that, but I heard her say it. Because I said, "Oh, you're talking about a widow there." "Oh, you don't know the trouble that this woman has been and her MP now." Well, the MP then got up in Parliament and discussed the Macfarlane Trust and he said it wasn't fit for purpose, so there you go.

Q. The concerns that you and some of your fellow trustees had about the direction the Macfarlane Trust was taking were expressed to the Secretary of State for Health --

A. That's right.

Q. -- Alistair Burt MP, and the Charities Commission.

A. That's right, letters were sent. I was -- I was a whistleblower by then. My MP was poor, rubbish. I had -- you know, I knew Alistair Burt through -- through a friend. And Alistair Burt wasn't my MP but he took a big interest in this, and I used to pass on the information, what was happening at the time, in the trust, ie that it wasn't being run as it should, rightly or wrongly, but I felt that it needed -- it needed to -- to be told, and so did Russell and Elizabeth. They were both trustees. Elizabeth was even -- bless her, she's not here anymore -- appointed

by the DOH. So even she was concerned about the way it was being run. So, you know ...

Q. One of the observations you've made in your statement is that when you raised these concerns with the trust, you were told that the trust was not here to advocate for beneficiaries.

A. That's right, that's what he said. He said that wasn't the trust's role, it wasn't the trust's role to ask for the money. They put a business -- as far as they were concerned, they put a business case in each year and they were just fortunate to get anything. (Inaudible), you know, and they used to treat the DOH -- well, it felt like the Macfarlane Trust had become an off-shoot of the DOH, to be honest, and I'm sure you're going to come on to that as well, aren't you?

Q. The "he" you're talking about is Roger Evans, for the benefit of clarity?

A. Yes, roger Evans, yes.

Q. You've then described in your statement how in response to these concerns one of the trustees who you've mentioned, Russell Mishcon, put together a letter.

A. Yes.

Q. The aim of that was for trustees to sign it and send

it to the Department of Health, saying that more money was required in order for the trust to discharge its duties.

A. We needed more money. We couldn't -- you couldn't operate properly. I mean, it was awful. I mean, it was getting to the stage where Roger Evans was telling the NSSC, what I was sitting on, "Right, you're going to have to manage the expectations", I think the words he said, "of the beneficiaries a bit better, and the money you are dishing out is too much", basically.

We were put in an impossible -- because Russell sat on it and Elizabeth the chair of the NSSC, and it looked to the outside as if we were heartless bastards, basically, but we were getting orders that, you know, you couldn't help these people that needed help, and that just wasn't right. And it just wasn't -- I mean, the charity shouldn't have been there in the first place, don't get me wrong, but it just wasn't fulfilling its role as a -- I mean, it was a charity in name only, to be honest. It didn't go out shaking tins or parachute jumps. I mean, all the money they got came from the government, so really it was just -- it was their plaything, if you like, just to keep us quiet; give us a bit of money, and that's what they did for years, you know. But it wasn't

a charity, not in the true sense of the word.

Q. What was the response of Roger Evans and Jan Barlow to this proposal from Russell Mishcon to have this trustee letter to the Department of Health?

A. We brought it up at a trustee meeting, that was -- I can't remember which one -- anyway, brought it up, and he was angry. There was very -- they had a set to, an argument -- didn't have a fight, but an argument, and he said he wouldn't accept the letter, he wouldn't send the letter, and if it was sent on Macfarlane Trust headed paper, he'd look into it legally. He wouldn't have -- nor would Jan Barlow.

So Russell -- me and Russell then tried to get the opinion of the other trustees privately, and some supported it, but some didn't and one -- there were -- unbelievable that a user trustee, who was a beneficiary, didn't support us sending the letter, and I can't name him, but I just found -- one -- it was difficult. It was -- it was what was needed. They needed to be sent to DOH. The DOH needed to be told the money they were giving us was nowhere near enough. But Roger Evans thought it would antagonise them. His words were they would probably give us less money. I thought: this is ridiculous. Anyway, it didn't get sent.

Q. In your statement you've identified some of the reasoning provided by Roger Evans for not sending this letter as follows, and I just wanted to go through these and see whether they are, as far as you remember, verbatim quotes of what he said.
A. Yes.
Q. "The money is simply not there."
A. That's right.
Q. "Don't bite the hand that feeds you."
A. That's right.
Q. "We are not prepared to rock the boat."
A. That's right.
Q. "Let's not forget the DOH set up the MFT and can close it down."
A. That's right.
Q. "There's only one winner if you pick a fight with the government."
A. Yes, these are all document -- yeah, stuff he said. That's his mindset.
Q. And you've also described in your statement Mr Evans saying that the MFT was really there to largely process funds.
A. That's right.
Q. And you've also said he described the MFT as "the arm of the government whether you like it or not".

A. That's right.
Q. There's just one letter we'll look at. You've provided the inquiry with lots that will be --
A. Yes, I know.
Q. Don't worry, no need to apologise, those will be fully investigated and explored with the appropriate individuals in due course.
A. Yes.
Q. But there's just one letter to put up now, 1122016. Sorry, it's an email. And it's an email dated 26 January 2013, from Roger Evans, and it was sent to all the trustees, including yourself.
A. Yes.
Q. Subject: "Minister letter":

"Dear trustee, in case you are still considering whether to send an individual trustee letter to DH, I want to clarify a few factual points with you before you decide.

"I note that several trustees are not prepared to sign such a letter. I agree with their rationale for not being prepared to do so.

"Several of you have asked me what influence DH has over the Macfarlane Trust. The answer is a lot. The government (through DH) set up MFT in the first place and could close us down at any time if they so

wished. DH appoints three of our nine trustees and they are our sole source of funding. The relationship is bound up in a trust deed and an amended version was agreed unanimously by our board a year ago. A DH-appointed trustee challenging DH in the proposed way would raise a number of questions within DH about loyalty, for instance."

And then he goes on to say that:

"A decision has not yet been announced by the Department of Health on funding. We will continue to chase them vigorously and draw their attention to the repercussions of a long delay.

"As I said at the board meeting on Monday, I know the way central government works. I suspect DH has already made a recommendation to the ministers on our funding and the reserves. This will not be an isolated decision and will be incorporated in a much bigger one of the entire health care spending programme for 2013/14 totalling billions of pounds.

"The information Jan gave us on Monday of her induction meeting with DH was very helpful but it was not new to you. It was identical to the information I have given you and beneficiaries for some months. I very much doubt that a letter from several individual trustees or from the board either will

influence whatever recommendation they have made. What it will do is antagonise them and badly damage our future working with civil servants who are supportive of MFT.

"In the future MFT will have to work with DH. We can't change our relationship [with] them in the near future, particularly as most of us have signed the trust/DH deed. Antagonism will not make for a meaningful, productive relationship. They will not want to work with trustees who have been hostile to them in this way. It risks future years funding allocations and will jeopardise discussions on other issues.

"For instance, the charitable relationship between DH and MFT and the meaning of charitable need have been raised by you recently. I agree that we should open a dialogue with DH on these when funding is known. I would be surprised if DH will be prepared to do so involving trustees who are hostile to them.

"In an email to me, Russel advocates taking the battle to DH. I don't recognise a battle in this context. DH have not started a fight with MFT and it would be very unwise for a group of individual trustees to pick a fight with DH and central government. You don't bite the hand that feeds you."

A. Mm-hm, there you go. It says it all. That's what we're up against.

SIR BRIAN LANGSTAFF: Could I just come back to the top of that letter. Thank you.

The third paragraph, the last sentence:

"A [Department of Health] appointed trustee challenging DH in the proposed way would raise a number of questions within DH about loyalty, for instance."

Do I take it that there was at least one of the Department of Health appointed trustees who wished to -- in words of Mr Mishcon-- take the battle to the DH?

A. Yes, yes, there was, yes, Elizabeth, bless her, who is not here now.

SIR BRIAN LANGSTAFF: So the author here was taking on board the battles of the DH?

A. Yes, yes, that's how he saw himself as part of the DH, I think, to be honest.

SIR BRIAN LANGSTAFF: Well, it's open to that inference.

A. Yes, yes, yes.

MS RICHARDS: But that was your perspective based upon your involvement and dealings with the Macfarlane Trust.

A. Yes, yes. That was -- yes. In the end -- I think

you're going to come on to this in a minute -- I become such an irritation to him that he asked me to resign in the end.

MS RICHARDS: We're going to look at your resignation letter. It's 1122017, please.

Sorry, sir, have you finished with that?

SIR BRIAN LANGSTAFF: Yes.

MS RICHARDS: So we can see that by January 2015, you have given notice that you are going to resign.

A. Yes.

Q. "I am giving notice that I am resigning my position as trustee of the Macfarlane Trust with immediate effect. My reasons are, having just read the minutes of the MFT board meeting, I was struck with the blatant hypocrisy from chair Roger Evans with item 72414, chairman's report, as follows."

Then you quote from those minutes, as I understand it, which said:

"'It was unanimously agreed that Roger Evans would write to Alan Burgess on behalf of the board to wish him well because he'd been unable to attend the recent board meetings due to ill-health. The trustees hope he will be able to attend the January 2015 meeting so he can be thanked for all he has done during his time as trustee.'

"This meeting was October 27, 2014. On September 15, 2014, barely 6 weeks before the meeting, I received an email from Roger Evans containing the following quote:

"'I think we have reached a point where it is doubtful whether your continuing as trustee until the end of your period of office is helpful or welcome. I doubt whether you or I can work productively together in the coming months given your latest correspondence.'"

Then you say this:

"The above quote was in response of myself in my role as trustee discussing how the trust was run; unfortunately, my views did not coincide with those of the chair.

"As I stated, I find the hypocrisy quite frankly staggering and this is the final straw for me with this chair, whom I have had issues with his running of the MFT in the past. Consequently I have no confidence in either the chair or the chief executive, Jan Barlow, to run the MFT in a fit and proper way to benefit beneficiaries and not the DOH.

"The Macfarlane Trust in general may like to reflect on the result of the APPG survey, which shows a minority of beneficiaries were happy with the trust.

I would just like to quote a passage from the survey:

"'A great deal of Macfarlane Trust recipients were of the view that the organisation was getting worse, its staff becoming more distant and it is becoming harder to access assistance.'

"With that fact in mind, perhaps it would be a good idea for the chair and chief executive to consider the ill-feeling towards the trust that initiated the survey in the first place. After 6 years as a trustee, it saddens me to see the Macfarlane Trust in a worse state than when I joined."

You ceased at that point to be a trustee of the Macfarlane Trust.

A. That's right.

Q. You not long I think before that had become a trustee of the Haemophilia Society, or on the board of the Haemophilia Society.

A. That's right, yes, I did.

Q. You've drawn a contrast in your statement between the Macfarlane Trust, which you describe as unwilling to make reductions in operational costs, and the Haemophilia Society, which was willing to try and make those reductions.

A. Yes, they had to -- I mean, they would've gone out of existence if they hadn't.

Q. Now, you've then described a meeting of trustees within the Haemophilia Society, at which it was reported by the chief executive, Ms Caroll --

A. Yes.

Q. -- that something had been said to her by Jan Barlow in a recent meeting.

A. That's right, yes.

Q. What can you recall about that?

A. Well, board meetings are not the most lively of places to be and you spend most of your time navel-gazing, to be honest, and some of the subjects are pretty mundane and what have you. But it was the point where Liz Caroll said she had this meeting with Roger Evans and Jan Barlow, and she come out with a quote that she said Jan Barlow said. Now, I'd like to read it out in its entirety, if I may.

Right:

"Liz Caroll was in a meeting with Roger Evans, chair of MFT, and Jan Barlow, CEO of MFT. Jan Barlow stated [this a quote from the minutes] Department of Health should wait as long as possible before making a decision as more people will have died and there will be less people to pay and fight for payment."

Q. We'll just have a look at the minutes of that meeting --

A. Yes, and I said then -- I said, "Whoa, whoa, can you repeat that?" She repeated that, and I said, "I want that put in the minutes, please, that has to go in minutes", and it was. But carry on.

Q. Henry, 1122015. Can we have the version which just has the three relevant pages, please. First of all page 1.

So we can see minutes of a board of trustees meeting held at the Haemophilia Society on 4 February 2015, and we see amongst those present yourself.

A. Yes.

Q. Can we then go to page 4, please, Henry.

And if we pick it up halfway down the page, we see:

"Meeting with Macfarlane Trust. LC [that's Ms Caroll of the Haemophilia Society] met with Jan Barlow, CEO, and Roger Evans, chair of the Macfarlane Trust (MFT). There were two main areas Jan and Roger wanted to discuss."

Then the first is about the Haemophilia Society's nomination of the Macfarlane Trust MPs.

The second is then this:

"The Haemophilia Society response to the recent APPG inquiry report and upcoming Penrose report."

And there's a discussion about that.

And then if we pick it up at the bottom of the page, it says this in the minutes:

"The possible implications of the Penrose report were then discussed and LC stated this will have an impact UK-wide and might bring things to a head early into the new Parliament. The Haemophilia Society would keep the pressure on whoever is in government to make an announcement as quickly as possible. Jan then expressed her opinion that the DH should wait for as long as possible before making any decision as more people will have died and there will be less people to pay and fight for payment. LC did not comment on this point."

We can put that away, thanks, Henry.

So you obviously were not present at the meeting between Ms Caroll and Ms Barlow and Mr Evans.

A. No.

Q. You can only report on what you were told at the Haemophilia Society meeting by Ms Caroll --

A. Yes.

Q. -- in the way you've described.

A. Yes.

Q. Your statement suggests that you asked Ms Caroll to report this to Alistair Burt.

A. Yes, yes.

Q. And that was done.

A. Yes.

Q. And there was a letter which repeated or set out the allegation that Ms Barlow had made this statement?

A. Yes.

Q. The response your statement describes of the Macfarlane Trust first of all was to deny firmly that this statement had been made, and I should make that clear, we don't know what Ms Barlow would say now.

A. No.

Q. Yet.

A. Yes.

Q. But we do know that at the time it was firmly denied.

A. Mm-hm.

Q. And then there was a threat by the Macfarlane Trust to sue the Haemophilia Society and Ms Caroll for defamation.

A. That's right.

Q. You wanted the Haemophilia Society to fight this.

A. I did.

Q. If necessary, in court.

A. Yes, yes.

Q. But your statement describes that the chair, the then chair of the Haemophilia Society, decided that the

Haemophilia Society and Ms Caroll would retract the statement and apologise.

A. It was a unilateral decision from Bernard Manson. I don't know how I managed it, but I managed to get the majority of the board to agree that we needed our day in court. I said this is manna from heaven, really. I said, "Let them take us to court, let the world see what an awful organisation the Mac Trust is", and naively, perhaps, I said, "If that's the truth, that's the truth, you know, truth will out", you know, because I'm a great believer, you tell the truth, everything will be fine.

But Bernard Manson unfortunately thought different, and he went above the board and ordered Liz Caroll to retract it and issue a statement, and basically grovel, which is what they done. And I was angry, because I thought we should've seen this through, because the papers would've absolutely loved this, and it would've shown everybody, you know, what an awful organisation, what an awful couple there was, you know, in charge of this so-called charity.

But, no, it happened, and I was angry as well because, believe it or not, there was a trustee that sat on the Haemophilia Society board, and also was a trustee of the Macfarlane Trust, and this particular

trustee, he was the blue-eyed boy of the Haemophilia Society anyway, and I said, "What is his role in all of this?" I didn't get an answer, and I was -- I said I can't believe a trustee -- it sounds ridiculous -- but a trustee of the Macfarlane Trust was also a trustee of the Haemophilia Society, but they wanted to close it down. I said, "But that can't be right, that's a conflict of interest, you can't have him on the board, I can't sit with him on the board." So he said, "Cheerio, then." I couldn't -- could not believe they'd rather have him sitting on the board, who wanted to take the Haemophilia Society to court, but that's why I resigned in the end. I had to.

Q. So you stepped down from the Haemophilia Society because of this issue and the response to it --

A. Yes.

Q. -- and the particular conflict you perceived a fellow trustee had.

A. Yes, I thought they should've stood up for the beneficiaries. I thought that's what the Haemophilia Society really should be all about. Because you've got to remember, we're all haemophiliacs, and also wives or partners who were infected, you know, all basically that was through haemophilia, really, the treatment for haemophilia. So the Haemophilia Society

should have supported Liz, and they should've really supported the beneficiaries, because in the indirect way, they would've been, because this would've been out in the public, this would've been aired, and these people would've known what these two individuals were up to, really, or what they were like.

Q. The way you've put it in your statement is this:

"The chair, Bernard Manson, went overboard ..."

I think you mean "over the board".

A. Over the board, yes.

Q. "... and capitulated to the demands of the collective boards of the MFT and the legal advice. Liz Caroll was forced to not only give a public apology but to deny that Jan Barlow had ever said what she did.

A. Yes.

Q. Just pausing there, I should make absolutely clear that we will of course be inviting the Haemophilia Society and Ms Caroll to set out whatever they wish to in response to that and to comment on the appropriate documents.

A. It will be interesting.

Q. Some of which you've provided to us.

A. Yes.

Q. But that led to your stepping down in any event from the Haemophilia Society.

A. Yes.

Q. You have in your statement included some more general observations or criticisms of the Haemophilia Society, and I just wanted to ask you, if I may, what you meant by them, if you can.

You say in your witness statement this:

"The Haemophilia Society never really wanted to face up to the contaminated Factor VIII tragedy. They gave Birchgrove money to advocate on our behalf, but we were very much treated like the bastard at the family reunion and seen as an unfortunate episode in our history."

Again, the Haemophilia Society may wish to say something very different about that, but what is your perspective? What is it that leads you to reach those views?

A. Well, because -- because what happened to us was -- I think they -- they looked upon it at the time as a dark episode in their history, because I'd found a copy of the bulletin -- I gave it actually to Collins Solicitors, they've still got it, I forget when it was. But in -- it was 1983, 1984, I can't remember when, but they were still -- it was an eminent doctor in there, still -- I think 11 haemophiliacs had died in America, and he'd said --

this was -- you've got to remember the bulletin used to be the Bible for a lot of mothers or whatever. They'd read this and think, "Oh, everything's fine." He said people should go on being treated with Factor VIII, even though 11 haemophiliacs had died in America. He thought that the benefits outweigh the risks, and he said he couldn't see a problem.

Well, I thought that was irresponsible of the Haemophilia Society to print that in a bulletin because people would've carried on treating, and 11 haemophiliacs was 11 too many. They should've then thought, "Oh, this is bad, we" -- stop it altogether, issue a warning to everybody. But, no, I think they were too cosy with a lot of the pharmaceutical companies who obviously gave a lot of us -- I mean BPL were British, but a lot of the pharmaceutical companies were sponsoring certain Haemophilia Society events and things like that, so they were too close.

So they tended to -- we were a little bit of an embarrassment to them, and they didn't really -- I mean, they got money from the government for AIDS help, I suppose. But the Birchgrove was set up so they gave the Birchgrove the money to basically look after the people they should've been really looking after. But there wasn't any advice, there wasn't any

counselling, there wasn't anything really forthwith from the Haemophilia Society. That all came from Birchgrove. We used to have weekends, you know, people could meet. But you got nothing from the Haemophilia Society, is what I'm trying to say. There was a particular chief executive there who really kept us at arm's length. Yes.

Q. The last topic I wanted to ask you about was just a little about your campaigning activities, and one of the meetings you had and some steps you took after that.

You have over the years undertaken a lot of different activities. You've visited Parliament to meet with MPs and ministers. You gave evidence to Archer.

A. Yes.

Q. You have written a lot of letters over the years to prime ministers and others.

You've described in your statement a particular meeting you had with David Cameron whilst he was Prime Minister.

A. Yes.

Q. And Jane Ellison, who was a minister within the Department of Health, I think.

A. That's right.

Q. What can you tell us about that meeting?

A. Well, I was lucky enough, along with another beneficiary, along with Alistair Burt, to be invited to see David Cameron at Number 10 and discuss the contaminated blood issue, you know. And so, yeah, I thought great, be able to go to him and we might eventually get something done, you know.

So we went along, we met him, there was Jane Ellison there, civil servants and what have you. I gave a statement to him regarding my life and everything, and he was quite moved. So was Jane Ellison. And he told us, you know, the contaminated blood issue, Bloody Sunday, Hillsborough, they were all issues he wanted to address, you know. He thought that these issues should be addressed and he wanted to help us.

I just -- I said to him at the end, "You can't give me health back, but you can give me financial dignity, and if you can do that, that will be something", you know. He said, "I'm sure that's something we're going to look into and we're going to try and help", you know. He didn't promise anything. He didn't say, "I'll stop the Mac Trust and you'll get compensation", or something, he didn't say that, but he just said he'd help.

I walked down the road with Jane Ellison afterwards, because she was quite moved, she wanted to know more, so I did, I walked down the road with her.

And then about three/four months later, yeah, they helped all right. Didn't help us. It came out there was going to be a consultation, and in this consultation the DOH were looking at taking money off us. And I thought: what? We would've been probably around about £4,000 or £5,000 worse off if these implications in this consultation had come about, and consultations normally mean, "This is what we're going to do, but it looks as though we're consulting with you, but this is what we're going to do."

So a lot of people protested in this room, letters were written and protests were made. And I -- I said to Alistair, I said -- he said -- he said, "I don't know how this has come about, really", he said, "This is -- I think this is shocking", and it wasn't anything he'd done, but unfortunately it was Jane Ellison that -- she didn't -- I thought he got it, but he didn't get it, you know, nor did she, and I said to my mate, who knew journalists, I said, "We've got to get this in the press."

He managed to get it into Private Eye. It went into Private Eye. I said Private Eye is not -- it's not read by the general population, really. I said we need something -- so he knew a freelance journalist and then we told the story to her, and she said, "I got the Sunday Mirror, they're very interested. However, they need a face to it." I was anonymous at the time, you know, I wasn't public. So I discussed it with my family. I said, "Look, what do you think?" They said, "Yeah, go for it."

So I did, I had to -- I had to come out, you know, I -- a picture of me in the paper, and the reporter done a YouTube video of me, and that's on YouTube now, and I came out.

And the only thing we lost, believe it or not, was a window cleaner for it, and I will explain that as -- Denise does my drugs, she puts it in the dosset boxes, and she has them all on the table or whatever in the kitchen, and he was cleaning the windows and he came in for some water and he said, "Bloody hell, somebody's ill", and she thought, "Oh, sod it, I'll tell him because Alan is going in the paper", so she told him, and he never came to clean the windows again, but he goes to the neighbours. So we lost the window cleaner. That was about it.

Q. The particular decision you had taken in response to what you understood was a threat to or a risk that

such financial support as there was being cut was to go on a treatment strike.

A. That's what I said and that's how we got in the paper, because I didn't know -- we didn't know what to do, because if they'd have cut the money, it would've been -- we were on precious little as it was, and it could've come down to the house having to be sold and downsizing, and it was nip and tuck, you know, money-wise anyway. And to do that, and also after I'd been to see him, and after I shook his hand and after he said he'd help, I felt betrayed again.

I mean, we'd been betrayed over the years by many politicians of all colours, blue, red, yellow. Norman Lamb shook my hand once and said, "You're in our manifesto, we'll help you, don't forget that." I said, "You probably won't get in." He said, "Well, you're in our manifesto, so we will help." Well, he got in, didn't he? Us and the students they dropped like a hot potato, didn't want to know.

So we have been lied to over the years, so we were used to being lied to, but I just thought that was one lie too many, really. There you go. So I said, "Look, I'm going to have to do something drastic." Sarah wasn't happy. I said, "I might not -- I'm hoping it don't come down to it, but what can

I do, you know, because I'm not having it." So I did. That was why the paper got interested, because --

Q. We'll just look at the newspaper article briefly and then we'll look at the video interview that you did with them.

A. Yes.

Q. Could we have, Henry, 1122014.

We can just see it here:

"Dad infected with HIV after NHS tainted blood scandal slams cruel Tory payments cuts for victims."

It describes you as vowing to stop taking life-saving medication over planned Tory cuts that will leave victims up to £7,000 a year worse off.

A. Yes.

Q. It refers to adding to your fury the news that victims of the blood scandal in Scotland were to receive new annual payments, and you say this:

"We feel betrayed. I can't believe I'm having to resort to a treatment strike, but I'm prepared to die for this. What else can we do to get their attention?"

A. Mm. Didn't want to, obviously, but just felt enough was enough, really. That was -- as I said, one betrayal too many, one lie too many.

Q. We're just going to play the video because, as you

said, up until this point you had effectively been anonymous; you'd kept your infection to yourself and to your family members.

A. Yes.

Q. Fellow campaigners --

A. Yes.

Q. -- knew, members of the Birchgrove Group, people on the Macfarlane Trust, but not the public at large.

A. No, no.

Q. So it was a big step for you to be in the Sunday Mirror and to give an interview.

A. Yes, massive step, massive step.

Q. Henry, are we able to play the video?

(Video played)

Q. You didn't in fact go ahead with the treatment strike because the particular proposals that had concerned you --

A. Were dropped, yes, luckily enough. Whether that had -- I'm not saying that that -- but they dropped them in the end, and good job they did.

Q. Alan, I just wanted to finally ask you about something you put in one of your statements. You said this:

"I am 61 years old now and I was diagnosed when I was 27. This is not over. The pain and trauma has been ongoing for all these years, compounded by the government's approach. It was alluded that I suffer from post-traumatic stress disorder, but there is nothing post about it because it is ongoing. Each story is a tragic story and no one size fits all."

A. No, everybody in here has got an awful story to tell. Mine is just one of many, basically.

Q. Alan, those are the questions I have for you. I'm just going to ask Mr Snowden if he has any further questions for you or Sarah. There are none.

A. Thank you, Jenny.

MS RICHARDS: I think there is something both of you want to say. I don't know which of you wanted to go first.

MS ADAMS: For the past 28 years and who knows how many more, not a day has gone by that I haven't worried about my dad. From age 11, when I would cry myself to sleep, to the present day, when sleep becomes a luxury, the main thing which preoccupies my mind is him: my dad, my hero, my world.

I watched my successful father lose his business due to ill-health and scrape for every penny he and my mum could find just to keep our family going. I watched him go in and come out of hospital on too many occasions and was always wondering if this is it. Is this the day we lose him? And this is still with me today. The wondering, the fear, the panic of: is

this it now?

As I've grown older and witnessed more and more suffering, it has affected my mental health too. I have to take antidepressants for help with depression and anxiety, and I'm currently signed off work as a result of this. At no point have I ever been offered any form of help with this by way of counselling and such from any organisation. There needs to be something in place for the affected and infected to be given help, a place where those like me can call upon an expert who knows our stories and is available to support us whenever we need it.

What we need to understand too is that this scandal has gone beyond second generation but now to third generation. My 13-year-old eldest daughter has also been profoundly affected by this travesty. She finds it very difficult to come to terms with her grandad's illness. Leading on to very recent events, due to the inquiry, I found it necessary to tell my 11-year-old daughter about her grandfather and what has led to this inquiry. Talk about out of the mouths of babes. When I had finished telling her of the whys and wherefores of this tragedy, she wiped away her tears and said, "Will someone go to prison for this?"

To lose a loved one is the hardest thing anybody

will ever go through. However, to have a father going through incredible illness with only one end in sight, I cannot help but feel like we're living a life sentence. The never-ending rollercoaster of emotional and psychological torture of his ups and downs that we are still going through today is debilitating, and the feelings of uncertainty anguish and fear for a man who is loved so extremely is always at the forefront of my mind.

Having my dad still with us comes with another set emotions too, guilt being one. Crazy as it sounds, I feel guilty that I still have my dad here with us when I know that the vast majority within our community do not. I am part of a group who have been named the fatherless generation, and that alone makes me feel torn. I have a sense of belonging to the group, with all their support and camaraderie, but I also feel that I'm intruding as, yes, Dad is still here on this earth.

However, I lost my dad 28 years ago. He is not the same man he would've been without having been infected. I see a man who struggles daily with the most everyday physical tasks. I see a man who has put on an act of, "Everything's okay", when he is suffering psychologically. I see a man who is the

shadow of a dad I once had.

This life we've been given has torn my family apart. We have gone through things no normal family ever would or should. I want the government and the pharmaceutical companies responsible for this nightmare to be held to account. We all need to know why on earth this was ever allowed to happen, and I want them punished. Both the infected and affected need closure, and we need a full compensation scheme in line with or similar to the Republic of Ireland.

I have campaigned alongside my dad for justice for all those infected haemophiliacs and affected families and have seen him diminish from a man with hunger for answers, and a passion for the cause, to a man who is weary and losing all hope.

We have such limited time now that the importance and urgency of finding answers and finally having our day could not be more paramount.

MR BURGESS: Right, first of all I'd like to give some thanks to people. I'd like to thank the Collins team for having faith in us when no other solicitor would touch us with a bargepole. They've been fantastic. I'd also like to thank Sarah, my daughter Laura, Mark, and of course my wife. Thanks to all of you.

Anyway, an earlier witness, Mark, quoted the line from a Queen song: "I've paid my dues, time after time, I've done my sentence, but committed no crime." Well, I've not finished my sentence yet. Death will finish that for me. However, I wish I had committed a crime, as in prison I would've received all the psychiatric and counselling help I've needed throughout the years.

You've heard, Sir Brian, from spouses, parents, children, carers, widows and those of us still living this nightmare, who are both infected and affected. We are in extreme need of help. We all have one thing in common: the fact that the majority of us have had to endure this with no psychiatric or counselling help at all. Unless you are prepared to beg and jump through hoops and go cap in hand to the so-called charities and now EIBSS, if help was then offered, it was only piecemeal, and as Tony pointed out, this help was not even offered to bereaved children of those that have passed away.

To cast our community aside and to be largely forgotten about is something continuous governments have excelled at. They have failed to ensure that those of us damaged by this disaster, outrage, tragedy, call it what you like, have all had to endure and we are still living with, getting zero

government-sponsored psychiatric or counselling help, and this is nothing short of scandalous. Successive governments have much to answer for, but for this omission, they should hang their heads in shame.

The inquiry acknowledges the importance of mental wellbeing for those giving evidence or attending the hearings by offering confidential psychological help and support that is provided by the Red Cross. However, once the Inquiry dates finish, we are then left to cope with this nightmare on our own yet again. As the government is funding an inquiry, they obviously recognise the psychological help we need during this, so how can they explain the complete lack of help and understanding when the inquiry concludes?

Two weeks ago at this inquiry, I met Christina Burgess -- she's no relation -- who I knew from my time as a trustee at the Haemophilia Society. Christina set up an organisation called Haemophilia and Bleeding Disorders Counselling Association, and they've got trained counsellors and psychotherapists. They want to give help where needed, and understand that ongoing psychological help will be financially out of our reach for most of us, so they're trying to attract funding for this worthwhile and important

project, but are not meeting with much success.

When the Macfarlane Trust was wound up last year, we were baffled, and, without consultation from any of the beneficiaries, the remaining money the MFT held was transferred to the Terrence Higgins Trust. Estimates of that money range from £750,000 to £1 million. That money was paid by the DOH to the Macfarlane Trust to help beneficiaries and their families.

Sir Brian, I can't think of another organisation that wants to help us as the HBDCA wants to, but lack of funding will not allow, and I cannot think of a better use for this money the MFT mysteriously gifted the THT. That money should now be released and used for the way it was intended: to give much needed mental and psychological help to our community.

Now to come on to my personal thoughts about this tragedy.

I was one of 4,670 British haemophiliacs infected with hepatitis C. I was also one of the 1,243 also infected with HIV/AIDS. As a result, around 2,500 have since died, with scores more needing organ transplants and dialysis, and some victims have inadvertently infected their partners. Imagine the outcry if these numbers of deaths in our community

were killed off in a one-off disaster. But instead these people have slipped away quietly, one by one over the years, forgotten victims of a silent and avoidable tragedy. Yet even after these deaths, families have received no counselling, no apology, and any questions thereafter have largely gone unanswered. That nobody has been held to account for this tragedy is nothing short of scandalous, and something I hope this inquiry addresses.

In France and Japan, people have been sent to jail for their role in this scandal. In Canada, the Red Cross was prosecuted for negligence. In those countries, as well as Britain, commercial interests were put ahead of safety. But in Great Britain, no liability has been admitted, and what makes our successive governments' attitude to this saga so shameful is not just the shortcuts, greed and incompetence that led to the tragedy, it's the cover-ups, the heartlessness of the successive governments that refused to admit their failings time after time again. And time after time they've rejected pleas from suffering families.

The role of the DOH can be summed up in a memo that was released a little while ago from the early days. It says, and I quote:

"Of course the maintenance of the life of a haemophiliac is itself expensive, and I am very much afraid that those already doomed will generate savings which will more than cover the costs of tests in blood donations."

This is from the DOH years ago. Unbelievable, an example of the contempt shown us to over the years.

Because of this scandal and tragedy, I've not only lost my business and livelihood, but my sex life, both my financial dignity and my dignity as a man, feeling totally emasculated. I've also lost over half my life, as I was 27 years old when I was diagnosed and received the letter advising me of my infection of HIV. I've lost many friends from this community. I nearly lost my marriage, my rock, who is my wife, and at times I've lost my mind and even my will to live.

We must have answers as to why this disaster was allowed to happen, and we must be offered full and proper compensation, and no more piecemeal payments to keep us quiet. This scandal has dragged on too long. There have been too many deaths, too much pain, too much grief and too many betrayals. This government must admit its failures and accept that it's let down this community in the most tragic way possible. And

then and only then it may bring some peace to the thousands of us caught up in this horrific tragedy.

That's it.

MS RICHARDS: Thank you.

SIR BRIAN LANGSTAFF: Can I thank you first, Alan.

MR BURGESS: Yes.

SIR BRIAN LANGSTAFF: And can I thank you first of all, and perhaps least of all, for sending me a video, which I got this morning. Those who are core participants should know it was a video about the Birchgrove memorial grove, and it was part of the inquiry's material.

MR BURGESS: Yes.

SIR BRIAN LANGSTAFF: So thank you for that.

MR BURGESS: You're welcome.

SIR BRIAN LANGSTAFF: Thank you, more importantly, for your evidence of the struggles which you have had, struggles with your infection, struggles with your financial dignity, struggles with your desire to ensure that those who are victims are put first when it comes to those bodies that deal with them, and above all, struggles with your own mental difficulties.

It was I think -- I forget whether it was Ms Richard's words or yours to say it was a massive

step to go for your interview in the earlier part of the millennium to the Mirror. If that was a massive step for a two-and-a-half-minute video, then to be on stage, as it were, for a whole morning, telling the world of your most intimate difficulties, and of your struggles, is beyond massive.

MR BURGESS: Thank you.

SIR BRIAN LANGSTAFF: And you deserve our sincere thanks for something I know that you were nervous about.

But if I may comment on one of your comments that you felt emasculated as a man in the way which I think from what you've said you see it, I think you fronted up to all your struggles before us.

MR BURGESS: Thank you.

SIR BRIAN LANGSTAFF: To you, Sarah. You broke down, we've heard, in front of Archer. Well, you haven't done that today, but it's been a full exploration of everything that you and your family have suffered. And you've shown us how one blood transfusion has so many ripples and aftereffects in so many different ways, destroying, as you put it, your family life, although you are here as testament to resilience and perhaps overcoming some of the struggles.

Thank you very much for what must have been remarkably difficult evidence to give, and, indeed,

each of you to listen to the other and to your sister.

So thank you very much, both.

MS ADAMS: Thank you, Sir Brian.

MR BURGESS: Thank you, Sir Brian, thank you for hearing us.

SIR BRIAN LANGSTAFF: Well, that was so interesting I suspect no one will have realised that they have missed their morning coffee break.

We will take lunch now. We'll start again to hear the rest of today's evidence, and we'll go on, as we do, until we finish. But we will start again at 1.55. So 1.55.

(12.45 pm)

(Luncheon adjournment)

(2.00 pm)

SIR BRIAN LANGSTAFF: Our next witness wishes to be known as Nicola, does she?

MS FRASER BUTLIN: She does.

SIR BRIAN LANGSTAFF: Nicola, please.

NICOLA JONES (sworn)

Questioned by MS FRASER BUTLIN

MS FRASER BUTLIN: Nicola, you are a haemophilia A carrier, and you were told at age 7 you weren't a haemophiliac yourself because it was a male disease, but that your levels of Factor VIII were low.

A. That's correct.

Q. You were treated at the Royal Free Hospital.

A. Yes.

Q. In 1980, when you were about 9, you underwent a tonsillectomy.

A. Yes.

Q. That was the first occasion on which you were given Factor VIII.

A. Yes, yes.

Q. Until then you'd always been given cryoprecipitate.

A. That's correct.

Q. The letter discharging you from your time in hospital for the tonsillectomy says you would be reviewed on a two-weekly basis to have your liver function tests done.

A. Mm-hm.

Q. Were those tests ever done?

A. No.

Q. At the time your treatment was changed to Factor VIII, were you or your parents told anything about it?

A. No. I knew later in life that I knew that it changed to Factor VIII.

Q. So at the time you weren't even aware that it had changed?

A. No.

Q. Before the tonsillectomy, you've described in your statement that you were a very active child.

A. That's correct.

Q. But that that all changed after the procedure.

A. Yes, it did.

Q. What can you tell us about that?

A. I just changed from my -- I ended up being a child that took to her bed. I would come home from school, would miss school, and just spend my time sleeping. I had skin rashes, aches, pains, and that was the change.

Q. You felt unable to do all the outdoor activities that you'd previously done.

A. That I'd previously done, that's correct, and my schooling, education, declined, you know. I missed a lot of school because I just wasn't well, generally unwell.

Q. In 1981 you were admitted into hospital for six weeks.

A. That's correct.

Q. What happened when you were there?

A. That was because I'd put on a lot of weight, and the ...

Q. Do you want me to read a part of your statement? You'd put on a lot of weight and your mother had raised concerns about your deteriorating health, so

you were put on a very strict diet, and you were made to go swimming and walking with the nurses.

A. That's correct, yes.

Q. You walked up and down the 12 flights of stairs of the hospital every day --

A. Yes.

Q. -- to try and lose the weight.

At the end of the period, you had only lost a few pounds, and the doctors accused your parents of smuggling in food when that hadn't happened at all.

You've obtained your medical records, and is there anything in them about that six-week stay in hospital?

A. Nothing.

Q. There's no record at all?

A. No.

Q. At the end of that six-week stay the doctors still hadn't identified anything wrong with you.

A. No, that's correct.

Q. Your mum kept taking you to the doctors.

A. Yes.

Q. What did they tell her was what they thought was wrong with you?

A. They thought ... they thought it was all in my head, and that I had psychological issues, and that -- that

was it really, just -- yeah, sorry, I've lost track.

Q. That's all right. Your mum was told it was all psychological.

A. Yes.

Q. Your school contacted the county council.

A. Yes.

Q. And the psychology service were contacted, and that was the approach that was taken: this was all in your head.

A. Yes.

Q. In 1984, when you were about 13, you were told you needed to be tested for HIV.

A. Yes.

Q. What were you told?

A. I was taken into a room, and it was videoed, I think for teaching purposes, and that there was -- a lot of haemophiliacs had developed HIV and that I should be tested because of the treatment that I'd had, and I was tested for HIV.

Q. Which thankfully came back negative.

A. Yes.

Q. But your concern is that you were in that room being told about HIV --

A. Yes.

Q. -- on your own.

A. Yes.

Q. Your parents weren't with you.

A. No.

Q. Now, when you wrote your first statement for the inquiry you thought you'd not heard anything at all about hepatitis C until 1995.

A. Yes.

Q. Since then you've been provided with video consultations that took place in 1990 --

A. Mm-hm.

Q. -- and 1992.

A. Yes.

Q. Were you aware that those consultations were being videoed?

A. No, no.

Q. In the 1990 consultation there's a discussion about HIV, and you were told that because you'd not had blood products since 1981 and had tested negative in 1989, the chances of your being infected with HIV were as likely as you flying to the moon.

A. Mm.

Q. Do you recall that being said to you?

A. No, I don't actually recall the video or the consultation, but obviously I was there, I remember being videoed in 1984 for the HIV, but not -- not for what's come to light, no.

Q. There was then a discussion on a video, we can see, about what hepatitis C is.

A. Yes.

Q. You were told there was little knowledge about it, and that the test could only show if you'd had it in the past, not if you were presently infected. You were then asked if you wanted to be tested.

A. Yes.

Q. You've seen the video.

A. Yes, I have. Yes, I have now.

Q. You can see that you said yes, you did.

A. Yes, yes.

Q. You were asked then if you wanted to be told the result and you said you did.

A. Yes.

Q. If we look at the note of that consultation in your medical records, it's 1756006, please Henry.

We can see in the middle of the page, towards the bottom of the current page, "Discussed hepatitis C", but there's no note that a hepatitis C test would be undertaken on the document. If we look at the bottom of the page we can see, "Review one year".

In your medical records, is there any note of a test being taken?

A. Not that I've seen, no.

Q. Is there any note at all of a result being given to you --

A. No.

Q. -- at any stage around this time?

A. No.

Q. If we go to document 1756016, please, this appears to be the next appointment that you have at the clinic, and in the middle of the page, middle of the entry, we can see, "HIV negative, hep B negative", but there's nothing here, no reference at all, to hepatitis C.

SIR BRIAN LANGSTAFF: Do we have a date for that entry?

MS FRASER BUTLIN: Sir, there's no date for that entry, but one can see, if one looks towards the bottom of the page --

SIR BRIAN LANGSTAFF: It must have been after August.

MS FRASER BUTLIN: It must have been after August and before October 1990. It's the best we can do.

So we have the 1990 video consultation, where you are asked if you'd like to be tested and asked if you would like the results, but then nothing in 1990 or 1991 that addresses any of that or any tests seemingly being undertaken.

Then in the 1992 video of the consultation, there's another explanation of what hepatitis C was, but you were told then, weren't you, that because your liver function tests were normal, it was unlikely that hepatitis C was an issue for you, and you were told that your physical health issues that you had been raising -- the tiredness, the aches -- would be looked into and hepatitis C would be checked. But, again, there's nothing in your records that you or your lawyers have been able to identify suggesting that the hepatitis C was ever done at that stage.

So as far as you're aware, you weren't actually tested for hepatitis C at that point.

A. Yes, I was not aware, no.

Q. So we get to 1995, and your mum saw something on the television about hepatitis C. What did she tell you about it?

A. She had seen -- I think it was on the news or something about haemophiliacs and this new strain of hepatitis, which is hepatitis C, and they listed the signs and symptoms, and my mum rung me and said, you know, "Have you seen this?", which I hadn't, and she said, "Every one of those is you. You're having treatment at the moment, why don't you ask them if you've ever been tested for hepatitis C, or if they will test you for hepatitis C."

I was having treatment for an ankle bleed, and when I was at the hospital, I said to the nurse who was giving me the treatment, "Have I ever been tested for this hepatitis C?" She laughed and said, "Oh, you won't have that." Went off and got my notes, and came back and said, "Oh, you were positive in 1991."

Q. You've since gone back through your notes and, as we've discussed, there's nothing in your notes between 1990 or 1995 or any indication of a positive test then.

A. No.

Q. So you're not sure why the nurse said that.

A. No, no.

Q. You were then seen by Dr Goldman either the same day or the following day.

A. Yes, yes, I was seen by Dr Goldman, who did a review sheet, and said, "Well, you're hepatitis C positive but I wouldn't worry about that because we don't know much about it and it might not affect you for another 20 years or so. Think yourself lucky you're not HIV positive."

Q. There is a letter in your medical records. It may have been sent in between the time you saw the nurse and seeing Dr Goldman, the chronology is not entirely clear in your mind, but it's important we look at it. 1756011.

It seems that perhaps you saw Dr Goldman and then saw her again a second time, but in this letter in August 1995, she wrote to you and said:

"The results of your recent blood tests were all normal except for a mild abnormality in your blood count which is probably not significant, but I would like the blood count to be repeated just to be sure."

And then you think you had that conversation with her about what hepatitis C was.

A. Yes, yes.

Q. But in this original letter to you, there wasn't a specific reference to hepatitis C.

A. No.

Q. You've said that once you'd had that second meeting with Dr Goldman where she said that it wouldn't affect you for some years, however the chronology was, you didn't then think much of the diagnosis from that point onwards?

A. No, I think because you're younger and sort of the mention of 20 years or so, "It might not affect you", I think I just put in my head, "Oh well, 20 years is a long time away" and kind of didn't think any more of it, just to get on. But I think in my mind it kind of almost answered I guess the questions of my health and kind of just tried to plod on, really.

Q. Did anyone say to you in 1995 that you were actually a natural clearer of hepatitis C?

A. No, because that was when Dr Goldman had told me that I was hepatitis C positive.

Q. So in 1995 you're very clear that that's when you were told you were hepatitis C positive?

A. Yes.

Q. In 2004 --

A. Mm-hm.

Q. -- you wrote to the Royal Free for information you needed to make a claim to the Skipton Fund.

A. That's correct.

Q. And at that point you were told that you'd tested positive in 1995, but then you'd been retested in 1998, and had tested negative.

A. Yes, yes.

Q. Again, had anyone said to you in 1998 that you'd tested negative?

A. No, not that I can -- not that I can remember. I think Professor Lee got involved, but, no, it was my GP that had suggested to make a claim to the Skipton Fund because that had come about, and it was him that applied to the Skipton Fund, and then I believe that the form goes to then the treating centre, and that's when Professor Lee had said I had naturally cleared hepatitis C.

Q. But from 1995, with the positive result, until 2004, as far as you were concerned, you were hepatitis C positive.

A. Yes.

Q. Although you were a natural clearer, you feel that the hepatitis C has had a very significant impact on your physical health over the years.

A. Yes.

Q. If we go back to when you were at school, you've said you were very tired with a lot of aches and pains, and in fact it got to the point where you started skipping school to come home and sleep.

A. Yes.

Q. As a result, you feel your educational progress was very restricted.

A. It was, yes. That's all I wanted to do was sleep. I ached, I hurt.

Q. You left school at 16 with just four GCSEs --

A. Mm.

Q. -- and went on to become a nursing assistant --

A. Yes.

Q. -- but struggled with that as well.

A. Yes, I did, yes -- the shift work, I think most people would anyway, shifts, but it was quite physically --

or you are quite physically active and I did struggle with that. And, again, I used to do my shifts or -- or do what I could with work, come home, sleep, and if I could I'd wake up to go to work, you know.

Q. You now work in an office-based role.

A. Mm-hm.

Q. But you continue to be very fatigued and unwell.

A. Yes, yes.

Q. And that restricts your ability to work and your ability to socialise?

A. Yes, I don't -- I don't really socialise.

Q. And you've said in your statement you also struggle to participate in family life --

A. Mm.

Q. -- and activities. You've talked about it impacting your role as a mother.

A. **(Nodded assent)**

Q. You've said:

"I can't participate in lots of family activities."

It takes you too long to recover from them physically, and you struggle with the effect that's had.

A. It takes all my strength to work, so when I've finished work, I just try and rest where I can, which

has impacted on my family, yes.

Q. You've had progressive elevation of your autoimmune antibodies.

A. Yes.

Q. Initially it was thought you might be suffering from lupus.

A. Yes.

Q. But since then your treating doctor has confirmed it's not lupus but it is attributable to your hepatitis C.

A. Yes.

Q. Despite that, you applied to the Skipton Fund, but were turned down.

A. Yes.

Q. Can you tell us why?

A. I was turned down the first time -- are we talking about the first time?

Q. Yes, the very first time.

A. Sorry.

Q. That's all right.

A. On the balance of probabilities that I cleared -- naturally cleared the virus within six months of probably contracting the virus, so, yeah, I wasn't awarded.

Q. You had confirmation when you made that application, didn't you, that you had a hepatitis C ELISA result

that was positive in 1997, and positive antibody by EIA results in 1995, 1997 and 1998, and you've said in your statement that Skipton concluded that the doctors had got it wrong.

A. Yes.

Q. And that the 1997 test must have been wrong as well.

A. Yes, they must have used the wrong test for it.

Q. So on that basis they said you must have cleared it within six months and so fell outside the rubric of the Skipton Fund?

A. Yes, yes.

Q. Professor Tuddenham wrote to the Skipton Fund on your behalf and we have his letter, 1756004, please. It says this, in the middle of the first paragraph, where he sets out your situation as a manifesting carrier. Then he says:

"However, it was the BPL concentrate given for the tonsillectomy which is the most likely cause of her seroconversion to hepatitis C antibody that was noted much later. By the time this was looked into in 1991 and subsequently, her hepatitis C RNA was negative with strongly positive antibody. However, on reviewing the case records it is evident that immediately after the tonsillectomy she had a period of pyrexia, marked tiredness, weight loss and skin

itching which persisted for years on and off. A letter in our notes from a clinician at the time remarks that she needed to have liver function tests done. However, these were never done and there is no doubt that was our error.

"Based on the symptomatology, I am convinced she had a period of chronicity of hepatitis C infection that would have shown up with abnormal liver function tests had they been performed. But by the time we tested her many years later, she had spontaneously cleared hepatitis C.

"Various chronic health problems she has had since can also plausibly be attributed to the undoubted hepatitis C infection she acquired from BPL concentrate and/or the cryoprecipitate. She has been known nearly eight years now to have progressive elevation of autoimmune antibodies, accompanied by symptomatology consistent with a collagen vascular disease for which she is under treatment. She has markedly elevated levels of antinuclear antibody.

"Recent studies have been published which show a strong association between hepatitis C infection and autoimmune disease. I would put this in the balance as an additional argument for her to be compensated for hepatitis C infection received or caused by infusion with NHS Factor VIII concentrate."

He notes that you've also got persistently elevated markers of chronic inflammation.

Despite that, your application was refused.

A. Mm.

Q. You then suffered from breast cancer in 2010 and approached the Skipton Fund again, and they refused to provide any assistance at that point either.

A. That's correct, yes.

Q. Why was that in relation to the cancer?

A. What they did was basically made us jump through hoops, get statements from my parents, and get whatever else we could remember or kind of find, and it was all produced to them, with the backup of Professor Tuddenham's letter there, as you can see quite clearly says, and they said no, on the balance of probabilities, I probably -- I cleared the virus within six months and that there'snot really enough evidence, yeah. It's almost like a little bit of a game now with the Skipton Fund, which I know is now EIBSS. It's just -- just applied just to really highlight how -- yeah, unfair they are.

So not only struggling as being seen as female with haemophilia or a low Factor VIII level, I think the decision-makers at the Skipton Fund struggle with that, and there is other people, mainly males, that have been awarded on the same grounds as me, but I personally believe that, because I'm female, they won't, and that's why they haven't awarded me.

Q. When you got to having breast cancer you applied again, and you've said in your statement that that was declined because it was the wrong sort of cancer.

A. Yes, it was. With the Penrose Inquiry, there's a statement in there that says that 70 per cent of people that received pooled products will go on to develop a cancer. So because I had the breast cancer, I applied again and, yeah, you're correct, I'd forgotten that, sorry, they did say, but it wasn't that cancer, yeah, I had the wrong one.

Q. Again, we have two further letters that Professor Tuddenham wrote on your behalf. I just want to have a look at those. 1756008, please. It's a letter to whom it may concern, but it was for your applications.

He notes in the middle of the first paragraph that:

"A contentious point arises over the unfortunate fact that she was never tested for liver function during the early period that she was so infected and only subsequently much later tested and found to have cleared the infection."

He refers to a letter that you'd written summarising your situation, and endorsed everything in that letter, and he then closes his letter saying this:

"I personally think that if she's refused any compensation on a highly restricted interpretation of the rules governing the disbursement of the fund then that manifestly is unfair."

And a subsequent letter from him, in October 2010, 1756014, please. He opens the letter saying this:

"Concerning the evident fact that Mrs Nicola Jones was infected with hepatitis C through infusion of NHS Factor VIII concentrate at the time of her tonsillectomy in 1980. These comments are based on records in case notes held at the Katherine Dormandy Haemophilia Centre. I believe that copies of these case notes are available to the panel, who are trying their best not to award what she is obviously due, namely compensation for having been infected by hepatitis C and having developed a degree of chronicity."

He then goes on to set out your history.

Despite those letters from Professor Tuddenham, you did not receive any support from the Skipton Fund.

A. No.

Q. You've got a son and a daughter, and we have their permission to discuss their medical conditions as well.

A. Yes.

Q. Your son is a haemophiliac.

A. Mm-hm.

Q. And you discovered in 2013 that your son had been tested for HIV and hepatitis C.

A. That's correct.

Q. How did you find out about that?

A. We were going abroad, and you have to have letters for customs and then if -- because you carry the treatment with you, and then a letter for if they need treatment for the doctor or whoever is treating them explaining how to give their treatment and what is wrong with them, like low Factor VIII level and this is their treatment.

And it was, yeah, in that letter, yeah, that I found out that my son had been tested for HIV and viruses.

Q. And you, as far as you were concerned, had never consented to those tests.

A. No.

Q. Or had even been asked to consent to such testing.

A. No.

Q. Your daughter is a carrier.

A. Mm-hm.

Q. And has a platelet disorder.

A. Yes.

Q. And you then discovered that your daughter had also been tested without consent --

A. That's correct.

Q. -- since birth.

A. Yes.

Q. We've had a response from Professor Lee from Great Ormond Street Hospital, sir, which will be put up on the website in due course in which she says the usual practice would be to obtain verbal consent for the viral screening tests, but she accepts this is not documented in the notes of the two children. She cannot say with certainty that consent was obtained, and if that's the case, then she has apologised for that.

SIR BRIAN LANGSTAFF: Yes.

MS FRASER BUTLIN: But for you, Nicola, because of your own experience, and the experience with your children, you now lack trust in the medical profession.

A. Yes.

Q. And it's had a very significant impact on your mental health.

A. Mm-hm.

Q. Can you tell us something of that?

SIR BRIAN LANGSTAFF: You don't have to unless you wish to.

A. I just struggle because of what happened to me in my childhood, and how I was made to feel, and I kind of -- part of me thinks: is it history repeating itself? That's what I worry about. Because the children have never had blood products, so why would they need to be tested? I worry about the impact that it had on me for the kids.

Q. It's been incredibly difficult, you say in your statement, for you to have to keep going back for your own treatment and to deal with your children's treatment --

A. Yes.

Q. -- in that context.

A. I avoid -- I avoid going now. My husband goes and he'll -- he'll take the children, but I try and avoid going anywhere where there's a mention of haemophilia or centre, yeah.

Q. Finally, you've also tested positive for hepatitis G.

A. Mm-hm.

Q. Can we have 1756002, please, Henry.

It seems to show a positive test in 1980, and a positive test in 1992, or at least a test done on samples from those dates. You saw the result in 1995, and decided to take a photograph of it in 2009.

A. Yes.

Q. Had anyone said anything to you about this?

A. No, no. I -- no one has ever said anything about it, and still hasn't. I did ring up the Haemophilia Society and ask them if they knew anything about hepatitis G, which -- no.

Q. And when you came to have your records for the purpose of this inquiry, was this document within them?

A. No.

Q. And then in 2004 you were also told you were at high risk of having contracted vCJD.

A. That's correct, yes.

Q. And subsequently that you'd received an implicated batch.

A. That's correct.

Q. You've said in your statement that that was really just one more thing.

A. Yeah, it was just one more thing. It was just a letter in the post. I was five months pregnant with my son. Yeah, kind of read the letter, showed it to my husband, and kind of said to him, "Just another thing to add."

Q. Hepatitis G and the vCJD was something else to add to the list of things.

A. To the list, yeah, put it away. Yeah.

MS FRASER BUTLIN: Those are the questions I have for you. I'm just going to turn to Mr Snowden to see if there's anything else he wants me to raise.

Finally, is there anything else you would like to say?

A. Yes. I was going to write a big, long thing, but I thought we might not have time, so I kind of narrowed it down a bit.

I think for me it's about what has happened, but protecting our future.

So the Children's Act 1989 allocates duty to local authorities, courts, parents and other agencies in the United Kingdom to ensure children are safeguarded and their welfare is promoted. When our children were born in 2002 and 2004, it is my belief there were elements of clear neglect from the doctors/NHS to safeguard the children from unnecessary tests, stress and indirect abuse. Yet when the Children's Act 2004 was updated, it clearly states that the interests of the children and young people are paramount in all considerations of welfare and safeguarding, and that safeguarding children is everyone's responsibility. Considering they have not received blood products, then why were the children tested? That's what I'd like to know.

I think from our point of view, haemophilia I know is a burden for everyone. We were accused of child abuse when Keira was 6 weeks old, because when she cried she had little bruises come out on her head. Then with Jake, when he was born, he was whisked off for a scan on his head because he was born with forceps, and the apology was to the doctors, not to us.

I just want to thank Sir Brian, the legal team and everyone here. Mark, for being here, and probably the only one who has had to listen to me harp on about my bits of paper. And also I want to thank my children and my husband.

SIR BRIAN LANGSTAFF: There's just one question which I have for you.

Will you have to pay for this, coming here to give this evidence, in terms of what happens to you tomorrow?

A. Yes.

SIR BRIAN LANGSTAFF: How long will it take you to recover, do you think?

A. To recover --?

SIR BRIAN LANGSTAFF: Well, to get over -- you pay in terms of tiredness, for giving evidence.

A. I'll probably go home and go to bed. I'm off tomorrow, I booked tomorrow off, because I thought I'll be too -- and then I'm back at work. But I booked tomorrow off because I know I'll probably just sleep today.

SIR BRIAN LANGSTAFF: Well, that's what I thought might be the position.

A. Yes.

SIR BRIAN LANGSTAFF: And I think it just emphasises what a great effort it's been for you to be here and how much you deserve our thanks for bringing yourself to do it, particularly when you knew there would be a cost. Thank you.

A. Thank you.

SIR BRIAN LANGSTAFF: We'll take a break until 3.00.

At 3.00 I think we'll probably go from one witness to another, but they must take however long they need, we will not rush any witness, and we'll finish when we finish, but just so that you know, there won't be another break except for a couple of minutes in between the next two witnesses.

(2.40 pm)

(A short break)

(3.00 pm)

SIR BRIAN LANGSTAFF: Our next witness wishes to be known as Stu, does he?

MS FRASER BUTLIN: That's correct.

STUART GREGG (affirmed)

Questioned by MS FRASER BUTLIN

MS FRASER BUTLIN: Stu, there were two things you wanted us to address at the very start of your evidence.

The first one was that you're a bit nervous of giving evidence because you have quite severe brain fog.

A. I do, yes.

Q. You're concerned about how that will affect your concentration.

A. Yes, I'm prone to lapses of concentration and forgetting where I am sometimes.

Q. But we've said we're just going to go nice and slowly and we'll keep on track.

A. If you'll bear with me, if that happens.

Q. Secondly, you've never told your partner's family about your infections.

A. That's right, yes.

Q. And many of your friends also don't know about your infections.

A. Yes, the majority of my friends and family aren't aware.

Q. It's only really your nuclear family.

A. Yes, so my mother, my sister, stepfather, stepmother, and my father's died, so ...

Q. Beyond that circle --

A. Nobody.

Q. -- nobody knows.

A. That's right.

Q. So giving evidence today is really significant for you.

A. Absolutely. It's important for us as a family, as well as obviously for our community.

Q. Starting at the beginning, you have severe haemophilia A.

A. That's right.

Q. And there's no history of it in your family; it was simply a genetic mutation?

A. Yes, it was a genetic mutation, yes.

Q. You were diagnosed at 18 months old, about, and received regular treatment at the Birmingham Children's Hospital.

A. That's it, slightly before 18 months but roughly, and I was treated at Birmingham Children's.

Q. Under Dr Hill. And you have some specific concerns about Dr Hill's general approach to treatment.

A. Obviously not when I was very young because you're not familiar with how things can be done differently, but in hindsight, a lot of the treatment involved heavy Factor VIII treatment and lots of bed rest. So just something simple like a muscle bleed into my thigh could end up with two to three weeks bed rest in hospital, which, looking back, is ridiculous. So -- whereas -- then all you're doing is weakening other muscles, weakening joints, so as soon as you get up again, you get bleeds in other parts of the body, so ...

Q. You've also raised concerns in your statement about the extent of Factor VIII product use, again in hindsight --

A. Again, in hindsight.

Q. -- was going on.

A. That's right. I was treated quite heavily. I wasn't a 0 per cent haemophiliac Factor VIII levels. I -- my levels tended to be between about 2 and 4 per cent. I'm not entirely sure what they are to this day. But I seem to -- I seem to bleed a lot more than my Factor VIII levels would normally -- as a haemophiliac would normally bleed with those sort of levels, but

I was treated very heavily. Since I became an adult and had more independence in my treatment, I'm able to minimise treatment completely compared to years ago.

Q. You were treated with cryoprecipitate until about November 1980.

A. That's right.

Q. Then you were given Factor VIII.

A. Yes.

Q. And your usual treatment was with Armour products.

A. That was the dominant -- the dominant treatment we had, roughly until the mid-1980s.

Q. What was your mother told about the Factor VIII?

A. So when I was first diagnosed, my mother -- because there was no history of haemophilia in our family, my mother spoke to Dr Hill. She was told that there was a treatment now available which involved a blood product. Ironically, looking back, she thought that was a real positive because it would be a safer product than some kind of chemical synthetic product.

Can you repeat the question again, please?

Q. What was your mum told about the Factor VIII and its safety?

A. Yes. As regarding its viral safety, that was never raised with her, she was -- we were -- she was told to keep on treating, basically. She did attend

a conference, a haemophilia conference, in Bournemouth in the very early 1980s, where there was a representative from Armour present at the conference. It was David Watters would've been the chairman of the Haemophilia Society at that time, and she spoke to the Armour rep herself and he spoke to people as a whole at the conference, and she was told things such as the blood products were safe, and that they had -- they knew where all the products were sourced from, where all the blood was sourced from.

Q. You've described in your statement that she was assured they were completely safe and that the products came from researched people.

A. Yes, there was like a registry of where the products -- of where the blood was coming from, yes.

Q. You were in hospital in November 1981 and contracted TB whilst in.

A. That's right.

Q. You think that's probably when you seroconverted.

A. Well, it's hard to say for definite when I seroconverted, and that might be looking at other parts of my medical records a little bit too early for the seroconversion, but I did -- so with the TB first of all, I -- I was in hospital for a normal bleed. We were on the oncology ward. There was another patient

there with a cancer-related health problem. That patient's family came to visit and someone had TB and infected some of the haemophiliacs who were on that ward.

So there was always a question why haemophiliacs who had higher, better immune systems, theoretically, became disposed to TB, whereas other people on the ward didn't who may have been more immunocompromised than the haemophiliacs.

Do you want me to go on to talk about the TB treatment now?

Q. Of course, yes.

A. Yes. Remind me in a minute to go back to the seroconversion bit.

So the TB treatment. So I wasn't -- when I was infected with TB, I wasn't aware, obviously. At a later date I went to -- I was admitted to hospital with another bleed, which was just a sort of routine admission. I was left in hospital overnight. My mother came to visit me the next day and I'd been moved to a different ward, which was ward 5. Anyone who went to Birmingham Children's Hospital in that period knew ward 5 wasn't a very cosy ward to be on.

I'd -- I was quite poorly. My arm had all swollen up, and there was no medical staff available.

Eventually my mother managed to speak to the nurse on the ward, and it turned out that I'd been tested for TB, I'd had a reaction to the test, and that's why I was poorly.

Apparently I was in hospital for the best part of a week, and with a spiking temperature.

Eventually I was let home, and then over the course -- just after that all my family were sent for chest X-rays to see if there was TB present. Following that, I was given an 18-month course of anti-TB treatment or similar. I think the names of the drugs will be in my notes.

Q. Yes, and you wanted to come back to the question of seroconversion, because in your statement you talked about 1981 and that instance of TB being when you seroconverted.

A. That's right.

So -- but looking at my records since then, it just seemed peculiar why we were infected with TB when others weren't, and it seemed coincidental, if my -- if my immune system was lowered, that could've been during the seroconversion.

But there was another occasion in about 1983 when I was rushed -- I seemed to be suffering from an asthma attack, but I didn't have asthma at the

time, and I couldn't breathe. I was taken to the local hospital. They gave me a nebuliser. That didn't work, so I was rushed in an ambulance to Birmingham hospital.

I can -- I can remember the journey now, and I eventually either fell asleep or just drifted off as -- on the journey. I was just very poorly and I was admitted to hospital again, and that seems to tie in more likely with the period of seroconversion.

Q. In 1984, your mum attended a meeting called by Dr Hill, and you've talked about it with your mum, about the availability of Factor products. What's your mum said about that meeting?

A. Okay, so there was a couple of separate issues there with meeting Dr Hill. So there was a meeting with parents Dr Hill had, and it was -- I might need to just read the actual notes she told me. So Dr Hill had said that he could no longer provide an adequate service, and was asking parents if they could approach their MPs to see if they could lobby government to get more funding and support.

That was for the overall service, so my mum would've written to our local MP, which was Michael Spicer at the time, and requested that. She's got those letters still.

Q. At that meeting, was there anything said, as far as your mum recalls, about the risk of infection from blood products?

A. No, no, no, there was never -- it wasn't about infection in treatment or anything like that.

Separately to that, at a later date, there was always a battle to get home treatment, and when we did have home treatment, there was two occasions where Mother was phoned up by the hospital, completely out of the blue, and asked to immediately return all products that we had, and she recalls one time it was close to teatime and she received a call and we were told to go straight up with the products, no reason given.

She says because there was -- there was no real correlation between what was happening and the products, it just never all fitted -- at the time it just seemed a request, it wasn't sort of -- any sort of ulterior motive for it, perhaps. Then again in hindsight it seems quite peculiar.

Q. Please can we have document 1252011, Henry.

We have here a series of results, and we can see, if you go down to the other half of the page, on the right-hand side that you were found to be hepatitis B surface antigen positive in 1985,

28 January 1985.

And then on the left-hand side, it's not very clear on this copy, but putting it together with other documents as well in your medical records, on the left-hand side, HTLV III antibody status 1984, result: positive. Other HCDO records you have suggest that the first positive result related to a sample from the 16 March 1984.

A. That seems to be the case, yes, and it was presumably from retrospective stored blood samples.

Q. If we go down to the bottom of the page, there is a tick box which -- on this copy unfortunately we can't see it quite so clearly as the original, but it says, "Parents aware", tick, but we don't know when that was ticked.

How was your mum told that you were HTLV III positive?

A. She wasn't, and it sounds quite strange, but it was -- her awareness of my HIV was in a very piecemeal fashion. It was -- she describes it as being almost drip-fed.

She said that at the time, when it first started being in the newspapers and the media, there was an underlying concern that all haemophiliacs were HIV positive, and that -- and they just -- the mothers were just hoping that that might not be the case.

Over time, things happened, things were mentioned. Some boys got ill, and it just became apparent that I was HIV positive, and -- but my mother was never sat down and informed that this was -- this was the situation, and this was the case.

Q. And looking through your medical records, there's no notes that suggest that there was a consultation at which HTLV III was discussed. There's simply nothing there.

A. No, and she's adamant that it just simply didn't happen, there was no conversation, and it just became apparent over time.

Q. On one occasion the ward sister simply said, "Isn't it sad about the boys?"

A. Yes, and that was -- it would've been presumably quite difficult for the -- some of the medical staff as well. But it was little comments like that which sort of built the picture up rather than actually being sat down and told: this is what's happened.

Q. Were you ever directly told that you were HTLV III or HIV positive?

A. No, there was -- again it -- it's hard -- I definitely wasn't sat in a room and said: this is the situation. But it's hard to sort of formulate an idea of when

it became apparent to me.

The best way I can think about it is I can clearly remember watching the television and seeing some of the adverts on telly, which would've been, I think, around about late 1986/1987, and knowing that that referred to me and my situation. So I think I had an understanding around about that time. But, no, I was never aware -- well, sorry, never told that this has happened.

The the other thing -- and that awareness would've continued because I remember Dr Hill talking to me about -- once I became a teenager, in my early teenage years, that if I was going to have a partner, to be aware of safe sex, and that was reiterated at clinical appointments.

Q. Using a condom and cleaning up any blood spillages was something that you were very aware of.

A. Absolutely, yes. So for my mother, she tried to -- she tried to -- like a lot of families -- not make people -- not -- she tried to hide the HIV from the community, schools, and so what she tended to do was use hepatitis, because it was a notifiable disease. She'd say to the school that I had hepatitis, and that if there was any accidents or spillages, that I would deal with it myself. And all I was told -- I remember

being told repeatedly as a child, "If you cut yourself, just deal with it yourself." And I just did, because I was quite capable of doing so.

But this was really important for my mother, and that's how she sort of -- she would -- the family had moved to a more rural location, and she wanted to try to bring me up as normal as could be possible in that kind of situation, and me to have a normal existence, rather than being institutionalised like some of the haemophiliacs ended up, I suppose.

Q. You've described in your statement that that responsibility of cleaning up any spillages, and latterly in terms of sexual relationships, weighed very heavily on your shoulders and had an impact going forwards into adulthood.

A. Absolutely, yes, because there's a burden of responsibility, rather than a burden of not wanting to infect anyone else, and that was your responsibility, you had to make sure that that happened. And so as I was a growing teenager, that was really important.

So I went to a normal mainstream high school. Other people would be forming relationships, and whilst I did, it was always -- there was always something in the back of my mind that there was a problem that I was very aware of.

Q. Over time there were also discussions at your clinical appointments about your CD4 levels.

A. That's right.

Q. You became very aware that as they reduced, then you were in trouble, and you said you had an understanding that you had very little time to live.

A. That's right. Yes.

So CD4s were the only real barometer of health, or probably disease progression is a better word. So I always knew that -- but the expectation was that I would die from my HIV diagnosis, so you just try to sort of get on with things, and having the CD4s gave you a bit of a barometer of how things were going. But obviously when they start to plummet, it's -- it's sort of a bit unnerving, perhaps.

I was very fortunate. I was generally asymptomatic, so I never had any serious infections, but my CD4s I know by about -- so by about 1993 they would've been -- I think they were around about 150, and they went down to 10, and they remained at 10 for a considerable time, and they were at 10 when I started my HIV medication in 1997.

Q. Which we'll come to in just a minute.

A. Yes.

Q. Before we get there, you've said you were constantly surprised to reach particular milestones in your life.

A. Absolutely.

Q. 16, 18, 21. Can you tell us a little bit of what the impact of that was on you emotionally at that age?

A. Again, it's hard. Because you're a child, you don't -- there's no context to sort of mark things against or -- but all I knew was -- I remember thinking when I was about 13 that I probably wouldn't live to be 16, and then when I was 16 I was reasonably surprised and I thought I probably wouldn't reach 18. And then of course 18, and you don't think you're going to get past 21. But you keep on hitting these marks, and it was, it was a positive surprise, I suppose. I'd never -- I'd sort of -- not in a negative or sad way, but I'd sort of adjusted myself to that was what the reality was and I wouldn't be reaching an old age, and I fully expected to be -- to die in my teenage years, yes.

Q. In relation to those teenage years you've obtained your medical records, and there are no letters from the hospital to your GP that refer to you being HTLV III positive until 1987. The first letter that there is is 1252012. If we could have that on the screen, please, Henry.

What we see here is it's dated 10 September 1987

and it deals with an admission you'd had because a cricket ball had struck you over your eyebrow, and then at the bottom there is simply an NB:

"NB. This patient is positive for hepatitis B surface antigen and has normal liver function tests. He is positive to HIV antibody."

Before 1987 there's no record at all in your -- there's nothing in your records to indicate any communication between the hospital and the GP of any results. But during that time you were still having treatment, including dental extractions.

A. That's right, yes.

Q. And so others were treating you and were seemingly unaware of your status.

A. Yes, there -- there were -- yes, that would've been a problem. It was something I was unaware of because I didn't know what kind of communication was happening between my GP and the hospital.

Again, I think I would've seen my GP, but generally speaking I spend more time with the hospital, and my mother thinks I probably spent somewhere between about 30 to 40 per cent of my time at the hospital.

Q. Now, you believe you were used for the purposes of research throughout your childhood and particularly

through your teenage years. You know your parents were asked if you could participate in a study in 1990 into the psychological impact of haemophilia, but you also think you were used in other research programmes. Why is that?

A. It's hard to say. There's very little that I can sort of bring up and say why I think that, but there was an awful lot of blood being taken. When I was in hospital, lots of tests were done, and the only thing my mum can ever remember them saying they were testing for would be inhibitors against my Factor VIII, which is something which is done reasonably regularly, I suppose, but wouldn't have constituted the amount of blood that was taken or the other testing that was done.

Q. Your sense is that because so much blood was taken on such a regular basis, they may have been testing for other things and using the blood for research.

A. It's an assumption, but I can't prove it, but it's -- it feels a bit excessive to take the amount that was taken for inhibitors tests.

Q. You've described the sort of growing knowledge around your HIV status as you were a teenager, but then in 1998 you said you became empowered and knowledgeable about it. What was it about 1998 that gave you that

sense of -- that understanding?

A. Okay, so prior to 1997 my sort of future and my health had been on -- going in one sort of direction, like I said earlier, which I was accepting of where that was going and I was quite sure that that was the end result eventually, that my death would be the end result eventually.

I wasn't empowered about HIV generally. I sort of -- I didn't try to avoid it, but I didn't -- I wasn't reading research papers, I wasn't learning about HIV at that age, and then in 1997, in January 1997, I started sort of pretty much out the blue really. My consultant at the time, Dr Wilde -- this will now be at the adult hospital -- he said that there were some new drugs to try and it might be worth me trying them. Obviously my health was in a precarious situation, even though I was asymptomatic.

Q. Until that point you had been on some AZT but not particularly complied.

A. I was -- yeah, so I'd been -- I'd been on AZT, so 1997 I started my HIV -- my heart regime. So probably -- definitely in the eight years prior, and perhaps even a bit longer, I had been prescribed AZT and DDI, didanosine.

I always got a feeling when they were prescribed to me that it was -- it just felt a bit wishy-washy, it wasn't really -- there didn't seem to be any substance. I don't know why I read into it like that. I did take them for a bit, they made me feel really sick, and I just generally stopped taking them, which probably wasn't such a good idea, but in hindsight it turned out to be quite good.

When I started my new regime in 1997 -- January 1997, it felt like a more positive step to take, it felt like this could actually have positive results, and I made a decision to give it a proper go, and to be fully adherent.

Q. That decision also coincides with starting a university course in health and social care.

A. Yes, so I started in 1997, I -- up until that time I -- I'd done okay at school, but I probably could've done a lot better. I'd been sort of floating around, I hadn't been working, and -- and it's hard -- especially when your friends work and you just look like you're sort of scrounging off the state to other people, I decided it was time to do something more positive and constructive, and so I started at university in September 1998, and I spent quite a long time at university following that.

And -- but that -- so by the time I started, about 18 months or so after my treatment, I was under the impression that my health was -- even though my CD4 count was really low still, probably still about -- it was 10 for years, so probably still about 10 then -- but I felt like things were moving in the right direction. My viral load was undetectable, and I wanted to educate myself, and some of the courses I took meant that I could learn more about HIV. I became much more empowered. I did voluntary work at a local HIV centre, which tied in with my degree, and I started to understand how HIV manifests, how it works in your body, how treatments work, and I was just completely ignorant up until that point. I -- it was like turning a switch on and I started to understand it better, and that really empowered me to take control of my own health and be positive about my own health as well.

Q. Because until you started studying it yourself, nobody had actually sat down and explained it to you in a way that you could understand and get to grips with.

A. It wasn't even explaining in a way I could understand; it just wasn't explained. It was just, "You're HIV positive", and that's it. "So these are your CD4s, these indicate how well you are." And that sort of

plummeting down -- there's nothing to tie anything to. There was no structure about improving my knowledge and my understanding of HIV.

That's probably not a doctor's role, but it just -- you're just sort of like an ostrich, you've got your head in the ground, you've got no idea what's going on, but by empowering yourself and becoming more knowledgable, you can really then take proactive steps in your own health.

I might talk later perhaps about a lot of haemophiliacs, especially haemophiliacs with viral infections, end up becoming expert patients themselves. They go to see their GP and the GP -- they know more than the GP about their situation, and that's -- but that's positive because that means they can make better decisions about their own treatment and care.

Q. For you, that resulted in you being on a better combination of drugs -- the combination of drugs was working more and you were starting to feel better, and since then you've been more compliant.

A. Yes. So I was always really compliant. There was very few drugs available in 1997, and we were always told -- so this was another thing about compliance as well, there weren't all the families of drugs there

are now. If you failed a drug or you stopped taking it and you became resistant to that drug, that was a serious problem because you only had so many options.

So I got really quite sick. I was hospitalised because of side-effects from the drugs. You get the normal things like sickness and diarrhoea and dizziness and all that kind of stuff, but I had something called haematuria, which -- it affected my kidneys. I would be passing blood instead of urine, and just those kind of things really.

But, yeah, you do learn about your own care.

Q. But throughout the 1990s and the 2000s, until about 2010 or 2012, you weren't treated by a specialist HIV doctor; your HIV care was simply within the Haemophilia Centre.

A. That's right, yes.

Q. You have some views about that now.

A. So I do. I mean, in hindsight, it would've probably been -- from a medical efficacy kind of perspective, it would've been better to have sort of expert -- an expert in HIV, an expert in haematology and an expert in hepatology, and perhaps some counselling or something else as well. But it -- because of the way HIV came into our community, it sort of stayed and we were sort of ostracised from the rest of the HIV community to a certain extent. It became the role -- the function of our haemophilia doctors to become our HIV experts, and that should never have been their role.

I'm sure most of them tried reasonably hard to do a good job, but they could never -- they could never be really good at looking after HIV because it was an evolving field, things were changing all the time, and do their job as a haemophilia consultant.

So in hindsight -- not for me, because I was really lucky, I got to 1997 without dying, and without being too dramatically ill, even though it was pretty tough. But the kids who died in the end of 1996, for example, I'm reasonably confident if they'd gone to an HIV specialist, they might have got different treatments quicker, access to trials, all sorts of things like that, which weren't available.

But I'd like to say that my haemophilia team at that time at the adult hospital, which was Dr Wilde and his nurses, were absolutely excellent, and for me at that time having a -- what I call a one-stop-shop was really, really great, because any problem I had, I phoned them up and they'd try and deal with it. And okay, it probably wasn't the best example of shared

care, but for me it worked. But for other people, I think it probably didn't work, and that might have been at their cost. But, yeah, my haemophilia team on the unit were always really supportive and really good.

Q. In terms of hepatitis --

A. Yes.

Q. -- you are hepatitis B positive and hepatitis C positive.

A. That's right.

Q. In terms of the hepatitis C, when did you become aware that you had hepatitis C?

A. Again, it's this -- this drip effect and learning things in a piecemeal fashion.

I -- so I knew I had hepatitis, definitely when I was a teenager. But it was never -- it was never talked about. I was never sort of sat down and told I had hepatitis. My -- like I said before, my mum was quite -- she wouldn't say, "I want you to clean up blood spillages because you've got hepatitis", it was just, "You must clean up all your blood spillages."

When I went to the -- I went to the QE, which was for the adults in Birmingham, I think it was at the start of 1994, and I just remember it being mentioned. Dr Wilde would talk about it, about

hepatitis, and -- but I didn't know where -- I didn't really know there was A, B and C, I just knew I had hepatitis.

But it started to become apparent to me that I had hepatitis C, and then eventually I realised I did have hepatitis B as well. But I wasn't -- it wasn't like a huge blow or anything, because I was going to die from HIV. I could have all the viruses in the world, it didn't really matter, because I was going to die anyway. So chuck another one in, it doesn't really matter.

Q. You have many hundreds of pages of medical records, and we've been through them. Is there any record in them of a diagnosis with hepatitis C?

A. There was -- so the only -- the only way we can relate hepatitis C in my records would've been I presented with hepatitis-like symptoms in the mid-1980s. I don't know which year without looking at my records. My mother took me up to see Dr Hill and said, "He's presenting." She said she was given reasonably short thrift, which was a common theme, but after a while it turned -- she was told that I had non-A, non-B.

Now, at that time -- it seems ridiculous now, but at that time my mother thought that non-A, non-B meant not hepatitis and it was some other kind of

problem, but she was never really sort of -- she never really understood what it was or what was causing me to present with those problems, and we just plodded on through, really. But obviously looking back, non-A, non-B, was probably hepatitis C.

Q. But there's nothing in your records after there's a formal hepatitis C test to indicate that you were tested and that that test was communicated to you.

A. For hep C?

Q. For hepatitis C.

A. No.

Q. There's just a blank in your records as far as that's concerned.

A. Yes. I really didn't know about hepatitis C. I know it sounds ridiculous, but I really didn't know until I was -- I was probably at the adult hospital, and it became apparent that I had these hepatitis viruses. But like I say, it wasn't a blow. It was just -- it was just the way it was.

Q. And your recollection that you weren't told is supported by your medical records, because there's simply nothing in them which suggests anything else.

A. Yes.

Q. You went on treatment for hepatitis C in 2010 and 2011 with interferon and Ribavirin. Can you tell us something of the effect of that treatment on you?

A. Yes, so -- so first of all, leading up to that -- that HCV treatment, we'd been trying to have a family, or we were in the midst of having a family, so to start my HCV treatment, I had to change my HIV treatment, which wasn't compliant or which caused an interaction with the HCV treatment, so that was one thing. But I couldn't change my HIV treatment because we were at the Chelsea and Westminster trying to have a baby, and if you change your HIV treatment it means you can't try and have IVF treatment, because when you change your HIV treatment you can have a dip in your viral -- your viral load can be detectable potentially. So we had all these things to juggle and we had a child as well already.

Eventually we managed to align things. I changed my HIV treatment and I changed -- I started hepatitis C treatment.

At the time, my hep C was relatively stable, I had a -- I'd had subcutaneous biopsies some years before, and I'd had fibroscans -- my fibroscans up to that point were around about 9, 9.5. That's like a moderate fibrosis. So not ideal but not critical either.

We were always told that there was new

treatments coming along, and I delayed having hep C treatment for quite a long time up to that point. And also we were being told that the longer you leave it, the more damage your liver gets, the less likely it is that hep C treatment would work.

So just simple things at that age, like just going for a drink or something, wracks you with guilt, because you think you're just compounding the problem on your liver.

And also -- I mean, I know health is important, but also you want to have a normal life as well, you want to go and have a drink sometimes with a friend or those sort of things.

Q. So eventually you started the treatment.

A. So I started the treatment. I can remember vividly I started in April 2010. Because of my genotype, I had a 48-week programme of interferon and Ribavirin. I was told it would be like having flu for a year, which it was. It was pretty miserable. It was like having flu, but just worse than normal flu. You -- it was the -- I was so -- felt so sick, I was on antiemetics all the time. I just -- it felt like it sucked the soul out of my -- out of my body.

I had no -- I couldn't eat, I couldn't eat with the family, I couldn't even walk down -- I couldn't

walk from here to the other side of this room. It was just debilitating. It was horrific.

And then part of, like I said earlier, about becoming adherent and compliant to medication, I saw this opportunity as a chance to get rid of my HCV, which would be good in the long-term. So I stuck at my treatment, and even though it was dreadful, I kept on going, and then I started -- I had -- I was really low a lot of the time, low mood, mood swings, that kind of thing, and then after 46 weeks I went into a really bad chemical depression, and I would be -- I can remember now right at the very end just being lay on the floor in the foetal position, just crying and just being -- it was so hard, harder than anything else. Just took all my -- took everything away from me.

Up until that point -- up until that point it was my mental and emotional fortitude that had got me through the physical problems in my life, my HIV, and ... I could defeat those physical things, and then -- but this very last hurdle which was going to try and clear my hepatitis C, it took -- it took my mental strength away.

It's an horrendous treatment, and I don't want to go into saying, "Oh, they wouldn't give it to --

they shouldn't give it to the worst people in the world", or anything like that, but it was just -- it was just horrific. It had a huge impact on our family, and it's had a terrible impact on me. And they took me off -- they took me off it after 46 weeks, and they said to me, "After six weeks you'll feel much better." Six weeks turned into six months, six months turned into six years, and I've never been the same person again. It's taken -- it's taken a huge part of me away, of what I was.

And it's only just recently, eight years later -- for the first six years or so I would've swapped -- I would've had the hepatitis C back and not taken the treatment. It's had a terrible effect on us.

Q. You've also said in your statement that you feel that you have some survivor guilt because so few within the co-infected community are still alive, and you feel you have something similar to PTSD.

A. Yes. I think those feelings are exacerbated. My emotional frailty since having my hep C treatment -- I was resilient up until then, but that emotional frailty highlights these things and I always -- I've thought about these things for a long time. So when I was doing a lot of research at the university, I used to speak to the social worker at Birmingham, he was really good, and I used to say that these feelings you get, and not just me, other people in my community, in the co-infected community, they are getting this sort of -- I don't want to belittle anyone whose got PT -- I don't -- I don't know what else to call it apart from PTSD, because when I've heard research -- read research articles or heard people talking about their experience of PTSD, it just resonates with what I felt and what I know other people in my community have felt. And so my social worker said it -- he wanted to do some research into that and see whether that was a factor in our -- in our community. Unfortunately he never did.

But I know myself that -- it might not be PTSD, but it's something similar to that, and I feel it a lot. And I also have this survivor guilt. "Guilt" isn't perhaps the right word, but I sit there, and especially in the weeks leading up to this day, I have thought about some of the boys who died, who I was in hospital with, that they had the same treatment as me, they were the same age as me, some of them almost to the day, and they died and I didn't. I'd see them -- they'd be on the ward with me, because we spent so much of our life on the ward, and then you'd see them

start to deteriorate and they'd be gone. They'd be taken off to the isolation ward. You'd never see them again. And we didn't know where they went. They went to this mythical place. And I don't mean heaven, I mean an isolation ward. And when you went to that isolation ward, you never came back.

And so, yeah, I don't know why I'm sat here today giving evidence and some of those boys aren't, and it could've been quite easily them giving similar evidence to what I'm giving today and me who died in the early 1990s.

Q. You've described that that has informed who you are from a very young age and has moulded your whole person, and that you're tired now.

A. Absolutely. It's an irrevocable situation, you can't change what's happened, and I'm -- up until I took the HCV treatment, I'd have said I'm proud of that, I'll take it on the chin, I'll battle this and I'll get on with it and I'll defeat it and I'll do my best to do that, and -- but now, yeah, it gets really tiring, and you can't escape it, and people say things like, "Ah, the treatments are better and this is better and your life -- you've got a better life expectancy", and all this kind of stuff, and it's rubbish because we've been damaged. You can't reverse that. You can't have

that kind of psychology in your head about dying, about accepting your own death at that age, and then suddenly go, "Oh, yeah, everything's fine, we'll just crack on as normal", because it doesn't work like that. Well, it doesn't for me anyway.

And whilst you try to have a normal life, it's -- it's insipid. It sort of gets into every detail of life. You can't sort of escape what happened to us. And it affects every major decision you make in life. It affects everything. It affects the psychology of who you are. You become who you are, and I'm proud of that, but that's informed by HIV, HCV and haemophilia, because it's inevitable that going through those experiences moulds the person you are.

Q. Throughout your teenage years, your early adulthood, were you ever offered any counselling or psychological support?

A. No. The only -- so when I was in my 20s, I'm sure I could've phoned up my haemophilia department and said, "Look, I'm in a really bad way, get me some counselling", and they probably would've done, but I was resilient then and I was -- I just got on with it.

But in the early days -- I mean, it was

a complete anathema. We were never told, let alone offered counselling. You can't be given counselling for something you don't know about.

I was offered counselling -- so when the structure changed through EIBSS and we had to be re-evaluated to see whether we deserved to have any kind of support, I had to go to my haemophilia unit and be asked some questions about my life and my situation. The first question I was asked by my now haemophilia team, which are great, was: has HCV ever -- has your treatment ever affected you? At that point I'd never been asked that before. Nobody had ever asked me. I finished the treatment, I was discharged from the hepatology unit, "Off you go and go and get on with it." And six years later, someone asks, "Has it ever affected you?" And it was just -- it all came flooding out, and it ended up being quite cathartic, but it was the first time I'd been asked and I sort of broke down and I said yes, and it helped me realise that I'd been quite damaged by the hep C treatment.

Then as a result of that meeting, that interview, they said I could access mental health services or counselling, but in our area there's an 18-month waiting list, so I've got on with it myself.

Q. And you've ended up seeking it privately?

A. No, just get on with it myself.

Q. Just yourself?

A. Absolutely, yeah. Nobody can help me.

At the moment I'm quite happy with my family and my friends, to sort of battle through, and I can come to my own resolutions. At the moment. I'm not saying that that's always going to be the case.

Q. You've also discovered there was a risk that you've contracted vCJD, but you've never been told whether or not you received an implicated batch. What's been the impact of that on you emotionally?

A. So there's the theoretical risk of receiving treatment obviously from patients who later went on to die from CJD. I'm reasonably fortunate in that there doesn't seem -- I've had a directly affected batch. Again, it's just another thing to try to compute and put into some kind of reasoning in your head. It -- I think most of our community are too preoccupied with trying to deal with the now and working out -- sort of navigating our way through the current situation that we haven't really -- we don't know what to expect either, but we haven't really started to worry too much about CJD, and fingers crossed it won't come back

to bite us.

Q. In terms of your family life, as you said, you went through a number of rounds of IVF. You now do have three children.

A. That's right.

Q. But the process was -- I think you called it pretty brutal for both you and your partner.

A. That's right, yes.

Q. You had to fund that entirely privately.

A. Not entirely, but majority --

Q. The majority.

A. -- was privately, yes.

Q. It's taken all your life savings.

A. At that time, yes. Well, it wasn't life savings. My father died, left us some money, and we used that money to facilitate going to the Chelsea and Westminster to pay for IVF for sperm washing programmes.

Q. You said in your statement you feel very strongly that you shouldn't have had to do that. You shouldn't have had to fund the IVF yourselves.

A. Absolutely. At that time -- now the given medical evidence is that it's accepted that if you're a serodiscordant couple and the positive person is undetectable, then it's safe enough and accepted by

the medical fraternity that it's okay to try for a child naturally.

Even though we knew back then that some people had had children and hadn't passed HIV on, the evidence wasn't there for us to make that decision, it was a really difficult decision for me and my partner, so we decided to undergo IVF, and we had numerous rounds, we had a round of IUI, we had -- we think -- we lost count, but we think it was four rounds of IVF, fresh cycles, and obviously from each round you can freeze embryos as well and then go back, so there's four rounds of fresh cycles interspersed in between with frozen cycles, if that makes sense.

The problem being was our first -- our first cycle, when we were at the Chelsea and Westminster, we managed to create a lot of viable embryos, but because the Chelsea and Westminster didn't have a storage facility, or freezer, whatever you want to call it, for a co-infected patient, we had to destroy those, so we had an implant from the first cycle, a fresh cycle, all the other viable embryos got chucked away, and then we had to start again with the fresh cycle next time we went. But if there had been a storage facility for our embryos, we could've frozen them and gone back rather than having -- my partner having to

endure all the injections, all the hormone treatment, all the procedures, the invasive procedures, all the things that come with that the kind of cycle.

It was pretty heavy going. It was emotionally hard, I think, and physically hard for my partner. And, okay, we're very lucky to have children, and anything is worth that. But it always felt like a bit of a -- after everything, it felt like a bit of a -- yeah, like a poke with a sharp stick. After -- we had to go there off our own backs and pay for everything. We spent nearly £20,000 trying to go all through this, and we felt like we were making responsible decisions that should've been supported, really, not us having to make responsible decisions and then pay for it as well.

Q. Because in your statement you make the point that if your partner or your children had been infected, then the NHS would've had to pay for the treatment and the care of them then.

A. Yes, if you choose to look at it in that way, then it would be much more expensive for the NHS to fund a lifetime of HIV drugs rather than a cycle of IVF.

Q. In terms of your education and career, you've spoken of going to university, but initially you hadn't worked particularly hard for your A levels because you didn't really see the point of it at that stage.

A. No.

Q. But then life became more stable and in 1988, as you say, you went off to university.

A. Yes.

Q. After you completed your degree, you went on to do your masters and then started your PhD.

A. That's right.

Q. What was the PhD in?

A. Okay. So first of all, just going back to my GCSEs, I didn't try for my GCSEs either, but I was able to just cruise through them, but you had to work a bit harder at A levels. There was absolutely no incentive for me to work hard and revise and waste my time revising when I was going to die in a couple of years. Absolutely no point. So I didn't bother and subsequently didn't get many A levels.

Then when I did do my postgraduate work, I was in a much better place, I was able to focus on it. My -- lots of my PhD work ended up looking at -- I wanted to look at my community. My thesis for my masters was a piece of qualitative research on the effect of HIV and hep C co-infection on my community, which was okay, nothing groundbreaking but it was okay, it was an interesting -- for me perhaps more than the people involved.

I then with my PhD chose to look more deeply at certain points of that, so I looked at the psychosocial impact on my community. I looked at a concept called iatrogenesis, which is a theory postulated by Ivan Illich in the 1960s and 1970s which basically talks about doctor-assisted harm on patients. Funnily enough, there's not a huge amount of in-depth work on that. And I also wanted to look at this notion of the expert patient and sort of tie all those together in regards to our community. Because our community do have a lot of knowledge which they're not always given credit for because of their experiences and what they've been through.

Q. Unfortunately you weren't able to complete the PhD.

A. No.

Q. Why was that?

A. Oh, there's a number of factors. A couple of dominant ones were my laptop was stolen out of my car and my backup memory stick got corrupted, so I lost most of my first year's work, which was pretty soul destroying.

Also, the department I was in was supportive. I felt a PhD was a conduit for me to be able to do -- it was sort of labelled as this -- this is your opportunity to do your own piece of research, you'll never have this opportunity again to have three years looking at something that you want to look at. But inevitably it got hijacked by the department, they said, "Oh, why don't you start looking at this or looking at that", because they had parameters which they wanted me to explore. So a PhD thesis probably wasn't exactly the right thing for what I -- I should've done my own research off my own back rather than doing it via a PhD.

Also there was my health, there was starting a family, a number of things, but I never really recovered after having my laptop stolen, no.

Q. Your health concerns carried on after not completing the PhD into your career, and you found it very difficult, you say in your statement, to have a career because your health is quite precarious.

A. Yes, I think anyone in our community, their health is generally precarious and they can be worse sometimes more than others.

After I left the university department and I -- we started a family, I then temporarily started a job, which was only just a bit of a stopgap, but it was working shifts. Nothing to do with my -- it was just in security, it was nothing to do with what I studied for. But the shifts were so hard and punishing, I was getting ill. I was -- all the time I was off work, I had sort of chest problems, breathing problems, and it was just the stress and the exhaustion. I couldn't -- I physically couldn't cope with having young -- a young child in the house and trying to work shifts, and all my health problems combined.

I went to resign from my job in 2009. The then manager, who was quite supportive, I disclosed my health problems, which I didn't need to but I felt it appropriate considering what I was going through, and she offered me again a temporary stopgap, but sort of for me to stay there to go on a zero-hours contract. They get a lot of bad press, but actually it suited our family really well, so I'm able to work -- because I still need to work, up until the recent structural payment -- the structural changes in the payments, I had to work. There was no other option. And so being able to work flexibly around my health was really important.

Q. You've also described that you didn't ever aspire to be in the rat race because of the psychological impact of all your experiences growing up.

A. Absolutely, yes. I don't know whether it's the same for other people in my community, or other people who have gone through hard times. You look at the structures in society and you look at the way people run around and you look at the way -- the emphasis on material nonsense, on just everything -- and you just think it's all pointless. There's much more important things in life, and sometimes we get our priorities skewed, and so it's always been important for me to -- if that's what I believe then I should try and live my life that way.

Q. You just said a moment ago that financially you did need to work until there were the structural changes.

A. Yes.

Q. In fact, financially things have been very difficult over the years, you said in your statement, and you were involved in the HIV litigation, or at least your parents were on your behalf.

A. Yes.

Q. They recall signing a waiver. What have they told you about that?

A. So my mother has said that whilst they knew signing the waiver wasn't the right thing to do, they were told if they didn't do it, nobody would get any support, and if they didn't sign you'd have to take on the American pharmaceuticals yourself and you'd have no chance. So there was a real -- sort of pushed into

a dead end, really.

My mum and dad had no real financial capacity to fund any kind of separate, individual litigation, and so we just joined everyone else, and because life expectancy was so short at that time, any kind of support was better than nothing. So -- but clearly it was wrong and inappropriate, not fit for purpose under the circumstances.

Q. You received initial payments from the Macfarlane Trust as a young teenager, and so you received the sum for single people under 18.

A. Yes.

Q. What's your view of that now?

A. Well, it's always sort of -- it always stank a bit, really. I don't understand why -- it's not -- it's not because I'm bitter, it's this concept of fairness. And you'll hear this throughout all sorts of things to do with the Infected Blood Inquiry, that there's things you'll find which always seem unfair, whether that's finances or whatever.

But because I was under 18 at the time of that payment, I would've been about 15, I had the under 18 payment. Obviously people older than 18 got twice as much and people older than 18 with children got three times as much. And it's never really sat right. And

so when I became 18, I wasn't eligible for the next upgrade. When we had children, I wasn't eligible for the next upgrade. That's life. You get on with it. But it just doesn't sit right, really.

Q. You've said:

"I wondered whether I was inconsequential due to my age and thought it was unfair not to then receive the uplift later."

A. Absolutely, and -- but then this feeling of being inconsequential and chucked on the scrapheap is repeated with various things, whether that's access to recombinants and all those other things that happened. You just sort of -- you just become sort of used to being battered by it all really and -- and it just becomes -- now we're in the situation, it seems incredulous, but at the time you just -- you don't have any choice but to get on with life, really. It's just the way things are, so -- but it was completely unfair, yes.

Q. You didn't realise until you were in your 20s that there were further grants you could apply for, but when you did apply for them, you felt that the money provided was a pittance, but also you objected to the requirement to have to provide quotes.

A. Yes.

Q. Can you tell us a little bit more about how the system made you feel?

A. In relation to Macfarlane Trust?

Q. Mm.

A. So Macfarlane Trust was set up in a rush. It was -- it wasn't fit -- structurally it wasn't fit for purpose from the outset. It was funded badly, and it was just like a bit of a perfect storm, really. While there was people trying their best at certain points in the trust's history, it was never fit for purpose, it was never going to facilitate what our community needed, really, and give the support that our community deserved to get as well.

Q. Before we talk about your role as a trustee at one stage, I just want to pick up with you the point about having to give quotes before you could obtain a grant.

A. So the quote system put people off a lot of the time. But it wasn't just even the quote system, some co-infected haemophiliacs didn't even know the trust existed until a few years ago, and so they never got -- people were in absolute dire need and they never got any support.

So you did need to provide quotes. Now, if you knew how to play the game you could -- you could get quotes out of thin air literally, but people who weren't as savvy about how the trust was organised and ran were sort of put off by that system, and they didn't want to trigger -- it was tiresome to get -- if you wanted a bit of work done on the house to get three people to come round and quote for it. It's really a pain really.

Q. You've described it as being totally disempowering.

A. Absolutely, yes, yes, because the people the trust were there to care for were some of the most vulnerable people, really, going through terrible things, and to have to justify and get quotes for those kinds of things, it just wasn't appropriate at all. And whilst the trust did some good things in some ways, a lot of things were really bad.

Q. You were a trustee of the Macfarlane Trust in 2002/2003.

A. I started around then.

Q. Started then until --

A. I was trustee for about two or three years, yes.

Q. What was your experience of being a trustee?

A. So when I -- when I joined -- I applied -- a position came up for the trust. I'd been getting a bit more immersed myself in HIV and my community. There wasn't loads of people going for that position. I decided to give it a go. And so I had -- when I started I had

very little knowledge of the trust.

The trust -- like I said a minute ago, the trust wasn't fit for purpose from the outset, so I don't want to sit here and demonise individuals because I worked -- at the time I was there especially, I worked with some -- what I feel is some good people, trying to do their best and in some cases making a difference for people. But because of the limitations of what they were working with, they were never going to be able to help people, and when people are in dire need, that's when the problem -- the clash becomes.

So it was really -- it became apparent over time that the trust wasn't resourced by the government -- funded by the government properly, and then there's an imbalance because of the nature of the trust and how it was incepted that -- I always remember people saying they weren't a lobbying group, the trustees. They shouldn't be lobbying the government for more money, that wasn't particularly their role, and there was always concern that if they struck up too much of a fuss that potentially funding could be withdrawn.

Now, in hindsight that probably shouldn't have been the case, and perhaps voices should've been louder, but at that time I can understand that that's

how -- I think they felt that they were just carrying out the duties as requested by the government.

So all these problems again stem from the government, because the trust was not fit for purpose from the start.

Q. What led you to leave and stop being a trustee?

A. Again, it was that time in my life before we had a family and my health wasn't -- was again precarious at times. I just think I felt -- in any voluntary role you do it's got to be like a two-way thing, and I've done lots of voluntary work in my life. You need to believe in it and you need to get something out of it as a volunteer. As much as what you're trying to help -- and I'm not just talking about the MFT here, in any voluntary capacity, and I felt I'd had my time there and it was time to move on, really. There wasn't any significant problem or issue going on that suddenly rose up and caused me to leave. But it was -- yeah, again, not fit for purpose.

Q. You described earlier that there had been a change in the environment and feel of the place though.

A. Yes, so as -- when I -- so that sort of happened at the time I was leaving, the chief -- the chief executive changed around about that time, I think just literally as I left, and so that was

another transition point which felt like a good time to move as well.

But I did notice and I have noticed that as the years passed after I left, the trust -- the way the trust operated seemed to change. It became more bureaucratic, it became less sensitive, although some might argue it was those things to start with anyway. And it just became an even worse beast, really. It was -- it morphed into something which was unhelpful.

I completely -- eventually I just distanced myself completely. I never applied for grants or anything ever again after a certain point, which I can't remember when it was, but it was just pointless.

Q. And your feeling is that EIBSS has a better approach so far. Why is that?

A. The -- I've not ever applied -- I can't say how structurally they work or how they are to approach because I've never approached them. But what I can say is over the last 18 months or whatever it is since our payment structure changed to something that's more in line to trying to help us live on a daily basis, it's taken a huge weight off our shoulders. If I'm ill now and I don't go to work, we can live, we can exist, we can get by, whereas before that was -- that just wasn't the case.

So having that financial change in the uplift in payments we received has been a huge benefit to us, because things were so hard before. Doesn't mean things can't be better, doesn't mean things -- things should be better, but this initial uplift made a huge difference to our family, and that's -- when I talk about things being better, that's what I'm relating to.

Q. Stu, those are the questions I have for you. I'm just going to turn to Mr Snowden who, as you know, represents you.

(Pause)

Mr Snowden just wants me to take you to a document. Before we go there, we were discussing earlier that there was nothing in your medical records that indicate a diagnosis of hepatitis C, no virology test or a record of a specific consultation.

There is a letter from 2001. Henry, it is 1252007. It's a letter from 2001. It's the only thing that they have found where there is simply bluntly put in the middle of it: "Diagnosis: HIV and HCV infection", in 2001. He just wanted to flag that up from 2001.

A. Yes, yes, so that would tie in -- yes, I probably

would've been aware slightly before that that I had hep C, but not a huge amount of years before.

Q. Is there anything further you would like to say?

A. I've got some final comments, if that's all right.

Q. Of course.

A. I know some of the other members of my community have said about accountability being a trickle-down thing from the government, from the pharmaceuticals, from the commissioning groups, from the hospitals, from the doctors, and like other people have iterated, I'm sure Sir Brian and his team will be looking at those things and how it all contributed to this problem for myself and my community.

I'm very aware of evidence sounding like excessive hyperbole, and I've been really cautious about how I choose my words because I want to make sure that it's frank, but you understand when things are a problem, that when I'm saying things which sound hyperbolic, it is because they -- it has been a problem. So I've tried very carefully to word this, but it's important for me to put across in this last bit how some of these things have affected me.

So, firstly, I cannot thank you enough, all of you here involved and behind the scenes for giving me the opportunity to share my evidence with you, and

basically what is my story.

Most importantly, I thank you for listening, for giving us and my community the time, space and the credibility to be heard, and the respect, and it's unbelievable after all these years that you're listening to us.

The last 35 years now seem quite surreal, that we were just drifting along with this burden upon us and with nobody knowing, caring or really understanding the true depths of what really happened to us. Even in times of clarity and wellness, there's been an ineluctable sense of pain and emptiness which has compounded every single year, and things simply don't get easier, it gets harder.

People think an absence of quantifiable pain, improvements in medication and more positive longer-term prognosis automatically equate to a happier and stable situation. But that's far from the truth. You can't just deflect the damage that was done to us.

Even after 35 years there's very, very few people who know my story, and the burden of stigma still weighs heavily. You remain in a cycle of shame, silence and oppression. Today, after all these years, giving evidence is my emancipation. Today is my

coming out, and I shouldn't be scared. My community should not feel downtrodden and these shackles shall be gone, to be replaced by pride in ourselves and the notion that my community has earned the right to be listened to and dealt with compassionately and with empathy.

So for those in my community who cannot be here, I also want my voice to be heard for you. Boys I knew from hospital who I grew up with there, boys such as Brett, David, Nicky, Ian, and many others, your lives were ended far too early. I was just lucky, perhaps. But I've not forgotten you. I don't know why it's me sat here giving this evidence when it could've been you.

I want people to understand our sufferance from those early days. What happened to us was wrong, and we have all paid a very heavy price, both those still alive and those who have died. Our lives have all been indelibly scarred by what has happened.

Most importantly, I want to speak to my family and friends. To this point, only my partner, my mother, my sister, my stepfather and my stepmother know my history. I've always valued your support. To the rest of my family, I'm sorry we have not discussed this before. I hope it will not change your thoughts of us. But there are reasons why this has not been spoken about.

I am sure you will continue to love us like you've always done, and that when I am gone you'll look after my family as they deserve.

To my friends and neighbours, who might come across this evidence, likewise, I hope you'll be understanding and supportive of my family and children, and this is my truth to share with you.

This has been my whole life. Even though I try not to let it consume me, this has identified me and has become me for as long as I can remember, even though I've tried hard to live independently of it all. It affects almost every facet and decision in life.

There are no winners, no happy ending to this morally impoverished situation. What has happened cannot be changed. The damage done to my community is irreversible.

There are depths of pain you can scarcely imagine until you actually get there. It's often taken my physical health, and more recently it's taken my emotional and mental fortitude. It's left me a shell of a human being at times. I have often felt broken, and I'm just tired.

However, even though giving evidence has been incredibly hard, I am hoping this will be a cathartic process for me and start to give me an element of peace.

I have great faith in Sir Brian and his team to reach conclusions that give us an element of closure so that we can take a big step in moving on in our lives and start to repair some of the damage.

I thank you for listening.

SIR BRIAN LANGSTAFF: There's one question that I want to ask you.

You mentioned a couple of times the structural problems of the Macfarlane Trust. Can you give any detail as to what you think was wrong with the structure?

A. So when the trust was incepted, it should've been structured in a much different way. It was a charity, funded by the government, which is something of an anomaly with charitable status.

The way -- the people involved perhaps should've been more government-led. It was poorly resourced. Everything just seemed to be done in a rush, and it could've been done much better. I'm not sure I have the answers to how it could've been structurally different, but what I'm confident in is that it wasn't

ideal in the way it was incepted.

SIR BRIAN LANGSTAFF: Thank you very much.

You have given us a frank account indeed, careful with your words. But I think you yourself used the words how incredibly difficult it was to give evidence, and I hope that those who aren't those in the know already when you came to give evidence -- your mother, sister, stepfather, stepmother and partner -- that others who know you and who become aware of what you have said, that they understand and respect you all the more for what has plainly been at times difficult for you. You've managed it remarkably well, if I may say so, and thank you very much for having the courage to come out.

A. Thank you very much.

SIR BRIAN LANGSTAFF: We'll have a break of just a shade beyond 5 minutes to 4.40.

(4.35 pm)

(A short break)

(4.40 pm)

SIR BRIAN LANGSTAFF: Our next witness is anonymous and will be known as Mrs AQ. Let me read out the order in her case.

I order that the name and address of witness W0859 -- that's Mrs AQ to you and me -- the name of

her late father and the name of any other member of the witness's family and any other identifying information, such as the witness's image or a description of their appearance, cannot be disclosed or published in any form unless express permission is given by me or by the solicitor to the inquiry acting on my behalf.

Witness W0859 must be referred to only as Mrs AQ.

This 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.

Mrs AQ, please.

MRS AQ (sworn)

Questioned by MS FRASER BUTLIN

MS FRASER BUTLIN: Mrs AQ, you're here to tell us about your late father.

A. Yes.

Q. And you've provided us with a photograph of him that we're going to put up on the screens in this room, but it is covered by the restriction order and it cannot be used outside of this room. But it will be on the screens for us to see. It's a picture of your dad in

France.

A. Yes.

Q. We'll keep that photograph up throughout your evidence.

A. Okay.

Q. You and he had a very close relationship.

A. Yes, very, yes.

Q. And you've described him as mild-mannered and easygoing.

A. Yes, yes, he was very much so, very kind, very humble, but he had a good sense of humour and I was very close to him. I was an only child so we had a very close relationship.

Q. He worked at various different engineering firms over the years.

A. Yes.

Q. In terms of his health before the transfusion that we're going to discuss, what was his health like?

A. Well, this photograph actually was taken only a year or two before he had the transfusion, and he didn't have any illness or any ongoing illness whatsoever. It was just normal, perfectly healthy.

Q. Your mother kept a diary throughout the time your father was unwell, and you've used those entries to help your understanding of what was happening --

A. Yes.

Q. -- because you were quite young at the time?

A. Yes, at the time of the transfusion I was only 11, and a lot of it -- obviously I remember him being very ill and the hospitalisation and everything, but I didn't remember the dates particularly, or even -- it's something in a way I've not been able to speak about, and it sort of goes to the back of your mind, part of it anyway. But -- so the diaries I've only recently come across, because my mum had to go into a care home, and we were sorting out her things in her bungalow, basically. I didn't realise she'd kept diaries from this far back, but I came across them, yes.

Q. And they've help you pin dates down.

A. They've helped me piece things together. It just started out initially as being a bit of a, you know, curiosity as to when things happened, and you just sort of find out -- well, in my case how bad things were and, you know, that period of time, which being only 11 you don't remember so well.

Q. In 1971, when your dad was about 39, he became unwell, and in March 1971 he was admitted into hospital and found to have a blood clot in the leg.

A. Yes, it was very sudden. It's nothing leading up to that. I mean, one day he just seemed to feel unwell, excruciating pain, and went to see his doctor, straight away into hospital.

Q. He had surgery that day and a further operation the next day.

A. Yes.

Q. And you understand that he needed 4 pints of blood.

A. Yes, that was written into my mum's diary, so I'm pretty sure on that, yes.

Q. Having been really quite poorly at that point, he managed to go back to work in the April, but by the June your mum recorded in her diary that he was unwell again. What was wrong at that point?

A. Well, he'd started to have cramps in his leg. There was excessive fatigue and tiredness. He was, you know -- sometimes I think he would go to work and end up having to lie down for part of the day at work, which is not like him at all, and -- or, you know, excessively tired, lots of aches, stomach pains. My mum describes them as kidney pains, but that just may be her interpretation of the pain he was going through.

Q. You said none of this was taken seriously by the GP.

A. No.

Q. And it continued throughout June.

A. Mm.

Q. And then on the day before you went on holiday on 9 July, your father's skin and eyes were very yellow.

A. Yes, I'd never seen anything like it. The whites of his eyes were like canary coloured yellow. It was just -- but somehow we still went on holiday. I don't know, he must have been feeling pretty bad, but we went nonetheless.

Q. And then he ended up in hospital while you were away.

A. Yes. I mean, there was no disguising -- I think we were staying in a guesthouse or something, but there was no disguising what he looked like, and I guess he went to the hospital to be checked out and we were straight away put into an isolation ward and my mother and me had to stay and just visit him. There was no treatment given as such, but that's what happened, yes.

Q. He was transferred after 10 days back to the hospital near your home.

A. Yes.

Q. And then discharged.

Did he have any follow-up after that?

A. No. I mean, the transfer from where we were, which I think was Blackpool, we were -- it was on the condition that he went straight, like immediately, not go home. My mother drove back and went straight to the hospital where he'd had most of -- for his, you know, operation and any treatment. So he was taken straight there and admitted virtually straight away.

Q. And then just a few days later he was discharged home, but there was no follow-up after that.

A. No, which I remember thinking -- I think at the time, you know, why aren't they taking any notice of how he is? Because it wasn't -- he was having all sorts of aches and pains as well as the obvious look of him, you know.

Q. Even once he had been discharged, you said that your father was still really very poorly for the next few months.

A. Yes.

Q. What was wrong with him?

A. Swollen legs, which I think -- fluid retention, oedema, stomach was swollen, was excessively tired. I recall him saying urine was dark, stuff like that, and it's just, you know, the jaundice -- I think the colour went away a little bit, but he was just all aches and pains in his legs and his stomach, really.

Q. In the October of 1971 your dad was readmitted to hospital to have fluid drained.

A. Yes.

Q. And to have liver tests.

A. Yes.

Q. And in November, after further tests, what was he told?

A. He was told that he had inflammation of the liver, and I think by the November they told him it was cirrhosis, which was a very fast progression of it, but he'd been suffering a lot.

Q. And you think it was around that time that he was diagnosed as having serum hepatitis.

A. That's what -- my mum's diary confirms that, that's what they were told, that it was serum hepatitis, and I think at that point it also records that they were told he must have had a faulty pint of blood. I'm not sure whether that was from a nurse, though, or from a consultant, but that's what she recorded that they were told.

Q. And your understanding is the serum hepatitis at that time would be what is now called hepatitis B?

A. Yes, and I, as you do, look it up and I've confirmed that, yes.

Q. But in the diary there is this clear note of being told that he must have had a faulty pint of blood.

A. Yes.

Q. But no more detail than that.

A. No, that's -- and unfortunately my mum is not well enough to ask her in more detail.

Q. What were your parents told at that time about the risk of having further children?

A. I remember -- I mean, only being sort of 11/12 at the time, I remember them saying -- discussing together while my dad was in a hospital bed something about, "Won't be able to have any more children." And, I mean, being only that young, you don't really take it -- take on board really what they mean by that. But, you know, I did think to myself, well, I wasn't expecting that maybe they would have any more children, but nevertheless I think my dad took it quite seriously. I think he kind of thought that it was a big thing to be told that, you know.

I mean, I had a very close relationship with him, as you know, and I think it -- maybe it was a bit of a blow to him really.

But apart from that I don't remember anything else about what they were told, as such.

Q. You recall that your father continued to be unwell and got worse in 1972.

A. Yes.

Q. With swelling, cramping, pains in the abdomen --

A. Yes.

Q. -- and pains in the leg.

A. Yes.

Q. And you have a particular recollection of putting your finger into his leg.

A. Yes, we just press -- I mean, press your finger into his leg and it just stays sunken in because there's so much fluid there. It's just -- you know, I remember it just -- just remember that -- one of those things that I did, and the mark was still there, you know.

Q. Finally, in 1973, he was prescribed prednisolone, a steroid, and you feel that then his health improved and he was quite stable for a number of years at that point.

A. Yes, yes. I don't know exactly the date the prednisolone was prescribed. My mum put in the November 1971 sort of bit that she wrote "liver tablets". Now, I'm not sure what she meant by that and when -- at what stage the prednisolone was prescribed. He seemed to be ill, though, for still quite a while up to at least November 1973, and then I feel that his condition stabilised somewhat, because the diary entries were more -- not about him being ill then. Yes.

Q. And that continued through until about November 1981.

A. Yes -- well, October, yes.

Q. And then your father was seen again as an outpatient --

A. Yes.

Q. -- in a fairly routine appointment.

A. Yes.

Q. The doctor he saw felt he was fit and decided to stop the steroid medication.

A. Said he was remarkably fit, and they said that if you were on prednisolone or steroids for more than ten years there would be side-effects. So he took -- told him that he would take him off the steroids, but they didn't carry on with any other form of treatment or monitor him, as far as I'm aware.

Q. And he came off the steroids very abruptly. There was no tapering of the medication.

A. No, which I find strange, really, because just more recent years, by complete coincidence, my mother has had the same steroid prescribed for polymyalgia rheumatica, and it was exactly that same prednisolone, and I had to monitor it with her to take her off these steroids very gradually. She was having blood tests every month, we were checking the protein in the sample, and only, you know, taking her off these at a very reduced amount.

Q. But for your father there was also then no monitoring

of him or any plan to do anything --

A. Not as --

Q. -- other than come off the steroids, as far as you know.

A. No, no.

Q. Four days later your father was unwell. What was wrong?

A. He started having aches all over his body, sort of -- of course, as I say, you look these things up and I think that maybe withdrawal of the steroids at perhaps such a high dose as he may have been on causes some kind of, I don't know, withdrawal symptoms almost, or it shouldn't be done so abruptly. But he did have lots of aches and pains, lots of feeling generally unwell, started to lose weight quite quickly, I think. I know that was something he was very concerned about.

Q. And in your mum's diary throughout the winter she records your father deteriorating.

A. Yes.

Q. Unable to put weight on.

A. Yes.

Q. Lacking energy.

A. Yes.

Q. Pains in his neck, his stomach, his shoulder, his

side.

A. Yes.

Q. Having some cramps and some diarrhoea.

A. Yes.

Q. And she also records that he went to the doctors very regularly at that point.

A. He would see his own GP, yes, and I know his concern was -- I think he must have probably read up about, you know, the fact that he had such a -- he had been diagnosed with cirrhosis. I think he must have read up that it could've progressed to cancer of the liver at some stage, and I think the fact that he was losing weight so rapidly was a concern to him.

Q. But at that stage nothing was done about it.

A. No.

Q. Your father kept working until the June.

A. Mm-hm.

Q. But then in the June of 1982 he was too unwell to drive to the holiday that your mum and he were going on together.

A. Oh, yes.

Q. And that seems to have been quite a marker for him and your mum.

A. Yes.

Q. Because he would always --

A. He was the one that drove. My mum didn't really like driving so, you know, it was a big thing really for -- she had to support him a bit more, and -- I think he very much tried to soldier on all the time, tried not to make a big deal of it, tried not to worry either my mum or me, tried to carry on working. But he must have realised how seriously ill he must have been feeling. I think he'd always put his trust before -- I think he felt he maybe got over a serious stage before, and maybe he -- it -- that would be the case again.

Q. And he kept soldiering on until later in the June, when he had a liver scan.

A. Yes.

Q. What was he told after that scan?

A. I still feel in the June they weren't really -- they were told there was nothing -- I think at that point he was told it was nothing serious and he may have had gallstones or something, and they may not need to do a liver biopsy then or something because they didn't really concentrate on his other symptoms. It seemed as if they were just in the dark as to know what to do with him. In fact I think my mum did record in her diary, "They don't know what to do with him." But they just kept saying it's nothing serious, you know, which is kind of I think what you want to believe, but at the same time you realise it doesn't seem like that.

Q. And then just a few days later at the very end of June someone at hospital mentioned a possible liver transplant.

A. It was really late on, but I mean he was so seriously ill by then. He wasn't sleeping. It was -- lots of pain. They were giving him painkillers and sleeping tablets but nothing worked, really. It was -- you know, nothing like how he had been before, only a few months earlier, really.

Q. Your mum's diary records that by then he was practically helpless and really very, very unwell.

A. Yes.

Q. By this stage you were getting married in the *[redacted]* --

A. Yes.

Q. -- of 1982.

A. Yes.

Q. And the night before your wedding your dad told your mum he wasn't sure that he would manage the day.

A. Yes, I can remember, as I was living with them at the time, the day before the wedding, I could hear something going on, background noise, I suppose

I perhaps was a bit nervous, wedding day next day, everything. Got up, they were sitting in the kitchen and my dad had his head in his hands, and I can remember him saying, "I don't know how I'm going to get through tomorrow", Which -- you know, we were planning the wedding and we had considered whether we should postpone it in view of how ill he was. But he was so desperate to be part of it, and give me away, and it was a huge thing for him, and he wanted to be part of the day, and with hindsight we're glad that we carried on with it because he wouldn't have been able to be part of it, you know, even in the small way that he was, in the end.

Q. He did manage to walk you down the aisle.

A. Just, yes.

Q. But then couldn't manage to join you after the ceremony.

A. No.

Q. You went on to the reception and he and your mum went home.

A. That's right. He was -- he had to sit through the service, but as soon as the service was over, we had to get the wedding car. He was not on any of the photos at the end, after the service, because he had to go straight home.

And another thing was, you know, the weight he had lost, the clothes that he was wearing that he had only bought something like in the March before the July of the wedding, just hung on him, you know, and people that hadn't seen him, because I did work with people that knew my parents and they came to the wedding, and they were shocked, you know, it had all happened so quickly.

Q. Your dad collapsed four days later.

A. Yes.

Q. And you were phoned to come home early from your honeymoon.

A. Yes, yes.

Q. When you went to the hospital you were told there was a possibility that your father had liver cancer.

A. It was right at the very end that was mentioned. They'd mentioned all sorts of -- well, as I say, they kept saying it's nothing serious, they'd done this, that and the other test, you know, and as I say gallstones was something, and some vitamin K deficiency or something, but then the liver cancer was mentioned right at the end. Possibility of a small liver cancer, I think, but you know ...

Q. That was the first time that cancer had been mentioned to anyone in the family.

A. Yes.

Q. Then the doctors said it had spread very quickly, and sadly your father died just two-and-a-half weeks later.

A. Yes. Well, it was actually -- yes, probably. It was the 23rd, our wedding day was the 10th, so, yeah, it was very quickly after we were married, yes.

Q. And on his death certificate the cause of death was hepatic failure, cirrhosis of the liver and chronic active hepatitis.

A. Yes.

Q. Since your father died, you have questioned why he deteriorated so quickly.

A. Yes.

Q. You've wondered whether he might have also been infected with something like hepatitis D. But there are no records available to understand what actually happened, but it is a concern for you as to why he deteriorated so quickly.

A. Well, yes, it was -- you know, obviously -- and especially with this inquiry, really, you hear other people's stories, and it seemed as if he had an unnaturally quick progression of his illness in the early part of it. To sort of go from a transfusion in March to October, November, when he was told he had cirrhosis, you know, permanent scarring and very advanced, really.

And even just last week, I was -- I contacted the hep C trust just as a bit of general sort of information about hepatitis, and they -- she actually said -- a very nice lady said, "I will have a word with one of the medical people we have on our team, a liver specialist", and he came back with -- he agreed it was an unusually fast progression, but he came back with a couple of thoughts, one of which was non-alcoholic-related -- which usually you have to have some sort of fatty tissue and he was not overweight, as you can see. Also he'd not got -- she said did he have any previous liver condition existing, and he definitely didn't have, he wasn't a drinker, wasn't in any of the high-risk groups that you would perhaps consider may be more susceptible, but then the one thing I did -- looked into was the fact that he could've been co-infected at the same time with hepatitis D, which relies on hepatitis B to get going and progress, and then it does become quite aggressive.

That to me made sense in my mind. I've got no evidence. Unfortunately my father's medical records are no longer in place, and we have tried, but only

recently and it's such a long time ago.

My mother really wasn't up to dealing with things earlier on when we wondered if there had been such a lot of negligence, and, you know, she just wasn't able to deal with it. So we never sought his records. But, yes.

Q. So you know he had hepatitis B.

A. We do.

Q. But you're left with questions about why there was such a quick deterioration.

A. It's a possibility, and when I look at it, it's a strong possibility because his symptoms were very fast and aggressive and -- I mean, I've looked up -- hepatitis D wasn't really recognised as such until 1977, I believe. Well, that was before my dad would've had all these tests, really.

Q. Your mother has struggled with your father's death.

A. Yes.

Q. She was just 48, and you had left home just a few weeks before he died to get married, so she was on her own.

A. Yes.

Q. You say in your statement she's been a widow now for 37 years and has never really moved on.

A. No, she hasn't. It created huge problems for her.

I mean, it's fair to say she's devastated. Just about every time I've seen her she would talk about how long she's been on her own, how much she misses my dad. I guess he was probably her life and the strong one in the partnership, and she's found it hard to cope. She's been on -- well, she is at the moment on antidepressants, she's had dark thoughts, suicidal thoughts, not wanting to be here anymore. So, yeah, it's affected her in a big way.

Q. Your own children feel you've bottled your grief up as well.

A. They do really. I mean, my husband and my children have been brilliant, and there's not many people, hardly anybody, that I've been able to talk to. But I have talked with them, and they do feel that, they -- and because there hasn't been anybody I've talked to very much, it's been quite nice to have the opportunity to come here and talk about it.

Yeah, it's just -- it's just quite -- quite hard, really. You know, because I think I feel, especially because it happened virtually as soon as we were married, I feel my mum needed our support, we weren't really able to have much of a normal time together on our -- you know, without that in the back of our mind. I'm not saying I mind, but it's been

different. It's not been what you would expect when you're newly married. And my mum being an only one and my mum couldn't cope, it was pretty hard to -- you know, I felt as if I had to be strong for her and try and get her to -- to try and cope with it as best as she could and try and involve her in things.

She wasn't working at the time but, you know, try -- but it was very hard because she didn't really want to do anything. A lot of the things they did, they did together as a couple. They did for instance sequence dancing, which I think she did try to go afterwards, but of course it just reminded her of the fact that she wasn't with my dad anymore, and it -- it just was very hard for her.

Q. You've also felt it quite strongly, now that you've got children of your own, that your dad would've loved to have met his granddaughters.

A. Oh, completely. He was such a family man. I mean, I remember such happy times with him. He was the perfect father for me, and he would've loved the two girls. Both ended up going to university, something he -- I think he would've been -- liked to have done himself, but the situation he was in at the time, the money didn't allow for that. So he would've been extraordinarily proud of that, and -- I have tried to talk to my daughters about him, and we look at photos, and -- because I felt it was important they understood why he had died so young. He was 49, you know. Most of their friends have got grandparents around, and of course they were curious, and it's been good to talk about that. But of course it's sad that he wasn't around.

Q. You feel quite strongly that he was badly let down.

A. Yes.

Q. Particularly, ironically, because he gave blood very regularly.

A. Yes. Yes, ironically he was a blood donor. He had been a blood donor for 20 years, and he was very proud of that. Got his badge and a certificate, everything, and -- yeah. But ironically, he was let down.

Q. Finally, neither your mum nor you have received any financial assistance from anywhere --

A. No.

Q. -- because it's hepatitis B --

A. Yes.

Q. -- and there's no provision.

A. Yes. I think as well, that is true what you're saying, I felt that my mum wasn't in a stable place to go forward with any trying to get compensation or to -- even medical negligence, if you like. I think

she felt that there was no bringing him back, you know, and every time it was mentioned -- I remember even at the time he died, we were almost fobbed off, you know. We'd been called into the hospital to go and see him, just a few minutes. By the time we got there -- it wasn't a long journey, but by the time we got there, he had died, and, you know, even then I think someone came in and asked if, you know, they could do a postmortem and all this, that and the other for research purposes on his liver, and my mum was just in pieces, and it was a bit insensitive to say the least.

And it just -- you know, she -- I don't think she was in a fit state to go forward with going for compensation, and we felt -- even then, I think at that point in time my mum said something about being serum hepatitis, and they said, "Oh, well, it could've been a virus or something." So it was almost being fobbed off even at that point.

Q. And she wasn't eligible under any of the trusts and schemes because it was hepatitis B.

A. Yes, not that I'm aware of, yes.

Q. Those are the questions I have for you.

A. Okay.

Q. Is there anything else you'd like to say?

A. Yes, I'd just like to say a few words if that's okay.

Thank you.

I just wanted to say thank you to Sir Brian and the inquiry team for inviting me to speak today. It does mean a lot to finally have a voice really on behalf of my dad. I'm so grateful to finally have the opportunity to tell my father's story, especially as he suffered so much with his illness, and also due to the fact that my mother and I felt that we were being fobbed off my doctors and consultants every time that we mentioned that he had contracted hepatitis through a blood transfusion.

There is no doubt in my mind that the failings of the NHS, starting with the contaminated blood being given, ended my father's life at the early age of 49 years.

I want to emphasise the huge impact this has had on my family, particularly for my mother, because it effectively ended her life too, causing her to have severe depression and suicidal thoughts.

My father was very humble, gentle and unassuming, but also so full of life and a real family man. He has missed so many things. Seeing his grandchildren would've given both him and them tremendous joy. Plans to go to Paris to celebrate my

parents' silver wedding anniversary the following year in 1983 never happened, and seeing his favourite football team, Leicester City, winning the Premier League against all the odds would've been so special to him. We still miss him so much.

My father was completely innocent and very trusting of the medical profession until the end. This trust was very much misplaced.

Thank you for listening to his story.

I sincerely hope that this inquiry succeeds in making everyone know about the injustices of what happened.

SIR BRIAN LANGSTAFF: Well, thank you for telling your story.

A. Thank you.

SIR BRIAN LANGSTAFF: And being so happy to do so, to give your father a voice. You very gently raised questions about the rapid progress of his illness and the puzzles that gave rise to it, and I think delicately shone a light on not only his suffering, but the hole that his departure has left behind, particularly in your mother's life, and how the ripple effects just go on. So thank you very much for that.

A. Thank you.

SIR BRIAN LANGSTAFF: Ms Fraser Butlin, tomorrow?

MS FRASER BUTLIN: The first witness will be anonymous, then we will hear from Malcolm Slater and Violet Slater, and then the following two witnesses will also be anonymous.

SIR BRIAN LANGSTAFF: Thank you.

10 o'clock tomorrow. 10 o'clock.

(5.20 pm)

(Adjourned until 10.00 am on Tuesday, 29 October 2019)

I N D E X

F: