Wednesday, 30 October 2019

(10.00 am)

SIR BRIAN LANGSTAFF: I understand that our first witness for the day would be happy to be called Martin.

MS FRASER BUTLIN: That's correct, sir.

SIR BRIAN LANGSTAFF: Martin, please.

MARTIN MACCLEOD (affirmed)

Questioned by MS FRASER BUTLIN

MS FRASER BUTLIN: Martin, you're here to talk about your late father, Keith.

A. Yes.

Q. We have a picture of him that we're going to put up on the screens while you give your evidence.

Thank you.

We have also had statements from your mum and your sister, so we're going to draw on those as well.

A. Yes.

Q. You've all described your dad as a very outgoing, gregarious person, and he worked as a publican.

A. That's correct, yes.

Q. I think you want to say a little bit more about what your dad was like.

A. Yes, he was very hardworking, a very, you know, good family man, loving husband, and fantastic father and grandfather.

Before his ill-health, Dad was very outgoing. He was born in the east end of London, and left -- Mum and Dad left London to have a family, and they followed their dream and ended up running a village pub in Devon. It was a very successful business. Dad never lost his east end accent, so wherever we went anywhere in Devon, people would say, "How long are you down here for?" and he would go, "I've been down here for years doing all this, doing all that". So it's -- because he had that accent, he had that energy, he always knew that where he was and what he was doing. He really enjoyed village life, he really got into that, with local sports, he would support the schools and all those sorts of things.

He was very respectful and appreciative of his customers as well.

He ran his business, he was the king of his business, and as children I remember it used to take us ages to walk anywhere with him because people would stop and chat, either in the village or in the local town or in the city, anywhere. My mum insisted on a holiday in Tenerife with him once, and someone goes, "Hello, Keith" a customer abroad, and Dad would always stop and chat. As kids you would just have to wait patiently, let him finish speaking to his customers then you would carry on with your business.

Q. Your dad had problems with his knees and underwent arthroscopies on several occasions in the late 1980s, and then in October 1988, when he had a procedure, he developed a chronic infection in the knee and he ended up requiring a knee replacement operation, which took place on 20 May 1991.

A. Correct, yes.

Q. It's during that operation that he was given a blood transfusion.

A. That's right.

Q. At the time of the operation as far as you're aware, was your father even aware that he had had a blood transfusion?

A. He was not aware. Back in those days, when you had a knee replacement, it was standard procedure, it was routine, to have a blood transfusion, and any -- the focus at the time -- because the infection was really quite savage, and Dad's knee had essentially fused and needed to be removed and replaced. And that -- you know, the blood transfusion didn't come into it; it was the replacement of the knee that was the focus. So Dad really wasn't aware, and if it had been mentioned in passing would certainly have not had anything -- understood anything of any risks or of infections or transfusions that would bring.

Q. As far as he was concerned subsequently it was simply a routine matter that he had been transfused?

A. Yes.

Q. He then had two further knee replacements, and did he receive a transfusion on either of those occasions?

A. No, the practice of transfusion during blood knee replacement -- or knee replacement had ceased shortly after his operation.

Q. Your dad then received a letter from the National Blood Service dated 31 July 1995. We're going to have a brief look at it. It's something we've seen with other witnesses, sir. It is 2028004, please.

We can see in the second paragraph that your dad was informed that they'd now discovered that the blood that he had been given may have been carrying an infection known as hepatitis C.

What was your dad's reaction to receiving that letter?

A. He was bemused by this letter.

He didn't recall having a blood transfusion. This was some years after that knee replacement operation and subsequent operations. And it says in the letter that it was at Musgrove Park Hospital, and he had never had an operation at Musgrove Park

Hospital. So the location stated on the letter was incorrect. So he -- to start off with didn't understand where this had come from.

Q. We can see at the top of the letter that there's some handwriting.

A. Mm.

Q. You've identified that as your dad's behind writing.

A. Yes.

Q. With a date of 9 August.

A. Yes.

Q. What was your understanding about that?

A. That is the date that he went for the blood test so he -- the initial blood taken for it to be tested to see if he was infected.

Q. Your understanding is that your dad had done as the letter had requested and telephoned the National Blood Service, the phone number that was provided, to make an appointment with Dr Anderson for tests to be done.

A. Correct, yes.

Q. Before we leave the letter, we can see in the first paragraph that Dr Anderson was writing with the agreement of your dad's general practitioner. You've obtained your father's medical records and there are two letters that pre-date this one dealing with the similar issues.

If we look at 2028003, please. This is a letter to the orthopaedic surgeon, and if we look at the first paragraph, we can see that the transfusion service has been reviewing the records of previous donations from donors now known to be infected with hepatitis C, and the health department have decided that the recipients of blood originating from these donors should be traced so they may be offered appropriate counselling, testing, and follow-up, including consideration of treatment.

There's then a reference to your dad having been transfused with red cells on 18 January 1991.

A. Mm.

Q. We know that's the wrong date because his surgery was 20 May 1991.

A. Yes.

Q. But then at the bottom of the page, we can see that the orthopaedic surgeon had the option of whether he counselled your father or whether it went back to the GP, and in this letter the orthopaedic surgeon declined to address it himself.

A. Yes.

Q. And then if we look at 2028007, we can see the letter that went to the GP.

A. Mm-hm.

Q. Which, again, sets out that the health department have decided to trace relevant people.

We see that in the second paragraph of the letter the date is correct for your dad's transfusion, but the hospital is still wrong.

A. Yes.

Q. And then it says, third paragraph:

"In accordance with the health department's guidance, the patient will need to be approached with a view to counselling and testing."

A. Mm.

Q. The next paragraph:

"I would be grateful if you would complete the enclosed questionnaire."

In relation to your father.

What you think happened was that in fact the GP didn't complete the questionnaire, but that the Blood Service completed the questionnaire.

A. That's right. The author of the original letter of invitation to Dad, we believe that was the person that filled in the questionnaire.

Q. We can see that on document 014 --

SIR BRIAN LANGSTAFF: Well, just before we leave that, could we just have a look at the end of that letter?

MS FRASER BUTLIN: Yes, sir.

SIR BRIAN LANGSTAFF: I had been wondering, given the tone of this letter, which says what is going to be done, why the earlier letter to your father said that it was writing with the consent of the general practitioner. Presumably this was the only reference to any form of consent, otherwise it's just a form of words.

MS FRASER BUTLIN: Yes, that's correct. That's correct.

SIR BRIAN LANGSTAFF: Thank you.

MS FRASER BUTLIN: So they then go to 014, which is the -- I'm sorry, sir, I'm incorrect, there is another reference to consent and it's on 014.

SIR BRIAN LANGSTAFF: Ah, thank you.

MS FRASER BUTLIN: That's where I was going next. Apologies. We can see a letter from Dr Anderson of the National Blood Service to the GP and it says:

"With reference to our telephone conversation regarding this gentleman."

SIR BRIAN LANGSTAFF: I see.

MS FRASER BUTLIN: So it appears there was a telephone conversation between the GP and the National Blood Service, and hence the letter to your father with the agreement of the GP.

A. Erm --

Q. Attached -- sorry, yes.

A. Chronologically the invite was 31 July for the test, and this is following those tests.

Q. Absolutely.

A. Right, okay, thank you.

Q. What we have attached to this letter is the results of -- copies of the results and the counselling form, which is what we're going to look at.

If we turn to page 4 of this exhibit, we can see at the top that it's been completed by Dr Anderson, so it's been completed in the National Blood Service rather than by the GP.

A. Yes.

Q. We can see the date of the counselling visit as 9 August 1995.

A. Mm-hm.

Q. And your understanding is that on that date your dad simply went for a blood test.

A. Yes, just to take some blood in order to confirm whether or not he was infected.

Q. As far as you're aware, was there any other discussion about hepatitis C at that stage?

A. No, there may well have been just an introductory as to, you know, "Thank you for coming and this is what we're about to do". But it was -- the blood test was taken and that was it. It was a matter of minutes.

Q. If we go down to the bottom of this page, there's a question that has been completed:

"Does the patient have any other potential risk factors for hepatitis C? Tick if appropriate."

We can see that all the boxes have been ticked.

A. Mm.

Q. "Other transfusion episodes."

Had your father had any other transfusions?

A. No.

Q. "History of injecting drug use."

A. No.

Q. "Occupational exposure to blood."

A. No.

Q. "History of skin piercing."

A. No.

Q. Did your father see Dr Anderson again after 9 August as far as you're aware?

A. I don't think so, because I think the results came via his GP.

Q. So you're left rather puzzled --

A. Absolutely.

Q. -- why those boxes were ticked.

A. Yes, yes, we have -- if Dad was asked those questions, of course he would deny them, he would say, you know -- Dad has never tried drugs, he's the most vanilla person, you know, he would not have anything like that. Skin piercings, my sister recalls he just thought they looked odd on men. It's just not something he would do. He's a landlord of a pub and his history -- his employment history shows no suggestion of exposure to blood, and we know that the only blood transfusion he had was unfortunately that one on the day when we had the knee replacement.

Q. When your dad was told that he had hepatitis C, you've said it haunted him for the rest of his life.

A. Mm.

Q. Can you tell us what you mean by that?

A. Those initial meetings, there's just some key things that really, you know, sort of lodged in his mind and sent him, you know, into, you know, panic almost.

Talking about what to do if we spilled blood, if there was a blood spillage, that -- even when, you know, years later when we had -- grandchildren are born, if dad ever cut himself -- he was always a practical man, so he would do DIY, he would do these things -- he would send us out of the room, he would not allow anyone to touch him. And that stayed with him forever.

Q. At the beginning he used his own towels, his own flannel?

A. Yes.

Q. At one point his own knife and fork.

A. Yes, because he shaved he was concerned with regards to any sort of blood in the house, and so, yes, absolutely used his own towels, flannels, cutlery, he even asked us all to -- he gave us all boxes of latex gloves to have in our homes just in case, you know, he cut himself.

Q. Were your parents ever offered any counselling following his diagnosis?

A. No.

Q. And you object to the terms of those letters we've looked at where it describes counselling?

A. Yes.

Q. Because in your view that wasn't true counselling.

A. No, it's not what we know today, and I don't think it's -- you know, it's -- it just doesn't reflect -- I don't think Dad was in that room when that form was completed. I think it was afterwards because obviously of the inaccuracies on there. There was no support, there was no -- it seems that the Blood Service exercise, the look-back exercise and the testing was a transactional piece of work, where they, you know, contacted the individual, tick; tested the individual, tick; confirmed the individual is infected, ticked, and then just moved on to the next person. It just feels that there was no support.

For them to suggest, we've seen, you know, in obviously letters and things that counselling took place, it's just -- it's offensive to us because that form was on Dad's records on his GP records for 21 years and there were opportunities for people to review that. And we don't know if that affected anyone's decision on the care that he was offered, we don't know if it changed their opinion of him.

He was very concerned about being thought of as someone that had brought this upon themselves, that had some sort of immoral or illicit behaviour, and sometimes you'd think, you know, it's -- you know, you're being paranoid, but then you see that these are actually on his records and maybe he wasn't so paranoid.

Q. Your dad was referred up to Musgrove Hospital, and there was a consultation in the October following his diagnosis.

What were your parents told about telling anybody about his infection?

A. They were advised not to tell anyone other than medical professionals that they encountered.

And that was especially hard for Dad because he's -- Dad can't -- Dad was never a secret keeper.

He couldn't keep secrets. If you asked how Dad was, you got to know how he was. He would tell you everything. And sometimes you're like, "Okay" -- but if you asked the question -- we would tell friends and family, "You ask him how he is, you're going to know".

So to avoid people asking him how he was, he would withdraw from social events, from village life. He kept himself to himself. He initially had the knee that he could talk about, you know, and if people would say, "How is your knee, Keith?" then that's fine. But if it's a more general question, he would rather not be there to have to lie.

And he felt very protective of the family. My sister, Susanne, was still at school. When they were informed, in a village, news like this can escalate, it can go across a village. Mum and Dad didn't have the business anymore, but they still lived in the village where Mum and Dad had the pub, so they were known.And it was very difficult for that to -- you know, for the family to have that as a secret.

Q. Your dad also felt particularly upset that when he was at the hospital that he had red dots on his medical records. Why was that?

A. Mm. The red dots on the outside of medical folders would indicate infectious. And Dad would see the

change in someone's demeanour, in their attitude, their response, and he felt -- he felt dirty, he felt that he was being judged. And it was -- because it was for all to see, if you're walking down the corridor in a public area, he just felt infected, you know, the infected, and so he really did not appreciate that at all.

Q. There was one particular occasion where a doctor said something to him that made him feel even worse.

A. Mm, yes. He was --

Q. Do you want to tell us about that?

A. He was staying in the hospital at the time and this doctor came in and said, "Well, you know, have you caught this in your misspent youth?" And that's -- so he -- and making it as a joke. And Dad had the greatest of respect for doctors, he wouldn't -- he couldn't argue with the doctor or put the doctor straight. But he rung Mum and he was very upset. And Mum actually got in her car, came down to the hospital and demanded an apology from that doctor. She got an apology from the ward or the management of the ward, not from that doctor.

But yes, he just couldn't -- he did not appreciate being thought of in that way.

Q. So you've described in your statement your dad

struggling with the stigma, but also the fear that hepatitis C brought.

A. Mm.

Q. And that fear didn't just haunt your dad, it also haunted your sister.

A. Yes.

Q. We've got permission for you to tell us what happened when she had given birth to her twins.

A. Yes. Sorry.

Susanne gave birth to two lovely girls and -- but felt quite ill and was really quite poorly. And this is -- and they said that she needed a blood transfusion, and having the experience, the difficulties and the trauma of seeing -- and what this has done to dad, my sister who adored Dad, she pointblank refused, she was not having it, and a number of medical staff were trying to persuade her because it was in her best interests, you know, she was ill, and she needed this. And she would not have it.

So Dad somehow caught wind of that, got straight in the car, came over, persuaded people to let him in outside of visitor hours and sat at Susanne's bed and talked it through and persuaded her that she was going to be okay. And only when Susanne heard those words did she allow the transfusion to take place.

Q. Before we talk about your dad's treatment --

A. Mm-hm.

Q. -- and what happened after that, there's one other set of documents that you've pulled out from your dad's records that you wanted to take us through.

A. Mm-hm.

Q. And that is the hepatitis C register.

A. Right, yes.

Q. In 1998 your dad was added to the register. Was he aware of that?

A. No, he wasn't.

Q. You've provided the inquiry with a series of letters, so could we have 2028016, please.

We can see that this is a letter to his treating consultant at the hospital, from the National Blood Service, and it says in the first paragraph:

"As relatively little is known about HCV infection transmission or the clinical course of the resultant disease, a national register of HCV infections is being created. This register has been funded by the Department of Health and will provide a facility for the future monitoring and long-term assessment of HCV infection within the UK."

The middle paragraph, if we just go down, Henry,

in bold indicates that no patient names will be sent to or held on the national HCV register but rather numbers will be used.

Then the penultimate paragraph:

"I have also enclosed an information sheet explaining the purposes of the registry which you may like to pass to your patient. No patient will be contacted directly. However, this information sheet has been provided for clinicians who feel they would like to notify patients of their inclusion in the register. Ethical approval for the register has been obtained from both the Public Health Laboratory Service and the UK Multi-centre Research Ethics Committees. There is no formal requirement to gain patient consent."

We then have a further letter in 2001 -- it's document 017 -- which indicates that your dad had been entered on the register, and there's a request in the second paragraph:

"We have been unable to trace any liver biopsy sections for this patient so I have taken this opportunity to request the sections again."

They are requesting the treating doctor to provide to the register the specific histopathology if your dad had had any liver biopsies to allow them to

look at those samples, and then again, if we go to the next paragraph, Henry, we can see this note:

"Ethical approval for the collection[sic] of these biopsies has been obtained from both the Public Health Laboratory Service ..."

SIR BRIAN LANGSTAFF: "Collation", I think.

MS FRASER BUTLIN: Apologies:

"... the collation of these biopsies has been obtained from both the Public Health Laboratory Service and the Multi-research Ethics Committees and there is no formal requirement to gain patient consent."

And note that the slides will be stored anonymously.

Those slides were requested by the gastroenterologist from the pathologist and provided to the register. We've seen that in another document. Then we have a letter in 2006 from the national register, the National HCV Register.

In the second paragraph, in which they chase up any further information -- it should be 013, please.

"We have been unable to trace a follow-up form for this patient, so I have taken this opportunity to enclose another. We are very keen to document the outcome of HCV infection in this unique group of

individuals, most of whom acquired their infections on a known date. I would therefore be most grateful if you could complete the enclosed form, even if you have not seen the patient since the date of their last report."

It requests summary information as well as details of any tests or treatment they have received since the date of their last report.

Throughout that time frame of 1998, all the way through to the letter in 2006, was anyone in the family aware that he was registered?

A. No.

Q. Or that samples were being provided to the register.

A. No.

SIR BRIAN LANGSTAFF: Did he have any biopsies during that period that you know of?

A. He would have, yes. They took place on occasion. The purpose of which was certainly not -- we weren't made aware that it was for a register or any form of research on this basis.

MS FRASER BUTLIN: We can see, sir, that there were sections provided to the HCV register for your dad. The document is 2028018, if we could have that, Henry.

It's a letter from the treating doctor to a histopathologist indicating that they have asked for four spare unstained sections of the liver biopsy specimens. Your understanding, from other documents in the records that we don't have, were that those four were provided to the register.

A. Yes.

Q. In terms of your dad's treatment --

A. Mm-hm.

Q. -- he had a number of different courses over the years, including interferon. What was the effect of them on him?

A. They were really quite debilitating. He struggled enormously with the side-effects. He would often be in bed, you know, he didn't have the energy to sit in a chair. He would be cold and have no appetite. It would really take a lot out of him.

It would worry us to see him this way. It was a struggle to watch. But Dad would say, you know, that -- and we would say, "Look, you don't have to do this, we can help, we can look at other things". He would say, "No, let's give it another week", because he always felt an additional week might just bring that breakthrough that everyone is looking for. So he would push himself to suffer that little bit longer just in case it brought the results. But he was very, very poorly.

Q. In 2011 he was referred to the King's College Hospital in London to be considered for a liver transplant.

A. Yes.

Q. But at that stage it was thought his liver disease was relatively stable, so there was no need for a transplant; is that right?

A. Yes, he wasn't ill enough.

Q. He then underwent further treatment in 2014 and cleared the virus in about 2015.

A. Yes.

Q. Around that time, you found another letter in your dad's records from 2014, 2028012. It's a letter from Public Health England to your dad's GP, which says:

"The above patient has been recently notified to us as being antibody positive for the hepatitis C virus."

Do you have any idea why this letter was sent by Public Health England at that time?

A. No, no idea at all.

Q. We can see then in the second paragraph there is discussion about if the patient is an injecting drug user, or in relation to infections via sexual transmission.

A. Mm.

Q. You're quite unhappy about that paragraph.

A. Yes, yes. It's -- again, it just shows this -- I don't know, assumptions or -- the -- everything that Dad feared that people thought, you then see official letters that suggest perhaps this person has caught hepatitis C through these means.

Q. There was nothing in 2014, August 2014, in your dad's treatment or anything at all that would suggest why this letter would be sent at that point.

A. Absolutely not. I mean, it is years upon years later from when his infection was found, and he would've been receiving treatment for hepatitis C and was just about to have that breakthrough of combating the virus.

Q. Although your dad cleared the virus in 2015, his liver was cirrhotic.

A. Mm-hm.

Q. And it wasn't in particularly good shape.

A. No.

Q. In the documents from the hospital, they've said that the condition of his liver seemed to improve after he cleared the hepatitis C, and he was generally quite stable from a liver perspective.

A. Mm.

Q. But the family's recollection is quite different; that in fact your father's condition was complex and he was

unwell. Can you tell us about that?

A. Yes.

With the original knee -- the infection that Dad got in 1988, the approach to that was to bombard it with antibiotics. They removed the knee and had medicated cement, and that's what led to the original knee replacement.

The virus itself -- it was believed that the virus had been combated, it was no longer there, but what we understand now is that that original virus had simply gone dormant. With all of the treatments that Dad had with the hepatitis C, it remained dormant, until when Dad finally cleared hepatitis C, that infection, that original infection, then came back.

So Dad was again suffering a very bad knee, a very bad infection, and they went to their original treatment where they removed his knee, they filled it with medicated cement and they bombarded him with antibiotics, and that was for months and months, maybe a year. And it was described to Mum, saying, "Look, this is so strong it's like we're putting bleach through your husband's veins."

So that -- obviously the original treatment was on a body that was a lot fitter than it is today, or was then. The cirrhosis of the liver was suddenly working harder than it's worked for years. You know, Dad didn't drink, Dad didn't do all the things he was told not to do in order to protect his liver, and when this infection came back, they had -- they felt they had no choice. But they did it -- or I believe, you know -- based on the man they knew many years ago.

Q. And so the family have described that your dad's physical condition declined and he became very unwell.

A. Yes.

Q. I just want to read a paragraph from your mum's statement, because she described gradually becoming your father's carer and she said this:

"Becoming a full-time carer was a slow process. You start off accompanying your husband when he visits medical staff. Then you realise there are times when he simply cannot take in the latest news about his condition, so you step in on his behalf. You start to make notes. You come home and type them up and refer back to them at the next visit. Then you are the one who is remembering details neither your husband or the medical staff can recall. People start to rely on you and relay information to you so you can discuss it with your husband when he is ready. You become the expert on your husband's condition, prompting him to go to the doctor as you sense a change in his

condition, or making sure he mentions something important when visiting consultants. You become the one breaking bad news to your children, to friends and extended family after your husband has received another setback which he doesn't want to talk about. You are the only witness seeing the impact of another drug trial fail, noticing more symptoms emerge and helplessly observing your husband's continued deterioration."

That's how your mum described what happened for her.

A. Mm.

Q. You and your sister also took on responsibility with caring for your dad more and more.

A. Yes.

Q. And you've said in your statement that your dad withdrew into himself even more, and seemed to become resigned to his own demise.

A. Yes, he -- it just seemed to be one piece of bad news after another. Something else would flare up or, you know -- and it would be, you know, high blood pressure, it could be bad skin, it could be piles, it could be the shaking of his hands, this is the thing, and he would just be quite bemused as to why these things would be happening to him. He would say, "It's

just another nail in my coffin, it's just something else I've got to deal with".

I don't think he -- well, we know he didn't really appreciate that all of these things were because of hepatitis C. You know, because of the portal hypertension, cirrhosis of the liver, the complications that that brings. He had varices, which were awful, they were quite life-threatening at one point. So his oesophagus -- he couldn't eat, he couldn't drink, and it was very painful.

But he never saw it as one challenge; it was always a series of challenges, a series of things that he had to do. And of course he would have to go and see other medical professionals and explain himself. Again, this is where Mum got into the habit of being the one that is remembering and taking notes and reminding people about previous conversations, about how, you know -- reminding Dad to mention something that may have -- that doesn't seem connected to that medical expert because they're concentrating on X, just to mention this, just as an aside, just in case it has, you know, a consequence.

Q. In about 2016 your dad was assessed for a knee replacement, because the medication for the infection wasn't resolving the issue with the knee.

A. Mm.

Q. And a week before the surgery it was noted that his liver was decompensating again. Was the family aware of this?

A. No. Not overtly. I think -- the relationship Dad had with that doctor was a long-established relationship between doctor and patient. There was a lot of emotional sort of investment between the two of them in getting Dad better.

I think if it had been mentioned, Dad fully trusted this doctor and with good reason, and, you know, there's no suggestion of any, you know, wrongdoing or anything like that.

This doctor would -- was keen to move ahead with it, and so those results, which in hindsight could possibly have been an indication of problems to come, and we've had it -- you know, we've had that independently looked at and thoroughly investigated, and the results were that, you know, it could've been 50/50. Another doctor may have decided not to go ahead with that knee replacement. The doctor looking after Dad did, and with every, you know, hope and desire and professional opinion that it was going to be okay. And Dad trusted that doctor and went ahead.

So if it was mentioned, it would've been mentioned in passing as a factor that's not stopping what we're doing.

Q. He had the knee replacement surgery on 16 May 2016.

A. Yes, mm-hm.

Q. But during the operation and afterwards he suffered kidney failure.

A. Yes.

Q. He was then moved to Derriford Hospital to receive specialist treatment for the kidneys and a possible liver transplant.

A. Yes.

Q. He then underwent paracentesis to drain the fluid, but during the procedure he suffered an internal bleed.

A. Yes.

Q. And following on from that, you and the family feel there were a catalogue of errors.

A. Yes.

Q. Particularly in relation to dialysis.

A. Mm.

Q. The hospital have responded to stay that the situation was very complex, and they would say there wasn't a failure to dialyse. We're not going to go through those details because I understand that you don't particularly want to criticise and dig all of it up today.

A. No, mm.

Q. But the point you did want to make was that you feel there was a lack of joined-up thinking about your dad's care.

A. Yes.

With the emergency operation, because the paracentesis that caused the internal bleeding and then the operation -- the emergency operation to stop that bleeding and the intensive care received afterwards brought back Dad -- brought Dad back from the brink, you know, and they -- and it took -- I think the emergency operation was on 2 July and Dad regained consciousness on 10 July.

So it's ... so the emergency of bringing him back, but the complex nature of Dad's body, the cirrhosis and the weaknesses that he had, and the -- it was -- intensive care, he moved from there to a general ward, and then you've got doctors who are looking at the patient and looking at symptoms that are presented, they're not looking at the silent killer in the room, almost, you know. They've got, you know, this other element in the room where they're not picking up on the subtleties of a liver that can't process the drugs. I mean, an anaesthetic is a poison, so your body has to process it out. Dad's

kidneys had already failed and were not getting better and they were giving more drugs.

The records show Mum continuously asking for dialysis, which in our opinion was of use. Obviously there is a difference of opinion and we're not crossing into any criticisms at all. But for the point of the inquiry, the one thing that we want to highlight is the fact that we knew Dad, we knew his body, we knew what he had been through, and as a family, when you're talking about that individual, we were the experts in the room. We were the ones who knew that he was just slipping away from us, we could see it. And we knew that he needed assistance. He needed help.

It wasn't just what was being presented to the doctors physically, you know, we could -- we knew there was more. And it just seems that for ourselves, the expertise that we had, that knowledge that we had, was not listened to. We were treated as silent observers, in our opinion. We were treated as people who were there to care for the patient, but not to guide any care for that patient.

It's one of the things that we do struggle with, the fact that we feel -- felt so helpless when Dad was so very poorly and so needed intervention that took

all of this into account, and we had that history, we had that knowledge, and we were not -- it -- we were not -- we felt we were not being listened to, that that knowledge that -- and that history wasn't being taken into account.

So everything that was being put into Dad, everything that was, you know, trying to help with something, in the end was just poisoning him.

Q. You said before today that the family felt that the doctors treating your dad had very limited understanding of hepatitis C.

A. Mm.

Q. And very limited understanding of the ripple effect of hepatitis C in relation to the physical consequences of it.

A. Absolutely, yes.

Q. And that in those circumstances, what you as a family were saying needed to be heard even more than normal.

A. Yes, yes.

The one thing that we've learned is that when someone is infected, if they go down, they go down fast and they go down hard, and it's very difficult for medical professionals to manage that, because they're trying to respond to what they're dealing with at the time, you know, immediately, they're responding to that, and quite rightly so. But there is this background that we have, and I think the one thing that we -- I would personally point out to the inquiry, to people listening, is to speak to your loved ones, speak to the people who are infected, and register power of attorney with those -- for those people. If we'd have done that -- because we didn't have that -- and if we had have done that, we would've had conversations with Dad to say, you know, "This is how we speak up for you, this is what we will do, this is how we will -- what do you want us to do, to say on your behalf?"

If we had power of attorney, we would've felt more empowered to speak up for Dad. You know, we felt overwhelmed by the situation. It happened so quickly, and things that we were asking for were not being responded to, sometimes not even being acknowledged, noted, and we have medical records that have Mum repeatedly asking for dialysis. But she remembers that whilst they're noting it, they're not answering, they're nodding and then going off to the next patient. You don't feel that you're able to step up.

I think if we had power of attorney over Dad, certainly, you know, from the medical side of things, we would've been more able or more -- felt more able

to intervene with his care.

Q. And sadly your father suffered from hepatic encephalopathy. He had some seizures and was then provided with palliative care until he died on 24 July 2016.

A. Mm.

Q. Can you tell us something of the impact of your father's death on you and your sister and your mum?

A. The way we lost Dad was traumatic. It was not -- there was no -- nothing gentle about it. We had -- you know, my dad's sister came down to see him because she knew there was this -- you know, he was in trouble. She's 11 years older than him. She was not expecting to say goodbye to her little brother.

Following the death of Dad, we've all lost a huge influence in our lives. Doesn't matter how we as children help Mum, she doesn't have that voice that says, "Jane, it's fine. Jane, don't worry about it."

(Pause)

My brother has lost his mentor. My brother is a builder, my dad was in the building trade. He taught Stuart loads. But not only about practical stuff; about customers, about running a business. Stuart doesn't have anyone now that's able to offer that really, you know -- that advice and guidance. My

sister, as I say, she's lost her best friend.

Throughout my forties, I've been the problem child in the family, going through divorce, family breakdown, finding new love. And Dad would just think it through. And go -- all you needed to hear from Dad was, "I understand".

He was the head of our family, he was the heart of our ... He was the heart of our family, and we in varying degrees are all lost without him.

Q. Your mum has had some added worries in terms of finances. Your mum and dad received a stage 1 payment and then your dad said he would receive a stage 2 payment. Your understanding is that he had a choice between monthly payments or a lump sum.

A. Yes.

Q. Your dad chose to take monthly payments.

A. Mm-hm.

Q. You're unhappy about that. Can you tell us about that?

A. Well, again, you know, this -- even, you know, with hepatitis and all this sort of situation, the whole thing is complex. When Mum was caring for Dad, she reduced her hours at work in order to provide support for him. Mum was on a final salary pension, and reducing her hours would reduce her final salary, so

she has had an impact financially on that, something you don't think of at the time, because your immediate concern is your husband.

So when it came to the payments, Dad decided to take it monthly so they had it coming in on a regular basis. But obviously we lost Dad far sooner than we anticipated, and we honestly don't believe that the -- you know, those payments have stopped and Mum doesn't have that financial security or that regular income.

There are alternatives which we may cover, but like -- you know, it's -- we just don't think there was a -- because it's linked to someone, and as I say, when the infected are -- when they -- when there are complications, they go quickly. And it's -- the -- there's no sort of way of balancing out that for the other individuals who are left, who are -- rely on that financial support.

It doesn't seem to be that whatever the lump sum was, that the difference is paid or that there's some sort of way of continuing or anything. It just -- it ceased immediately.

Q. Your mum was moved to the EIBSS, but she is constantly worried about the EIBSS payments.

A. Yes.

Q. What's her concern?

A. After Dad passed, and, you know, those payments stopped, EIBSS -- they asked her to fill in a form and to give three months of financial statements, which Mum did, and the result came back and it was confirmed that she would receive a regular payment through that support system, but no explanation as to how they came to this conclusion. There was nothing for us to double check or qualify or -- and Mum's initial response -- because it was an improved payment to what she had previously, but Mum would take it out of her account and put it into -- and hide it in another account because she had -- she was convinced that they were going to come back and say, "We've made an error", you know, because we had nothing to confirm what was correct.

And now it is a yearly response. So Mum, last year, has filled the forms in, given the three-month statements. Her financial situation has not improved. Her costs have certainly increased. And this time her payments have gone down, and they've gone down by a significant amount per month, and again, no explanation as to why and -- so you have nothing to challenge.

Mum doesn't feel that she has financial security. It is a constant concern that this annual

event and this annual result will dictate whether she's -- you know, how she is for that forthcoming year. But it doesn't have any other -- you know, she can't think long-term money-wise, she hasn't got a long-term, she's got an annual basis, that's it.

Q. Those are the questions I have for you. I'm just going to turn to Mr Lock and Ms Gibbs to see if there's anything they want me to raise.

(Pause)

Just two points that they'd like me to raise. They've asked that I read out a section from your mum's statement in relation to the financial security question.

A. Right.

Q. She says this. I just want to find the context of the paragraph, if I can have a moment.

(Pause)

Yes, she discusses the discrepancy in payments of 25,000 and 40,000, and she says this:

"£25,000 doesn't go a long way if you have to keep a family or have to keep your house going. I would like to say I did receive a sum as a widow's one-off payment. Whereas that helped immediately with expenses, it angered me, because I looked after my husband from 1995 to 2016. This payment made me feel

that I was a very cheap carer for the government."

That was your mum's view.

Earlier you were discussing the lack of joined-up care and the family's concern about that.

A. Mm.

Q. They've asked me to just highlight a particular exhibit. It's 2028009, please, Henry. It's the first three paragraphs:

"Thank you very much for taking over the care of this gentleman."

And they are requesting advice regarding a problem with LFTs. This was in 2003.

The letter says this:

"He came in for a routine check of blood and we spotted his ALT had written to 100 and his platelet count had fallen to 131. I have enclosed a printout.

"On reviewing the reasons for this I suddenly realised to my horror that he has been making nizatidine for over five years. It was started by my previous senior partner and unfortunately Mr Root's prescriptions are being issued by my senior partner's successor.

"On further investigation of his medication I discovered that the cefradine which he takes for prophylaxis of infection in his knee, the transfusion

for which originally caused his hepatitis C, is also labelled in the BNF as causing liver abnormalities and thrombocytopenia."

There is a request for someone to liaise over a choice of an alternative drug. That was a letter to the GP from the hospital specialist and they asked us to highlight that exhibit as a good example.

Martin, do you have anything else you'd like to say?

A. I have a statement that mum has prepared that she's asked me to read out on her behalf.

If I get my glasses, that would help.

"My husband's life was cut short because the government decided to continue to use untreated infected blood. They not only ruined my husband's life, they ruined my life and our family life.

"As with all couples, we had plans for the future, long into our old age. This was taken away from us in a most cruel way. I had to watch my husband die bit by bit, year after year, knowing I could do nothing. I was a loving wife who became a carer and suffered every step with my husband.

"I hope this inquiry will make the government admit to their horrendous actions, and I thank Sir Brian, the support staff and all the legal teams for their hard work."

And just a short statement from myself.

I would just like to point out that you don't need to win to be a hero. Dad demonstrated a quiet determination across the years and throughout his life, with all the areas of challenges that he's faced. There was no fuss, no bother. Dad would face all his disappointments, all the setbacks, all the frustrations, and he would simply pick himself up, dust himself down and stand tall and face the next round.

I'm so proud of my dad. My dad is my hero. My dad is my hero.

Thank you.

MS FRASER BUTLIN: Sir.

SIR BRIAN LANGSTAFF: Well, I don't know why you're thanking us; it's we who should be thanking you. Your direct and powerful evidence, commenting on things revealed by the records, are balanced by the equally powerful, rather different way in which you've shown the rawness of grief, and reminded us sometimes that it's just the very little things, when you remember them, that make the throat choke and the eyes fill, things like when you first mentioned his desire to make sure that no one cleaned up blood which he had

spilt.

A. Mm.

SIR BRIAN LANGSTAFF: When it affected you personally, you showed clearly how much everything mattered, and so thank you for that.

A. Thank you.

SIR BRIAN LANGSTAFF: Well, we will take a break until 11.30.

(11.05 am)

(A short break)

(11.30 am)

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

MS FRASER BUTLIN: That's correct, sir.

SIR BRIAN LANGSTAFF: Carol, please.

(Pause)

CAROL CARRUTHERS (affirmed)

Questioned by MS FRASER BUTLIN

MS FRASER BUTLIN: Carol, you are here to talk about your late husband, Ollie.

A. Yes.

Q. You've provided us with a photograph of him that you'd like to be displayed throughout your evidence.

A. Yes.

Q. You met Ollie in 2003.

A. Yes.

Q. You married in 2011.

A. Yes.

Q. Can you tell us a little bit of what Ollie was like?

A. Ollie was -- he was a very kind man, he had a fantastic sense of humour. Loved his family, loved life, and he loved travel. Up until the point of his infection he worked as a service engineer, travelling all over the world. He loved to travel. And when we met, we carried on, we travelled. He never let his infection get him down. He was a founder member of the Contaminated Blood Group, CBC, that are here today.

Although he was doing all that, he kind of kept it a little bit away from our life together. He didn't want to be Mr Hepatitis C; he wanted to be my husband, my Ollie. That was him, really.

Q. Ollie had haemophilia B.

A. Yes.

Q. And when he was tested in 1974, his levels were categorised as mild.

A. Yes.

Q. In 1977 they were seemingly severe, but in reality you've said he rarely had bleeds and required very little treatment.

A. That's true, yes.

Q. Ollie was treated at the Royal Victoria Infirmary in Newcastle and had dental extractions in 1977 and 1979 --

A. Yes.

Q. -- when he was given Factor IX prophylactically.

A. Yes.

Q. He then lived in America for a few years in the 1980s.

A. Yes.

Q. While he was there in 1982, he had to have a tooth extracted.

A. Yes.

Q. What was Ollie told by the US dentist about having blood products prophylactically?

A. When he was in America, he was told that the blood products were very risky, there were risks of infection, and they wanted to remove the tooth but to have the factor on standby in case he bled.

So their attitude there was, "We'll wait and see what happens. If you bleed, we'll treat you". The risk was -- seemed greater to give prophylactic treatment than to give treatment in the event of a bleed.

Q. On that occasion his tooth was extracted, and did he need any factor products?

A. No, he didn't bleed.

Q. In 1989, Ollie was back in the UK and needed another tooth extraction.

A. Yes.

Q. And he met with Dr Jones to discuss it.

A. Yes.

Q. What did Ollie tell Dr Jones, as far as you understand?

A. As far as I understand it, originally he went to the dental hospital, who then referred him back to Dr Jones and the Haemophilia Centre. Dr Jones basically said they wanted to do prophylactic treatment and Ollie stated that he did not want prophylactic treatment. He had been told it was risky. He explained to them in America that they had removed the tooth, he hadn't bled, and that they had it on standby in case there was a problem.

Dr Jones at the time appeared to accept everything that he was saying, and Ollie's sort of understanding was they were going to look into things. So he was a little bit surprised when he turned up and they treated him anyway.

Q. Ollie gave evidence to the Archer Inquiry and we have the transcript of his evidence.

A. Yes.

Q. He says exactly the same, that he told Dr Jones about what he had been told in the US.

A. Yes.

Q. And that on that occasion he hadn't needed factor products.

A. Yes.

Q. We also have a note of that consultation, if we could look at 1850005, please, Henry.

We can see in the middle of the page the date is 15 March 1989:

"Ten years since last visit. No problems. Tooth extraction in USA in 1983 without treatment. No bleeding. Needs upper left premolar query extracted. Would not want factor treatment if possible."

So we have that in the records.

As you have said, Ollie's understanding was that he would have the extraction and have factor on standby.

A. Yes.

Q. Ollie's Factor IX levels were also tested at that appointment.

A. Yes.

Q. What were they?

A. I believe they were at 9, which is considered mild.

Q. On 16 May 1989 he went to the RVI for the extraction.

What did Ollie say happened at that extraction?

A. He said they just got on and gave him treatment. Nothing was said to him at all.

Q. And he said in his own evidence before that he trusted that the doctors wouldn't knowingly put him at risk.

A. Yes.

Q. And accepted the treatment.

A. Yeah. I mean, the doctors were gods then. You just did what they said. You wouldn't stand up to a doctor and say no, whereas nowadays I think the culture is a little bit different.

Q. He was given BPL Factor IX.

A. Yes.

Q. As far as you understand, was anything discussed then about the risk of infection? Ollie having raised it, was anything really discussed?

A. No, I don't think it was. He certainly never mentioned it.

Q. We've had a response from Dr Jones this morning, and I'm just going to read some of that response.

He says this:

"I would have spoken to Mr Carruthers prior to his dental extractions. Noting that his Factor IX level was below that needed to secure haemostasis during and after surgery, I would have explained the

need to cover the procedure using a Factor IX concentrate. I would also have covered, as a routine with all patients, the risks of blood-borne infection. This risk was already known by Mr Carruthers. This routine continued to be followed beyond the introduction of heat-treated concentrates from December 1984 onwards, despite the probability that such heating largely eliminated the risk of viral transmission. Mr Carruthers would have had to give his informed consent, both for the extractions and the haemostatic cover provided.

"At no time would I have suggested that we adopt a wait-and-see policy to only give Factor IX in the event of excessive bleeding. Such a policy could be extremely dangerous both because of overt haemorrhage and because of soft tissue bleeding leading to airways obstruction."

Ollie had also felt that the reason he was given Factor IX at that stage was because of convenience and cost.

A. Definitely.

Q. And Dr Jones has responded to that:

"I strongly deny the suggestion that NHS costing had anything to do with the management of this case, or that it was convenient to give Mr Carruthers

Factor IX. It was essential to secure haemostasis during and after the dental extractions."

I think you wanted to respond to that.

A. Yeah, really just to say that obviously Ollie's blood factor levels had been quite high prior to the treatment. His medical history was such that he presented as very mild, and his experience in America, having had a tooth extracted in the same circumstances and he had not bled, it doesn't feel like it was essential treatment to me or to Ollie. He certainly did not feel that treatment was necessary.

Q. I should say that the full statement from Dr Jones will go on the website in due course.

Three to four months later, Ollie was working in Iraq and became unwell.

A. Yes.

Q. What was wrong?

A. He had headaches, he felt nauseous, he was just generally feeling tired all the time, and under the weather, so to speak.

Q. He returned to the UK and saw Dr Jones. What did he ask Ollie?

A. He asked him if he had been messing around in Iraq, implying he had been messing around with other women in a Muslim country, which would've just been plain

stupid.

Q. Ollie took exception to that suggestion.

A. He did.

Q. Very strongly.

A. Yes.

Q. Dr Jones's response says that he had to ask questions around sexual history in order to obtain a full history and to allow diagnosis.

In the October, Ollie was tested and diagnosed with hepatitis C.

A. Yes.

Q. That was October 1989.

If we look at 1850009, please, we can see the date in the top-right corner, and that at this early stage in 1989 there is a request on the right-hand side, "Hepatitis A, B, C status, please", and then on the left, "Hepatitis C antibodies detected".

So we can see it's hepatitis C, rather than non-A, non-B on this date.

A. Yes.

Q. Ollie was told he was the first person in the north of England, possibly the UK, to be diagnosed with hepatitis C as opposed to non-A, non-B.

A. Yes, that's what he told me.

Q. And Ollie was sure that he contracted the hepatitis C

from the 1989 batch.

A. Yes.

Q. Why was that?

A. Ollie had not received treatment for over ten years. He had been perfectly well in all that time. He had been travelling the world with his job, just carrying on life. He received that treatment, and six months after that treatment he started to get symptoms of what he -- at the time he clearly didn't know what the symptoms were, but Ollie was into research. Once he found out what had happened, he was reading everything he could, and his understanding of the disease was that not everybody gets symptoms at all, but if you're going to get them, you usually get them within six months. So he believed that that was the case -- the one that had infected him.

Q. And when he obtained his medical records, he also saw that his ALT levels were raised.

A. In all fairness, we're not medical experts. We didn't understand what ALT levels were. It was only when it was pointed out to me, looking at his medical records, what had happened to his ALT records, that there was a correlation there. He would never have known that.

Q. Ollie wrote to BPL in the 2000s about having been infected in 1989, and they responded that they were

never informed of any products being contaminated in 1989. He also wrote to the RVI in Newcastle in 2008 and we have a copy of their response. 1850010, please.

It's a letter from October 2008. It's page 3, please. The next page.

We can see the date there, 17 October 2008, and it's written by a haematologist who wasn't Ollie's treating doctor. But we can see at the bottom of that first paragraph what they said. They say:

"Viral inactivation of plasma derived products was introduced in 1985. BPL have not issued any alerts about contamination of any batches subsequent to this date and there was no evidence that there was any problem with the batch you received in 1989. However, you clearly did receive plasma derived treatment in 1977 and 1979 and it is likely that these were responsible for exposing you to hepatitis C virus."

Ollie didn't accept that.

A. No, he didn't.

Q. Because of the reasons we've talked about.

A. Yes.

Q. As Ollie got older, his factor levels went up.

A. Yes.

Q. He was used as part of a journal paper, although you're unsure if it was ever published.

A. Yes.

Q. The reason you've highlighted this was the terms of the letter that he received, or you're not even sure if he received the letter.

A. I don't think he even received it, no.

Q. But you found it in the records and you wanted us to see it. 1850013.

It's a letter from Dr Jones saying that his colleague had:

"... identified the cause of your haemophilia B and wishes to report this in the medical literature, anonymously of course."

Then:

"Dr Green has now written back to me expressing interest in your early history but I have no records of your childhood. I would therefore be very grateful if you could drop me a note telling me about any bleeding episodes that you can remember, or anything else you think might be helpful to judge the clinical severity of your haemophilia B in your early years. Naturally, all of this will be kept confidential."

The reason you wanted us to highlight this letter is that Ollie was simply told about the paper;

he wasn't asked to consent to be part of the study.

A. Yes.

Q. As far as you're concerned, he was never asked to give his consent --

A. No.

Q. -- for any form of study.

A. I don't think he knew anything about it, and I'm not even convinced that he ever received this letter.

Q. But even if he had received the letter, it was simply informing him that he was going to be part of it.

A. Yes.

Q. Rather than asking him whether he was willing to be.

A. Yes.

Q. Ollie had some other concerns that he may have been used for the purposes of research. Why was that?

A. Because he didn't bleed, he's -- obviously they -- the note -- everybody knows that they were starting to heat treat the blood, but they didn't really know if it was working. Given that it was highly unlikely he'd got any infections because he hadn't been treated for ten years, and he'd done a lot of research amongst the haemophilia community, where they had been looking at records and they'd got things written on their notes that implied that they were not infected so they could be used, he always wondered if maybe they'd done

the same thing to him, but there was nothing in his notes that indicated that that had been the case.

Q. He had a specific concern about a liver biopsy.

A. Yes, he was asked to give a liver biopsy. Now, bearing in mind they can't extract a tooth without factor cover, a liver biopsy in somebody with bleeding problems is not something you do as a matter of course.

He asked whether he had definitely got hepatitis C, to which they said yes, and he said, "So what's the liver biopsy going to tell me?" At which point I think they realised he was not going to comply with what they wanted.

Q. And he declined to have that liver biopsy --

A. Yes, he did.

Q. -- the year after his diagnosis.

A. Yes.

Q. But he was always concerned about why they were asking him.

A. Yes.

Q. But it's fair to say there was nothing his records that gave any indication --

A. No.

Q. -- of research?

A. No, that was just his feeling.

Q. Ollie described to you and in his evidence to Archer that he was told very little about hepatitis C when it was diagnosed.

A. Yes.

Q. What do you recall of his understanding at diagnosis?

A. He was told basically he had it, and that was more or less it. He left the room stunned, not knowing what it was. He got on the internet, as people do, and started doing his own research. He found the action groups and it wasn't really until he started talking to them that he actually found out what he'd got.

Q. He also reported pains in his liver --

A. He did.

Q. -- quite early on. What was he told about those?

A. "It proves you're human."

Q. And, "It proves that you're mortal."

A. Yes.

Q. He was also told that the hepatitis C itself would be short-lived.

A. Yes. There's actually another comment in his notes, which actually says, "He appears to be getting over it". And given that you don't actually get over it, it's an odd comment for a medical expert to write.

Q. We have that document, 1850012. It's a letter to his GP. It's the last couple of sentences:

"Apparently he had an episode of possible hepatitis C subsequent to his teeth being taken out and given factor concentrate last year. I am pleased that he has got over this."

SIR BRIAN LANGSTAFF: This is from the same department, is it, which had the first test in the north-east, the previous October, showing that he had it?

MS FRASER BUTLIN: It appears to be so.

SIR BRIAN LANGSTAFF: So "possible hepatitis C" is not faithful to the records.

MS FRASER BUTLIN: No.

SIR BRIAN LANGSTAFF: Thank you.

MS FRASER BUTLIN: After his diagnosis and some time later, as he became aware of what hepatitis C really was, Ollie realised that since the diagnosis in 1990, he had underplayed some symptoms that he had over the years. What were those symptoms?

A. Sorry, I can't remember.

Q. I'm so sorry. You talk in your statement that after a few years Ollie became very aware of the impact of hepatitis C on him.

A. Yes, yes.

Q. And he was suffering particularly from brain fog.

A. Brain fog, yes.

Q. Can you tell us how that impacted him?

A. He couldn't think clearly. His thoughts would get confused and muddled. He had been working as a service engineer, as I said, all over the world. He needed to be on his game, so to speak, and the brain fog started to affect his ability to do his job.

He -- it really is just that ability to think logically, to think through problems, to be able to solve problems.

Q. He also started to react to the chemicals that were used in the factories in which he was working.

A. Yes.

Q. What was his understanding of what was happening?

A. I think it's -- obviously when you -- not knowing that much about it, he was obviously inhaling toxins into his body, and the liver is responsible for dealing with those things. I think it was struggling to get rid of those toxins in his body and he was beginning to feel very unwell.

A lot of the symptoms were non-specific, just, "I don't feel right."

Q. He started taking lower level jobs, less --

A. Yes.

Q. -- responsibility and travelling less.

A. Yes. Well, he had to give up the travelling completely.

Q. Ollie also felt that his hepatitis C had affected his first marriage and his relationship with his children.

A. He did.

Q. What were his particular concerns?

A. He felt that because of the way his brain and that wasn't operating, that his tolerance level was reduced. So he started -- I guess they were arguing more. I mean, we didn't talk too much about what happened in his first marriage. But, yeah, his marriage broke down and he felt that his state of mind was -- well, it certainly didn't help it.

Q. That's how he described it as well, that he couldn't put all the blame on it, but that it certainly hadn't helped.

A. Yes.

Q. Including his relationship with his children.

A. Yes. I mean, he always had a good relationship with his children. He still had access, he still saw them, he -- even when he moved down south to be with me, we would still go back up north on a regular basis to visit.

Q. Ollie wanted to have treatment for the hepatitis C, and this again is before you met.

A. Yes, yes.

Q. He asked for it at the Haemophilia Centre. What was

their response?

A. I believe that funding was an issue. And that there was no funding available. Because, again, Ollie had done all the research, he found out quite early on that there was a treatment available, so he naturally wanted that treatment.

He was refused treatment, and then he was reading a paper, and he saw about a prisoner who was complaining about the treatment he was being given and he was really, really angry about this. He went to the press to try and say, "Look, here I am, I've been infected by blood transfusions, in effect, I can't get treatment and there's a prisoner here, no idea how he's been infected, but he's been offered treatment, this isn't right."

Q. He then did start treatment in 2001, but that didn't clear the virus.

A. No.

Q. He then started pegylated interferon and Ribavirin in 2003, but had to stop quite quickly.

A. Yes.

Q. Why was that?

A. He was told that the pegylated interferon would not have the side-effects that the normal interferon had had.

He told me on the second course of treatment, which was also up in Newcastle -- I think after the first treatment he was violently ill, and just thought, "I'm not going through that again". Because on his first course of treatment they started off treating him for six months. At the end of six months, he hadn't cleared the virus. They don't -- I don't think they understood that much about the treatment at the time, and they suggested another six months, so he did a full year of treatment the first time, and still did not clear the virus.

So when he was so ill after the first dose, on this second course of treatment he just said no.

Q. His care then transferred to Basingstoke when he moved to live with you.

A. Yes.

Q. He was given pegylated interferon in 2005.

A. Yes.

Q. What happened when he had that treatment?

A. He was okay for a while. I mean, understanding that Ollie was a very private person, and when he wasn't feeling well, he was never one to complain. So a lot of the time I never really understood how bad he was feeling.

We had a holiday booked and we went on holiday.

He wasn't very well, and he was struggling with his breathing whilst he was on it. He had an appointment when he got back and we went to see the gastroenterologist in Basingstoke. She was very, very good, and she immediately decided to stop -- she listened to his lungs and she could hear crackling in his lungs, immediately decided to stop treatment, did all sorts of scans, and came back saying he had drug-induced pulmonary fibrosis. So she was saying that the interferon had caused a problem in his lungs.

Q. And what was Ollie's health like after he stopped the treatment?

A. Ollie was okay for a while. I think that although -- the short time he was on that treatment, it had reduced his viral load by a certain amount, so he felt okay for a little while. We always had lots of doctors' appointments and scans and God knows what else with checking everything. But generally for a while he was in good health.

Q. You've said in your statement he needed to nap at times because he still had quite a bit of fatigue.

A. Yes, he would get tired, but I suppose I just took that as that was life with Ollie, really. That was just part of it.

Q. In 2007, Ollie was diagnosed with bowel cancer.

A. Yes.

Q. You're unsure whether that was connected to the hepatitis.

A. Yes, it's an odd thing. A lot of Ollie's research was saying that the hepatitis C virus can affect more than just the liver. I mean, we've already talked about brain fog. And I know, talking again with other people in the haemophilia community, we found a number of people who have had cancers in other parts of their body. We don't know if it's linked, and I think that's one of the things we're finding out, is that the medical professionals really don't know that much about this virus. They're still finding out things.

Q. He had an operation.

A. Yes.

Q. And was ultimately given the all clear from the bowel cancer.

A. Yes.

Q. But he still had difficulties with the pulmonary fibrosis?

A. Yes.

Q. And was having very regular scans of his lungs.

A. Yes, yes.

Q. Then in July 2012 you went on a cruise together.

A. Yes, we did.

Q. Can you tell us what happened when you returned?

A. Well, it sort of started while we were on holiday. There was a cold going around and I caught the cold, as you do. So Ollie started coughing and we naturally just thought he had caught my cold.

However, it never really developed into anything and when he -- when we came home I said, "Do you know, you've had that cough quite a while now, I think maybe you should go and see the doctor". So he went to the doctor, and, as with all these things, the doctor gave him a course of antibiotics. A week later he had taken the tablets, no change at all, he was still coughing, so he went back, they gave him a course of steroid tablets. Again, a week later, no improvement, so he went back to see the doctor. The doctor then decided to refer him back to the hospital, back to the lung people, that he had already --

Q. The respiratory team?

A. The respiratory people, yes, the people he had already seen anyway because of the pulmonary fibrosis.

So he had an appointment and he went over there, he saw them, and they decided to have a look inside. So they did a bronchoscopy, and I think that was on the Monday. By the end of that week he started to feel very, very unwell. So I think it was the

Thursday he went to see his GP, and the GP listened to his lungs and said, "I think you've got fluid around your lungs, we'll need to refer that to the hospital, come back in the morning and if there's no improvement I'll send you over to the hospital."

So we went back the following morning, I went with him, and he sent him over to the hospital. When we got there, we did see the respiratory specialist who had done the bronchoscopy. He said, "I haven't got the results back yet, but I know what I saw."

So without any confirmation he told us that Ollie did have lung cancer, he had fluid around his lungs and they needed to draw the fluid off.

So he stayed in hospital on that Friday night. They gave him factor cover and drew off the fluid from his lungs and they discharged him on the Saturday morning.

I got him home. I don't know how we got up the stairs that night because he was still struggling with his breathing. And on the Sunday he came downstairs and he literally just sat on the sofa and he said, "You're going to have to take me back to the hospital, I can't breathe."

So I took him back. This time we didn't have the referral from the GP so we had to go through A&E

and all that. They admitted him back into hospital. They attempted to treat him and to stabilise him. I think it was on the Sunday when I phoned Rob and his daughters and said, "Look, he's very not very well at all, I don't know what's going on, I'm worried."

Rob came down on the Monday and his daughters just made it on the Tuesday, the Tuesday that his results were finally due in, and he actually died on that day. So it was all very, very fast in the end.

Q. He died on 28 August 2012.

A. Yes.

Q. Aged 63.

A. Yes.

Q. You've said you miss him terribly.

A. I do. I do. We lived -- we did everything together. We travelled, we had a caravan, we had a really happy life. We just liked getting away and doing things. And I realised it was the first time I'd ever been on my own, and it was hard. It was very hard.

Q. Your understanding was that the hepatitis C could cause pulmonary fibrosis or that the interferon could induce it.

A. Yes.

Q. So you asked for hepatitis C to be put on Ollie's death certificate.

A. Yes, I did.

Q. You also wanted a post-mortem to be carried out.

A. I did. Ollie, as I said earlier, was convinced that the hepatitis C virus was causing damage to other parts of the body. That -- and he was concerned that particularly all the support mechanisms were all geared up around liver cancer. He'd got pulmonary fibrosis, he was entitled to nothing -- well, he had his stage 1 payment, which was a one-off payment at the time during Ollie's lifetime. He was convinced that this virus affected more than just the liver, it was affecting his lungs. If it -- he looked on the -- was it the Lung Foundation Trust that actually said that the hepatitis C virus can cause pulmonary fibrosis? And then he's going: so was it the interferon or was it the virus? We don't know, but obviously he'd got two risk factors in there, so -- both of which were linked.

Q. And that was why you wanted the post-mortem.

A. Yes.

Q. To try and understand a little bit more of what had happened.

A. Yes, I wanted -- Ollie would've wanted to have helped the rest of the community out there because there are other people getting similar symptoms, and the one

thing he would've wanted was to pass things on to other people.

Q. What was the doctor's response to your request?

A. Initially he was kind of okay with it and said he would organise it, but actually he didn't. So -- I mean, it was a bank holiday weekend and things were left, and then they said there would actually be too much deterioration to find anything. Dr Brooks, who was the gastroenterologist, did do some liver cores, and even in the results that came back it did say that there was a certain amount of deterioration in those liver cores.

Q. But you felt that the earlier doctor, the first doctor --

A. He failed to actually do what he said he would do.

Q. You said in your statement that there was a suggestion that the reason you'd asked for the post-mortem was so that you would be eligible for further Skipton Fund --

A. Yes. No, it wasn't, it was more about: would this information be useful to other people who were going through things now?

Q. But you've said in your statement that you felt that that was the suggestion from the doctors.

A. It was, yes.

Q. That the reason you wanted it was for money, when actually you were saying it was about the information.

A. Yes.

Q. In fact, if we look at the financial assistance, when Ollie had applied to the Caxton Foundation for some things when you were together, you had been unhappy that Ollie had to provide them with your income.

A. Yes. He was very unhappy about that as well. He didn't -- we were a couple, but as a man he didn't want to be dependent upon my income. He had always had good jobs and held down good jobs. Why should he now be dependent upon me when this wasn't his fault?

Q. And you had been very independent people with independent careers and independent finances.

A. Yes.

Q. Ollie also disliked applying to Caxton because he felt it was a begging bowl.

A. Absolutely, yes, I think anybody would agree with that.

Q. As you said, he received the Skipton stage 1, felt that was really very little to receive.

A. Yes.

Q. You received a funeral grant when Ollie died.

A. Yes.

Q. And the winter fuel allowance was transferred to you.

A. Yes.

Q. But other than that, you've not received or applied for anything from Skipton or Caxton.

A. No, definitely nothing -- I did have the 10,000 that was announced fairly recently as a widow's pension, widow's grant, or whatever it was, I can't remember.

Q. But you haven't applied for anything else.

A. No.

Q. So the suggestion from the doctors that you were trying to have more financial assistance particularly grated.

A. Yes, I'm not entitled to anything else because of my personal income, so I've had nothing for Ollie, really.

Q. One of Ollie's particular concerns when he was campaigning was the system of grants and ex gratia payments.

A. Yes.

Q. I think you wanted to say a little bit more about his and your concerns about it.

A. Yes, basically it's all about making ex gratia payments. If wrong has been done, then people should be properly compensated, not ex gratia payments. Ollie felt very strongly about that.

Not this drip, drip, drip, giving people bits and pieces of money. Give people what they deserve to compensate them. If it had been any other kind of medical accident, they would be properly compensated.

Q. Those are the questions I have for you, I'm just going to turn to Mr Lock and Ms Gibbs.

A. Okay.

MS FRASER BUTLIN: They have no further questions they would like me to raise. Is there anything else you would like to say, Carol?

A. No, I think I'm fine.

SIR BRIAN LANGSTAFF: There is one question which I would like to ask you just for the record, really.

A. Yes.

SIR BRIAN LANGSTAFF: You were married in 2011.

A. Yes.

SIR BRIAN LANGSTAFF: You plainly knew him for quite some time before that.

A. Yes.

SIR BRIAN LANGSTAFF: About how long?

A. We met in 2003.

SIR BRIAN LANGSTAFF: So it was nine years before he died.

A. Yes. He moved down and moved in with me in 2004. So we were living together for a long period before we were actually married.

SIR BRIAN LANGSTAFF: Did you know him at all before 2003?

A. No, no.

SIR BRIAN LANGSTAFF: Let me turn to other matters then.

It's not easy, is it, giving evidence there?

A. No, no, it's not.

SIR BRIAN LANGSTAFF: You found it okay?

A. I'm okay. It's not easy. I have to do this for Ollie.

SIR BRIAN LANGSTAFF: I wondered if that was the case.

A. Yes, I feel I have to do this for him.

SIR BRIAN LANGSTAFF: Because you've done him proud --

A. Thank you.

SIR BRIAN LANGSTAFF: -- if I may say so.

A. Thank you.

SIR BRIAN LANGSTAFF: Obviously bits of it are very raw.

A. Yes.

SIR BRIAN LANGSTAFF: But well done. Thank you very much.

A. Thank you.

SIR BRIAN LANGSTAFF: Well, we'll take lunch now, and we will come back at 1.25.

(12.20 pm)

(Luncheon adjournment)

(1.25 pm)

SIR BRIAN LANGSTAFF: Now, our next witness is anonymous, and in her case there will be no live-streaming of either sort, obviously visually but also not orally from this room.

In her case I make the following order.

The name and address of witness W0047, the name of her late husband, 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 W0047 must be referred to only as "Mrs AT".

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

With that protection, may we please have Mrs AT.

MRS AT (sworn)

Questioned by MS RICHARDS

MS RICHARDS: Mrs AT, you are here to tell us about your late husband. To make it easier for you to give your evidence, we are going to call him by his first name, *[redacted]*, but that is covered by the restriction order, and so those in the room will hear it, but it's not to be broadcast by anybody beyond that.

A. Thank you.

Q. He was born in 1935 and he had severe haemophilia A.

We're going to look at a few photos of him.

Henry, could we have 0047020, first of all.

We can see him there. When was that photo taken, do you think?

A. I think it was probably sometime in his thirties.

Q. And then we're going to have 0047019, please. There must be a story to this one.

A. We had just moved to Cardiff and the -- he was under Professor Bloom and they had a haemophilia unit, so for the first time in his life he met several haemophiliacs and he was -- I don't know if the treatment started then, the better treatment, but he was able to learn to swim and to take up archery, which he was not able to do before that.

Q. Then if we have 0047018, please.

A. This was probably in his late thirties, early forties. He had crutches since a young child, always walked with crutches, except when -- the archery he could walk a few yards back and forth to pick up the arrows. He had a great interest in natural history and we were living *[redacted]*, and so he was collecting insects and looking at wildflowers. But he was able to get around on his crutches really well.

Q. Then 0047017, please.

A. We're up in the Brecon Beacons and he could get around, and we even went there in the snow, but as I say, he's got his crutches, and he was pretty fit for a haemophiliac.

Q. And then 0047016.

A. Oh, we had just moved house. We did need a downstairs toilet, because he'd -- I think he probably had a hip operation by then. The house was fairly modern, so the garden wasn't done, so he was very keen on gardening. His father, after he retired, had set up a little local nursery, so he knew a lot about plants and was really interested and was very good, you know, at planting.

He still had his crutches.

Q. Then 0047015, please.

A. And that's probably only a couple of years before he died, in his seventies. We used to go down on holiday to a farmhouse in Dorset, because I grew up -- well, we both grew up in Dorset. He could get out and about but he had a lot of problems, health problems, getting worse.

Q. Okay. Thank you. We'll leave that up for the moment, that photograph, and then when we go through the documents, Henry, we will take it down and then go back to it at the end.

Because of his severe haemophilia and the era in which he was growing up, he spent a lot of time in hospital and had very little formal education, but he was an avid reader who educated himself; is that right?

A. Yes. I think -- he never went to school, but his mother had a friend down the road, and she would come a couple of days a week and taught him to read and write, and then he didn't do O levels and A levels until his late teens and later than most people. And he did very well. He won prizes, actually.

Q. And in due course he undertook teacher training and he gained a degree in philosophy.

A. Yes.

Q. You've told us a little about what he was like. Can you tell us a little more about him?

A. What, his personality?

Q. Yes.

A. Very determined. Talking to everyone. Always -- and so lots of friends of all ages and a good sense of humour. And so many interests: music and history and books and literature and all that.

Q. And you've shown us a diary that he kept in the 1980s with exquisite handwriting, but also which shows his very many wide interests and love of life.

A. Yes, yes.

Q. And although, as you've described, he needed the crutches for much of his life, he didn't let that hold him back in any real respect.

A. No, not at all. When he became a teacher and taught his first job in a very difficult comprehensive school, and he could see some of the boys, I think in the reflection in the window, gesticulating with a knife one of them had, and so he turned around and I think he said thumped his crutches on the desk and said, "These crutches aren't used just to help me to walk". He said he saw the other children all laughing and then he didn't have any problems.

Q. Now, the two of you met in 1962. You were a student nurse at the time.

A. Yes.

Q. And you married in 1963.

A. Yes.

Q. And you had your two children.

A. Yes.

Q. In 1966 you moved to Cardiff, and that's when *[redacted]* came under the care of Professor Bloom.

A. Yes.

Q. Your statement explains that in the early 1970s

Professor Bloom suggested to *[redacted]* that he should start some form of support group, independent support group for haemophiliacs, which he did.

A. Yes, by then they had -- when we first went to Cardiff there was just the Cardiff Royal Infirmary, and then they had a new hospital built -- I think it was 1971, the Heath Hospital, UHW, it was called, and Professor Bloom had a little unit then, separate unit for haemophiliacs, there was a nurse and a doctor, so then he would go to see them.

Q. We're going to look at a handful of documents from his medical records. Henry, could we have first of all 0047010.

We can see this is dated 1969. It's a letter from Dr Bloom to probably a GP, and it refers to cryoprecipitate being given to your husband, and then it says:

"This centre is taking part in a survey arranged by the MRC cryoprecipitate working party in order to discover whether transfusion jaundice occurs in patients suffering from haemophilia or Christmas disease who have been treated with blood, plasma or plasma concentrates."

Then it asks the GP to complete a form, and there's a handful of these from 1969 onwards in your

husband's medical records.

Do you know whether your husband knew that he was part of this survey?

A. I don't remember him mentioning any surveys then. I think -- I suppose he would've probably told me because he did mention other surveys later, but not that one.

Q. Now, up until about 1975, *[redacted]* was treated with cryoprecipitate largely whilst he was at Cardiff.

A. **(Nodded assent)**

Q. And we have a transcript of an interview that he gave as part of the haemophilia and HIV life history project, and I'm just going to read a passage of an answer he gave when asked about the difference that was made to his life by starting cryoprecipitate.

A. Right.

Q. He said this:

"It was different because you didn't have to have it -- you didn't have to always go into hospital. You had to go into hospital to have it but you didn't have to become an inpatient. You could go in, have it, wait around and as long as the haemorrhage wasn't too bad, and most of the haemophiliacs know a haemorrhage is coming on very early, being a specialist haemophilia unit here, it was soon

doctors were made certain by Prof Bloom that if a serious haemophiliac came and said he had a haemorrhage, even if they couldn't see it, they were to give treatment. So it made a great deal of difference. You stopped having very serious bleeds. 1966 was really the very last severe bleed I had again really. I've never really had life-threatening bleeds like that."

So whilst he was on cryoprecipitate in the 1960s through to 1975, he no longer suffered serious life-threatening bleeds.

A. No.

Q. You lived quite close to the hospital, so it was --

A. Yes.

Q. It was not inconvenient for him to go in and receive cryoprecipitate when he required it.

A. It was -- he could have done, yes.

Q. But in 1975, he started on Factor VIII concentrate, cryobulin to start with, and we'll look at 0047002, please, Henry.

We can see this is a letter from Dr Bloom, again to the GP, dated 10 February 1975, and it says this:

"This patient who suffers from haemophilia has been selected for home treatment. His wife has been instructed in the method of making up Factor VIII concentrate for injection from a freeze-dried preparation and has become proficient in the technique of intravenous injection of this material. We shall be supplying directly enough concentrate together with sterile syringes, needles, swabs, et cetera, to prepare two separate doses to be given when necessary. For minor bleeding episodes, such as non-weight-bearing joints, home treatment should present no difficulty, with a major saving in travelling and waiting time. For more major bleeds, the patient has been instructed to administer a full dose at home to cover the journey to hospital."

Then it says this:

"The risks from the use of this preparation, especially allergic reactions and hepatitis, have been explained."

Then it goes on to say a little about allergic reactions, and then says this:

"A small percentage of these freeze-dried preparations contain unavoidably the virus of serum hepatitis, and are therefore potentially dangerous to the patient, his relatives, et cetera. Arrangements have been made for the disposal of syringes, needles and ampules at this hospital."

Do you know whether the risks of Factor VIII, at

least in terms of the transmission of serum hepatitis, were explained to *[redacted]*?

A. I honestly don't remember, but I do remember that when we had the home treatment we were given gloves and aprons and we could take the used treatment back to the hospital in a yellow plastic container. So we were I suppose aware. I don't know whether it was -- whether it was just that it was blood, but I can't honestly say I can remember specifically -- I don't remember being told. They might have done.

Q. Do you know if *[redacted]* was ever told that there could be the risks of a serious, life-threatening infection from the use of Factor VIII concentrates?

A. No, I don't remember -- I don't remember him saying anything about that, no.

Q. Do you think if *[redacted]* had been told that, that's information he would've shared with you?

A. I think so, because he did you know -- I can't remember exactly what year it was, but I would be giving him his treatment at home and he said to me suddenly, "You realise this comes from criminals and drugs addicts in America?" And I was horrified. I thought it had always come from the British, you know, transfusion service, and I said, "Oh, that's awful". I said, "Go back to the hospital and ask them

if you can go back on the cryoprecipitate you were on before."

And he -- I think actually it was *[redacted]* by then, so it must have been quite late, and -- or perhaps Professor Bloom was away, I don't know, but he -- so he did go to the hospital and I said, "What did the doctor say?" And he just said -- I think *[redacted]* said that he said it was messy or something, then we had a little chat and we -- I think there was the thinking then that perhaps it costs too much or they wanted more of it, and maybe it was, you know, the money, but that was just a general chat. And that's all I heard. It was just: "No, you can't".

Q. As I understand it, although for *[redacted]* the Factor VIII home treatment was convenient because it could be given at home --

A. Yes.

Q. -- having cryoprecipitate had not been particularly problematic for him because you lived close to the hospital and he'd managed to carry on working as a teacher throughout the time that he received cryoprecipitate.

A. Yes, yes.

Q. In 1976, he fractured his hip and had to have surgery.

A. Yes.

Q. It was during a routine blood test during that hospital admission that it was showed that he had contracted hepatitis B.

A. Yes.

Q. We'll just look at that in a document, please. 0047003, Henry.

We can see it's a letter dated 21 January 1976, Bloom to the GP:

"This is just a note to let you know that the last blood test on [your husband] showed that he was positive for hepatitis associated antigen. Presumably he has picked this up from the Factor VIII concentrates from which he is treated and we are keeping an eye on his liver function."

Now, as I understand it, the hepatitis B did not in fact cause your husband to have any particular symptoms or problems.

A. No.

Q. In the early 1980s, he picked up from media reports information about what is now known as AIDS.

A. Mm-hm.

Q. And we can see that your husband raised that himself with his doctors.

A. Mm-hm.

Q. If we have 0047011, please.

This is a note from 27 January 1983, and we can see it says in the last two lines of that first entry:

"Worried about AIDS. Has been reading New Scientist avidly."

We know that from early February there was a report in the New Scientist about this condition and the connection with haemophiliacs, and your husband had read that.

A. Mm-hm.

Q. And then we see a letter at --

SIR BRIAN LANGSTAFF: Could I just make clear what you've just said? You said the article was published in February, I think it was February 3.

MS RICHARDS: 3 February is the date of the journal, which may have come out earlier than 3 February, we don't know the precise date.

SIR BRIAN LANGSTAFF: That's the hypothesis?

MS RICHARDS: That's the hypothesis, sir.

SIR BRIAN LANGSTAFF: Thank you.

MS RICHARDS: We can see at 0047004, a letter written on 28 January, following a clinic on 27 January 1983, a Dr Liddell, a registrar to the GP. It talks about your husband having been reviewed in Professor Bloom's clinic, and it says this:

"He has no new problems relating to his

haemophilia, although of course he remains a carrier for hepatitis B virus. Being a well-read man, he is somewhat concerned about the possibility of acquiring the acquired immunodeficiency syndrome, although of course there is no grounds for suspecting the diagnosis in him. I have taken off blood for the usual tests and we will see him again in six months' time."

So we can see that your husband raised this issue expressly with Professor Bloom or Professor Bloom's staff in early 1983.

A. Yes.

SIR BRIAN LANGSTAFF: And that they appear to have credited it as a reasonable possibility.

MS RICHARDS: Yes.

SIR BRIAN LANGSTAFF: So a real risk.

MS RICHARDS: Yes.

Now, at some point in 1983 or 1984 -- the precise date I think is not entirely clear, but that's not a problem -- your statement suggests that your husband was told by Professor Bloom, first in a private meeting and then in a group meeting, that he had what is now referred to as HIV.

A. Yes.

Q. *[Redacted]* talked about this too in the interview he

gave for the life history project. We have some of what he said as an exhibit to your statement. Henry, can we have 0047007, page 5.

I am actually just going to read out something that is a little earlier than that page. We don't have it exhibited but we do have the full transcript, and we can see from *[redacted]*'s own words how he recalls learning about HIV.

He says this:

"The first I knew of it was in the early 1980s, though looking back a little bit, about a year before that Professor Bloom had said to me when I was talking to him, because we used to talk sometimes, because he knew I knew a little bit about such things, he said he'd found that some haemophiliacs had a problem developing with their immune systems, and I didn't really take much notice of that because, you know, people take -- because anybody who has had lots and lots of treatments and all the various cryoprecipitates and things [then we pick up the page that's on the screen] would be liable to have immune problems, so I didn't take that on board too much. But then, about a year later, I saw in the New Scientist, which I took regularly, a report about gays having a disease, a strange disease which affected

their immune system that was causing great problems and some of them had died, and they reported that a haemophiliac had also died and they thought it was a related condition."

And then your husband said this:

"So I looked at this, with haemophilia, obviously, I took note of it more than I would've done otherwise, and I phoned up Professor Bloom and I said, 'What's this I hear about people in America getting an immune disorder and a haemophiliac dying with it?' And he said, 'How do you know?' And I told him. And so he said, well, all he could say is that he knew about it, he was aware of it, as he would be, but he didn't know any more, and there was no idea why it was or what was causing it. And that was it then.

"And perhaps, you know, a year, a year went by, and there was one occasion when they decided to put us all on British treatment. I'd been using American treatment up to that time because the British treatment never really suited me. I never really got used to it for various reasons. And so I'd always been on American, and I think quite a few people had been. And suddenly they decided to change everybody to British treatment. Then shortly after that -- I was never told, I think several people will say this that they weren't told, taken in and said, 'Well, I'm afraid you've probably got this', whatever it is, HIV, but they didn't call it HIV then, this immune disorder, but suddenly we were put on this British treatment.

And then a bit later on, Professor Bloom had a meeting -- called a meeting in the bowels of the hospital, a very strange place. It was a very odd situation inasmuch as it was sort of secretive, and this is, I suppose -- is one of the things which you noted very much in the early stages of HIV coming to light. It was some hole in the corner. And we had this meeting and there was a -- there was myself and ..."

Then we don't have -- that's a different page, Henry, so don't worry about that.

[Redacted] continues:

"There was myself and about *[redacted]*, all of whom I know, most of them younger than me, and Professor Bloom said, 'Well, there was this problem which we were aware of', and he didn't -- he couldn't say what was going to happen, but he thought it might be a good idea if we tried to form a help group and would we like to discuss that amongst ourselves."

So that was your husband describing a first,

smaller meeting with Professor Bloom.

Then he continues later on in the transcript -- we don't have it on the screen -- he says this:

"Then we had -- we held a big meeting. A big meeting was held in the hospital with Prof Bloom. And I remember that and he said to everybody -- everybody came along to that and he -- not only people with HIV but everybody in the Haemophilia Society, I think, and he said there was this problem but nobody knew what it was. It was suspected it was possibly a virus, which was pretty obvious, it was something like that, although it might be a protein, they didn't know, you see, and that it was likely that some people would become affected with it. But they didn't think at that time there was necessarily any danger to partners because they thought it was almost certainly infecting from blood products. So really I think people asked about it, but they -- it was really rather made light of at that time."

A. Mm.

Q. Now, you remember that second, bigger meeting.

A. Yes.

Q. You went to it.

A. Yes, I did.

Q. What can you tell us about that from your memory?

A. It was a meeting and people came from Bristol and Swansea, not just Cardiff, and haemophiliacs and their wives, and he told us what he knew, but he said -- he said, "Oh, you know, the ladies don't need to worry", and at the end of the meeting the haemophiliacs were sort of -- they were saying, oh, well, they'd come over the Severn Bridge and they could've been killed on a road accident, they weren't going to worry about it, but I think they probably did. And I think when -- you know, when any -- well, for myself, when anybody in authority tells me not to worry about something, that's when I start worrying.

But -- so that -- that was it, we just, you know, went back that -- and I -- well, that's what I remember.

Q. And you've said in your statement that there was really very little information provided. Whether or not the doctors knew any more, you didn't know, but very little was provided to those of you at the meeting.

A. Yes. That's all he said, really, that there was this problem with it, and probably you were infected with it, but they didn't really know anything else.

Q. Now, there are various references in your husband's medical records -- I won't take the trouble to put

them up on screen, but we've seen various references in your husband's records later on to him having been HIV positive since July 1984. But your solicitors have been through all of his records, which are fairly extensive, and there's no test from that date in his records, and no reference to any notes of a meeting in which your husband was given his diagnosis, and you I think can't remember the precise date in any event.

A. No, all I can remember -- it must have been around about that time, 1984/1985, and I think because *[redacted]* was often going back and forth to the hospital so -- and -- Professor Bloom mentioned this at some point talking about the AIDS, and he said to *[redacted]* -- they had samples back into the 1970s, I think, they must have kept several samples, and he said that -- so they thought -- I think *[redacted]* was told by Professor Bloom that he probably had been infected long before 1984.

Q. You've described in your statement the mental effects on you and on *[redacted]* of being informed of this diagnosis as very traumatic.

A. Yes, because nobody knew what was happening. I mean, probably at first and even at the first meeting the haemophiliacs were maybe thinking, well, it's all happening in America. America seemed a long way away.

But as, you know, the newspaper reports were coming, more and more people were dying, and the -- you know, the stories were pretty horrible. And there was a stigma against the homosexuals anyway, and so we all felt a little bit as though we had a sort of plague in the house, which seems sort of strange now, but it was like that, because we knew also by then, probably by the late 1980s, we'd been to various meetings with the Haemophilia Society, we'd heard of a couple who lived up in the valleys and their son had AIDS and somehow the locals got to know about it and outside -- their house was scrawled with the words "AIDS" all over it, and they had very upsetting remarks and so they had to move house.

So we didn't want -- especially as it was -- *[redacted]* was teaching, we thought, you know, he'd lose his job, which would've been, you know, a disaster.

Q. One of the things that he worried about was the possibility that you might become infected and that the children might be orphaned.

A. Yes, yes.

Q. The physical effects of the HIV infection got progressively worse over the years.

A. Yes.

Q. Your statement says he caught coughs which would last for years and developed difficulties in swallowing.

A. Yes, mm.

Q. He developed a fluid-filled lump on his neck, lipodystrophy.

A. Yes, he couldn't wear a tie or do up his shirt, and there was a big sort of lump and he'd often ask myself or my son to massage his neck because there was a bit of pain with it as well.

Q. In the 1990s he was started on AZT treatment.

A. Yes.

Q. You've described in your statement how he had to set his alarm for two o'clock in the morning to wake up to take the drugs.

A. Yes, he had to have them several times, and in the night he had to have food as well, and I think the side effect wasn't nice. He used to feel bloated and sick, but he was still working then so he had to keep on working.

Q. In 1996, his treatment regime for HIV was changed to a triple therapy with significant side-effects for him.

A. Yes.

Q. Rashes, itchiness and the start of some very painful throat problems.

A. Yes.

Q. And he had recurrent tonsillar pain and was diagnosed in due course with an HIV related retrotonsillar abscess.

A. Yes, it was very strange because the pain he'd get in his throat would suddenly -- he'd suddenly grab his throat and really, really painful, lasts for a few minutes and then it would sort of go, but that happened often. We had to have several visits to the hospital and he was seen by the ENT people, and they said they couldn't find anything, but eventually they did say there was an abscess.

Q. Then he learnt -- it's not quite clear when, I think, the records suggest a test in December 1990 -- he learnt that he had hepatitis C as well.

A. Yes. Yes, he told me and said he had hepatitis C, but he didn't have any symptoms. Although when I was reading his diary, which I'd only read recently because I never used to read his diaries, it mentions that he was getting very tired, which he doesn't, you know, many places, so I don't know whether that was the hepatitis -- the effect of the hepatitis C or not. But, you know, otherwise he was okay.

Q. If we have up on screen, please, 0047006.

We can see this is a letter from 2004 from

Dr Dasani to your husband's GP. It refers to having seen your husband in the routine review clinic, and then it says this at the end of the first paragraph:

"He is hepatitis C antibody positive but PCR negative."

So by this time that was his hepatitis C status.

Then it says this:

"I have discussed the implications of ex gratia payment announced by the government last week for hepatitis C with him today. I have informed him that in view of his PCR negative status without treatment he does not qualify for the ex gratia payment."

Also around this time, your husband was notified of the public health risks of vCJD and the possibility of having been exposed to vCJD. We can see a letter that he wrote. Henry, it is 0047014, please. It's a letter written by him on 10 February 2004, and it says this in the first three paragraphs:

"Regarding the proposed ex gratia payments for hepatitis C, I am aware that I fall into that tiny category of people infected by hepatitis C but asymptomatic. I have heard that there have been some doubts as to our status regarding this payment, so I rang the MFT office and spoke to the new chief executive, Mr Martin Harvey. He said that the new Skipton Fund, through the Macfarlane Trust, would be issuing guidelines which would take a very broad remit with regards to payments and would include all those who have been infected by the virus. I have certainly been infected by the virus and, like anyone infected, have suffered the initial trauma and worry of knowing that they have been infected. This deserves some recompense, it seems to me. The fact of current dormancy I know is no guarantee of future development of symptoms. *[redacted]* was asymptomatic for eight years before developing any symptoms.

"I am also aware that the situation is getting worse re new variant CJD. I have heard that upwards of 16 blood donors whose donations were used in the manufacture of haemophilia factors have since developed new variant CJD. Who received this treatment and when I presume is still being investigated. I was told initially that I did not receive any CJD infected blood, but is this still true?

"The Pandora's box of viruses and other agents seems to go on and on. Will it ever end? Professor Bloom once remarked to me, long before AIDS or hep C came on the scene, that using human blood derivatives as treatment for coagulation disorders was 'a double-edged sword'. How tragically prophetic those words turned out to be."

Those were your husband's observations on the facts of his infection with hepatitis C.

A. Yes.

Q. And the concern about vCJD and who knows what other viruses, to paraphrase.

A. Yes.

Q. We can see if we look, please, Henry, at 0047013, one practical consequence of the potential risk of vCJD. This is a letter from the Welsh Institute of Dermatology, 30 August 2007, and it says this -- it's written to the consultant haematologist:

"Thank you for writing concerning [that's your husband] who had a shave excision of a lesion on his left temple which was shown to be a basal cell carcinoma. I remember that we proposed to remove the lesion fully, but became somewhat delayed over the issue of surgical instruments. In particular, it was my impression that we were obliged to use disposable instruments in view of his HIV status, and thereafter we spent some time trying to find suitable instruments, at which point I think he was lost to follow up. I wonder if you are aware from your perspective whether special arrangements need to be made for surgical instruments."

Now, that's a references to HIV status, but we've seen in other records that the issue of instruments arises most acutely in relation to vCJD.

A. Yes.

Q. Whichever it was, there was a delay to a procedure that your husband was supposed to be having because of the fear of a public health risk.

A. Yes.

Q. You've already alluded to the fact that you and he didn't really tell people about the HIV infection because of the stigma.

A. Mm-hm.

Q. I think on one occasion you were asked by a relative, by your sister, and you effectively said, "No" when she posed the question and said he'd only ever had British treatment.

A. Yes.

Q. You told the children when they were older.

A. Yes.

Q. And again that delay was very much because you were acutely conscious of the stigma associated with the condition.

A. And *[redacted]* seemed to be, you know, managing.

Q. Now, he had to retire early from teaching at the age of 57 because of his health.

A. Mm.

Q. And with a much reduced pension as a result.

A. Yes.

Q. I think you had also qualified as a teacher and you were working as a supply teacher but full-time.

A. Well, some of the time full-time, but a lot of the time just part-time, yes.

Q. You say in your statement you had to give that up as he became progressively more unwell.

A. Yes, yes.

Q. But despite your husband's illness and progressive ill-health, your statement says he remained enthusiastic about the many interests he had in life and enthusiastic about his family.

A. Yes.

Q. In your statement, you've described the medical care and treatment which he received as generally very good and supportive.

A. **(Nodded assent)**

Q. What about counselling and psychosocial support? What can you recall about the availability of that, if any?

A. Well, I think when he was diagnosed with HIV, the hospital, they said that they had a social worker, and she used to visit and have a chat. And later, when we were given some money, they would write to the Macfarlane Trust a letter for us, so they liaised with the Macfarlane Trust.

But the -- they were quite -- yes, well, I thought they were quite young, the women, social workers, and I felt it would've been perhaps nicer -- as it was all the men who were becoming ill, I thought it would've been nice if they'd had a man to talk to, a male social worker. But they were very sympathetic and I -- but ... yeah, so we had social workers.

Q. Was that practical support or advice that was offered, or was there any form of counselling or psychological support that you can recall?

A. I -- it was just a chat, really, how are things and -- that's all I can remember, really.

Q. In due course your husband suffered some minor strokes, and then in 2012 a massive stroke from which he never recovered.

A. Yes.

Q. And he died in the autumn of 2012.

A. Yes.

Q. It's your understanding, based on information that's been I think given to you by doctors, that the medication that he received for HIV may have been a contributing factor in that respect.

A. Yes, and we had heard I think in the last year or two that -- there were one or two younger haemophiliacs we knew well, and we'd heard that they'd died suddenly with very similar -- something similar. Well, it sounded to us very similar.

Q. Henry, could we have back up on screen, please, the photograph 015. Thank you.

When *[redacted]* died, you and he had been married almost 50 years.

A. Yes.

Q. How has life been for you and for your family without him?

A. Difficult, because he was -- well, and for his friends because he was such a presence wherever he was. He wasn't someone who was just sitting quietly doing nothing. So that's been hard.

And I miss conversations, because I think I was telling somebody here that he never went to school, but he read widely, and sometimes he would say to me -- mention some historical fact and I'd look blank and he'd say, "Don't you know that?" And I'd say, "No, never heard of it". And he would often say, "Well, I'm glad I never went to school". Because I had had just a conventional -- you know, I went to the local grammar school, but it was a country grammar

school, not the best.

So I miss all that stimulation, that -- and his -- you know, his brain. He didn't suffer from any Alzheimers or anything like that, but -- and he was walking up until the day he died, really, yes.

Q. Your children have lost a much loved father.

A. Yes.

Q. And your grandchildren, a very special grandfather.

A. Oh, yes, he loved -- he did live to see his young grandchildren, and I suppose I thought when my children were, you know, doing their O and A levels, it was in the height of the AIDS thing, and I think looking back I felt that I really wasn't able to give them a lot of support the way other parents -- because I was so concentrating on keeping *[redacted]* well or keeping him going, yes.

Q. Your daughter-in-law has said in her statement -- the phrase "a very special grandparent" is hers, and she says that the grandchildren have been deprived of a very valuable relationship with someone who would've been a wonderful guide, teacher, inspiration and friend.

A. Yes, that's very true, yes. My grandson, who was only about 3 to 4, spent a lot of time with him while I was getting the meals and that, and was very upset when he

died, and -- yes.

Q. What has been the financial effect of *[redacted]*'s illness and having to take early retirement and you having to cut back on your work? What's that been on you?

A. Well, we did have some compensation, and, I mean, it was hard to begin -- you know, when he first got a job, we were saving hard for a house, neither of us really inherited much, houses or anything, and all that. So -- and he -- but he was -- and he said that, he was able to retire early because of ill-health, and so we sort of managed. We had -- we weren't, you know, the sort of people who are always going on exotic holidays. We used to have holidays, but not expensive ones. And so as -- but we did hear that other people who had HIV in other countries had a lot more compensation.

We had probably more than single people because my son was still in full-time education, but when you hear, you know, other people are -- have much more money for rather trivial things. So, yeah, I think -- I suppose we were a bit annoyed. But we still sort of managed to, you know, get on with our lives and do what we wanted to do.

Q. We're going to play a little bit of the interview that your husband gave to the *[redacted]*, so we'll hear his voice, his concluding words in the interview he gave in 2004.

Henry, if we could play that, please.

(Interview played)

MS RICHARDS: Thank you.

Before I ask you whether you've anything to add, I'm just going to ask Mr Williams if there are any further questions he wants me to ask.

A. Okay.

(Pause)

Q. There's nothing further, but I think there's something that you would like to add.

A. I would just like to say that when *[redacted]* was born, at two weeks old he had pneumonia and was given the last rights, not expected to live, and then they discovered he had haemophilia. He came out in bruises and his mother was -- the doctors accused him of beating him, but it was haemophilia.

Then at the age of 7 or 8 he was living in London and was -- during the Blitz, when all the roads were closed, he was going in an ambulance to Great Ormond Street Hospital, where they suffered a direct hit, and he remembers all the children screaming, all the lights going out, and the air raid wardens

arriving, the nurses trying to protect them, there was glass everywhere. And of course living in the war, the bombs -- he lived near the *[redacted]* air drone where the -- so there was a lot of bombing. Despite all that, never went to school but educated himself.

Once he had the cryoprecipitate, for 10 or 15 years his life was good. Got married, children, bought a house, learnt to drive and go on holidays and had a job that he loved doing.

So I personally feel really angry and sad that when the bombshell of HIV came, it was a new sort of thing -- another thing -- problem to deal with.

But being *[redacted]* he was very determined. He carried on with his interests, still walking with his crutches, even though he had to have another hip operation, and then a wheelchair for several months and the doctors said, "You must just use the wheelchair now, don't use the crutches because your knees are so bad, they'll give out any time". Anyway, the physio helped him and she said, "I can probably get the muscles working and get you back on your crutches again". So he was doing this, walking on his crutches, getting out and about, you know, playing with the grandchildren. And, you know, still had friends and new interests, right up until the day he

died.

So to sum up, I'd just like to say that really, like most haemophiliacs, he was tremendously courageous and very inspiring, and an extraordinary man. I think.

MS RICHARDS: Thank you.

Sir Brian.

A. Thank you. Thank you very much for listening.

SIR BRIAN LANGSTAFF: I've been privileged to have seen a copy of the diary which he wrote in what I can only describe as an immaculate italic hand, detailed and showing a picture, as you have said just a moment ago, of an extraordinary man.

A. Yes.

SIR BRIAN LANGSTAFF: With so many interests.

A. Yes.

SIR BRIAN LANGSTAFF: Lovingly described, beautifully written, and showing the man he plainly was.

A. Yes.

SIR BRIAN LANGSTAFF: We've been privileged to listen to your account of him and his interactions with the medical world. A compelling, revealing, generous, but to me, for a number of reasons, a disturbing account.

Can I thank you on behalf of all us for the evidence which you've given.

A. Thank you very much.

SIR BRIAN LANGSTAFF: Well, we'll take a break until 2.40. The next witness is not anonymous, so the live stream will be back on.

(2.20 pm)

(A short break)

(2.40 pm)

SIR BRIAN LANGSTAFF: We are now going to hear from Mike, are we?

MS RICHARDS: Yes, sir.

SIR BRIAN LANGSTAFF: Mike.

MICHAEL O'DRISCOLL (affirmed)

Questioned by MS RICHARDS

MS RICHARDS: Mike, you were diagnosed with severe haemophilia A in 1965 when you were about 6 or 7 years old.

A. That's right.

Q. And you'd had numerous bleeding episodes up until then.

A. Yes.

Q. Your recollection is you were treated with whole plasma and then cryoprecipitate.

A. Yes, I'm pretty certain that was it.

Q. That was mostly at Worcester Royal Infirmary, occasionally the Oxford Haemophilia Centre.

A. Yes. I think it was in Oxford for dental extractions, but my regular bleeding was usually into my knees, and that would just be bed rest, legs strapped up and cryoprecipitate until it settled down.

Q. In 1971, you and your parents moved back to Ireland.

A. That's right.

Q. And you stayed there until June 1979.

A. Yes.

Q. Living in the Cork area.

A. That's right.

Q. Again, you had numerous bleeds throughout that period and, as far as you can recall, you were treated with cryoprecipitate.

A. That's right.

Q. You moved back to London in the middle of 1979.

A. Yes.

Q. And then you came under the care of the Royal Free Hospital.

A. That's right.

Q. Dr Tuddenham, Dr Kernoff and later Dr Lee.

A. That's right.

Q. You stayed with the Royal Free Haemophilia Centre until June of 1987.

A. Yes, it was -- yes, I think it was. It may have been May, I think. May or June.

Q. You were put on home treatment with Factor VIII in late 1981.

A. That's -- yeah, that's right.

Q. And from that point onwards you received Factor VIII products rather than cryoprecipitate.

A. I can't remember for certain whether it was -- you know, once I was Factor VIII whether I ever had cryoprecipitate again, I don't -- can't really recall. But I remember certainly by 1981 it was all Factor VIII because I never had cryoprecipitate at home. So I'm, you know, probably 90 per cent sort of Factor VIII. There may have been cryoprecipitate, I can't -- I can't recall.

Q. Henry, could we have up on screen, please, 2384024.

This is a list of products that you received.

If we go, please, Henry, to the last page.

You can see there, Mike, a list of products from 1981 onwards.

A. Yes.

Q. And we can see in the column headed "Product", "VIII Conc-immu".

A. Yes.

Q. So cryobulin, probably.

If we go to the next page, please.

We can see that you continued to be treated --

sorry, the page before that, my apologies, Henry. The document is in reverse chronological order.

Thank you.

So we can see that throughout 1981, into 1982, that was the product you continued to receive.

A. Yes.

Q. If we then go to the page before that. We can see in --

SIR BRIAN LANGSTAFF: You skipped a page.

MS RICHARDS: We have, yes, if we go to page --

SIR BRIAN LANGSTAFF: 6.

MS RICHARDS: -- 6, please, Henry. Thank you. We can see in 1982, from the bottom of the page going up, you received NHS concentrate, and then the reference to "Factor VIII Conc-Trave", which is probably "Hemofil". Then you continued to receive that through 1983.

If we then go to the previous page, please, Henry.

We can see again receiving that product at the bottom of the page. Then through 1983 you were on NHS Factor VIII until 1984.

If we go to the page before that, so page 4, please. Then we can see, again, you're on NHS Factor VIII through until the end of 1984, and then we see references in 1985 to alpha prophylate, but we

don't go into those for the reasons that will become obvious, I think.

A. Yes.

Q. So we can see you received a range of different Factor VIII products, both NHS and commercial.

A. Yes.

Q. Were you ever given any choice as to which product to have?

A. No, not at all. And to be honest, I never really questioned it. To me it was just Factor VIII and, you know, these were the doctors, these were the experts, so you assumed that they knew what they were doing, and if they were changing you from one product to another, that -- you know, that it would've been medical reasons, I presume. But I never -- I never questioned it. It was just Factor VIII and it was allowing me to live -- you know, to be more independent, as far as I was concerned. I mean, once I was on home treatment, that meant I had to spend less time in hospital. I could treat a bleed quicker.

So, for me, it's -- not knowing what was further down the road, at that time I thought: this has really improved the quality of my life.

Q. Were you ever given any information or advice or warning about any risks of infection associated with

the products?
A. No, no.
Q. You met your wife, Yvonne, in February 1981, and you describe a whirlwind romance and getting married in August 1982.
A. Pretty fast, yes.
Q. You both had good jobs in London.
A. Yes.
Q. And you decided to start a family.
A. We did.
Q. That was in 1984, and by February 1985 Yvonne was pregnant.
A. She was.
Q. You both had plans for a big family.
A. Yes. I came from a good Irish Catholic family, so I was one of nine, Yvonne was one of four, so it was never our intention to have an only child, you know, we planned to have two/three kids. That was the plan and, you know, we had talked about that.
Q. Now, it was in 1985, whilst Yvonne was pregnant, that you received a letter from the Royal Free Haemophilia Centre inviting you to come to a meeting.
A. Mm-hm.
Q. We don't have a copy of that letter. It's not been traceable in your records.

A. No.
Q. But what can you recall about it?
A. I -- to be honest with you, I can't recall anything about the letter because they would just send me a letter saying, "Come for your regular appointment". So I would've gone to that meeting assuming that it was just for a regular monitoring.
Q. You say in your statement it would've been either Dr Kernoff or Tuddenham.
A. Yes. I never knew which one I was going to see in advance. They seemed to have the same level of authority. They were like the co-bosses of the Haemophilia Centre there, so it really didn't make a great deal to difference to me who I saw.
Q. When you got to the hospital for this meeting, the Royal Free's social worker from the Haemophilia Centre Riva Miller was also there.
A. I can't remember if she was there at the first meeting. My memory is either Kernoff or Tuddenham, I can't say for definite which one, and myself in the meeting. I don't think Riva Miller was at the first one, she may have been, but my abiding memory is that it was a very -- as soon as I walked into the meeting, I can recall that the doctor was extremely awkward that he had something to tell me.

I -- by that time sort of stories had already started to appear in the media of possible links with -- between HIV -- or HTLV III, as it was then -- and haemophiliacs, particularly in America. So I had -- I had -- I don't know why, but I had an inkling that it could be to discuss that. I didn't think they were going to tell me that I was positive because I had -- as far as I was aware, I hadn't even been tested.

So I think once I had that inkling, and I could see his awkwardness, I thought maybe he's going to tell me of the risks rather than a diagnosis.
Q. What in fact did he tell you?
A. That I was HIV positive, which came as a shock. You know, having had this awareness that there was a link, you know, you don't automatically assume that you're going to be told that, but you might be told that there was a potential risk and you might have to change your treatment. So it was a shock.

And I think that -- I can't really remember much about the rest of the meeting after that because, you know, it goes into your head, and then you -- they are continuing to talk and you're not really listening because you're almost in a state of shock.

I asked about prognosis. The stories I'd heard

and was familiar with in the media about gay men who had been infected, the prognosis wasn't good. But I asked anyway, thinking it might be different for haemophiliacs, and was told that the prognosis wasn't great, perhaps two to three years.

They -- there was also a comment that, you know, "We don't really know and we don't really know, you know, when you'll start to develop symptoms", but I was told perhaps two to three years.
Q. And you had to leave that meeting, go home --
A. Yes.
Q. -- and tell Yvonne, who was pregnant --
A. Yes.
Q. -- this information.
A. Yes.
Q. What can you recall about that?
A. I would've been travelling on the tube, probably coming home in a state of shock. Not -- you know, not knowing how I was going to tell Yvonne. Given that she was pregnant, given that -- I mean, they didn't tell me -- they didn't tell me then when I'd -- when I'd become positive, I had no idea whether it's something that had happened just recently or had happened two or three years ago, so, you know, we'd been having a normal sexual relationship, so -- and

I knew that certainly in the gay community the virus was transmitted sexually, so there was every chance that I might have infected Yvonne. So I think I was almost panicking.

But, anyway, I got home, and we talked, and Yvonne was as shocked as I was. It was -- it was, you know -- I was 20 -- I was 25, Yvonne was 27. You know, suddenly you've been told that you'd had in effect what was a death sentence. It's not something that you can say or you can just sit down and say, "Okay, well, we've had that chat, let's get on and make dinner now and watch Coronation Street on the telly", you know, it was profound.

But I -- other than, you know, initially telling Yvonne, I can't remember much else about how even for those first couple of weeks, how we coped, because we had a follow-up meeting, which is the one you were referring to with Riva Miller.

Q. We'll come on to that in a moment. We'll look at a couple of documents to try and establish the date during which you seroconverted.

Henry, can we have, please, 2384021.

We can see this is a later letter, 2003, from Christine Lee at the Royal Free. It says this:

"I am enclosing for you a summary of the HIV

antibody test that we have on Mr O'Driscoll. As you can see, we have one negative value on 13 April 1982, and the next value was positive on 8 March 1984. Thus he seroconverted between these dates. We have no further samples and cannot give any further information."

Then could we have, please, Henry, 2384025.

We can see here the list that was attached to that letter. Anti-HIV tests. We see the negative result on 13 April 1982, and then the positive result on 8 March 1984, and then a number of subsequent positive results.

There's no reference there to any testing of any samples in the course of 1983, and you don't know why that is.

A. No. I assume -- like most haemophiliacs, every time you went to the hospital, they took an opportunity to take blood for their various tests for inhibitors, Factor VIII levels.

If -- I mean, I assume that certainly the earlier ones of these were all retrospective testing, but I know from looking at my notes since that they were testing regularly for various hepatitises.

So it seems strange to me because I had a number of bleeds throughout 1983. I mean, I wasn't treating

prophylactically at that time, I do now, but I would treat on demand. So I had a fairly active life, so I used to get regular bleeds, treat myself.

So, you know, I would -- it's not possible that from sort of April 1982 to March 1984, so nearly two years, that I wouldn't have had bleeds and that they wouldn't have taken bloods.

Q. Such records from the Royal Free as have been provided to you don't contain these test results --

A. No.

Q. -- and don't have any record of you being given the diagnosis.

A. No.

Q. You then had the follow-up meeting with Riva Miller at the Royal Free. What can you recall about that? I think you and Yvonne both went to that.

A. Yes, we were invited to go along. They knew Yvonne was pregnant, either I had told them at that meeting or had told them before that. I think it was their sort of policy with any haemophiliacs having children to want to sort of monitor them to see whether the child was male or female, and if it was a male then the child wouldn't be a haemophiliac anyway, but there was a chance that my daughter would be a carrier, so they would've wanted to sort of monitor things like

that. I think that was pretty standard.

So, anyway, they asked could I come back with my wife to meet Riva. I had met Riva Miller a couple of times. She was a social worker attached to the Haemophilia Centre at the Royal Free. I didn't really know what the purpose of the meeting was. I assumed maybe some sort of counselling or psychological and social support telling us perhaps a bit more about what it meant, what treatment options might be available, you know, that's the sort of things I think we were expecting.

But at the meeting -- so we talked about Yvonne being pregnant, and Riva Miller's advice, and strong advice, was that we should terminate the pregnancy straight away. And by this stage Yvonne hadn't even been tested, so we didn't know whether she was HIV positive or not. So we heard that advice, and Yvonne started crying in that meeting when she heard that.

We didn't know how to react. We were stunned. I mean, you know, this was our first step on the road to parenthood, and she was just four months pregnant and this is the advice we were getting. Instead of sympathy and counselling and some kind of understanding, this is what we're told.

You know, we didn't really say much throughout the rest of that meeting. I think we were both so stunned and so upset. But the further advice was, "Have a termination. If you decide not to have a termination, abstain from sexual intercourse for the rest of the pregnancy, and then your future life then will be safe sex for the rest of your life", and that was it.

So we went away. So Yvonne was told -- was offered a test. I don't know if she was tested that day or, you know, a couple of days later, but she was tested and then we had the period of waiting. I think it was about two weeks then before the result came through. So that was horrible.

We're trying to -- we were both working, going to work every day. We both worked in the City of London. My wife worked for a merchant bank. I was working for a recruitment consultancy. And you had to just pretend that nothing had changed in your life.

I didn't tell my friends and colleagues that I was a haemophiliac. When I was growing up I -- my parents, teachers, doctors, made decisions for me about my life and about what I could and couldn't do, and I was always resistant to that, so when I became an adult I made decisions for myself and I made the

decision that I wasn't going to tell anyone about my haemophilia because I didn't want to be defined by it.

So we're in the workplace, and suddenly, you know, I'm carrying this, that I've got HIV. My wife knows this as well, and we're sitting amongst fellow professionals, listening to banter about AIDS and gay people and people, you know, just making jokes about it, and, you know, you've got this kind of toxic sense of guilt and shame and anger, and you just have to bite your lip.

So we had that for two weeks, and then we go back to the hospital to get Yvonne's result, and thankfully she was negative, and once we knew that she was negative we made the decision: right, well, we're going to carry on with the pregnancy. If she's negative, there's no risk as far as we could see to the baby, so we decided to proceed against Riva Miller's advice.

Q. Your daughter was born late 1985. You describe it in your statement as, though it was a very happy moment, it was tinged by sadness, because you didn't think you'd live to see her grow up.

A. That's right. This was supposed to be the highlight of our lives thus far, the birth of your first child. You know, in June or July, whenever it was that I was

told, I didn't even know if I'd make it to -- you know, I wasn't ill, but, you know, I had no idea -- you know, I think the doctors didn't know that much more about it than I did, so you didn't know how quickly you could become ill.

Anyway, I made it to my daughter's birth and it really was kind of a happy moment. But, you know, that was there in the back of my mind. We both talked about it, whether I -- there were all these milestones down the road. Would I see her first steps? Would I hear her talk, her first words? Would I see her on her first day of school? All of these things. You know, we had other friends at this time who had started families, and they -- we were seeing their kids starting to grow up and starting to walk and we were looking forward to that, and suddenly that was all thrown into doubt.

Q. In 1986 you describe in your statement having to take some time off work because of flu-like symptoms.

A. Mm-hm.

Q. You hadn't wanted to explain your diagnosis to your employers and some scepticism was being expressed to you as to why you needed that amount of time off work.

A. Yeah, "Why did you need two weeks off work for a cold?" And, you know, I didn't know for sure that

it was anything to do with AIDS. I mean, in retrospect now I think that it was, but it was like a very severe cold, high temperature, fever, and all I could do was stay in bed, drink fluids and take paracetamol, and that's what I did, but that went on for two weeks. So my employers were very sceptical about it.

I wasn't going to tell them my diagnosis, I thought, you know, just get through it, which I did, and eventually went back to work, but was finding it -- I had quite a high-pressured job. By this time I was managing a branch in Ilford, and we specialised in -- the recruitment consultancy I worked for specialised in the construction industry, so recruiting anything from architects to tradesmen, plasterers, carpenters. So the branch that I was running, we supplied mainly shopfitters to the construction industry, and I had a decent salary, but most of my income was commission. So, you know, the harder you worked, the better you were at your job, the more money you earned, and it was expected, as branch manager, that you would put in the extra hours, that you worked harder than your staff. I was finding it increasingly difficult to perform at the level that I had been.

Q. You've explained in your statement over the course of that year finding it harder to cope with the demands of the job. You were taking out your feelings of anger and helplessness on Yvonne.

A. Yes.

Q. You ended up going through the process of marriage guidance counselling for a period.

A. We did. At the time that I was ill, it had got so bad -- one of my brothers was living in London, and I went and stayed with him for two weeks as things had deteriorated so badly between the two of us.

When I got sort of back on my feet, and was still trying to cope with my job, things got a little bit better with us and Yvonne suggested that we go to Relate, or the Marriage Guidance Council as it was then, for some kind of support to maybe help us work out what was -- I think at the time, you know, we didn't think this was anything to do with HIV, we thought this is, you know -- there was no financial pressure on us at that time, I mean, we both had good salaries, but we assumed these were the sorts of things that any young couple goes through, and it's only later that I realised that I had repressed all these fears about being HIV and what it meant, and, you know, that those fears were coming out in other

ways.

They weren't -- we -- I don't think we were talking much at this time, because what was there to talk about? You know, the clinicians had nothing to tell us, there were no treatments, we weren't being offered any sort of other support, any psychosocial support. Our only support was ourselves. And at this stage it got to the stage where we weren't talking. So all this -- and it was rage that I had, would be taken out on Yvonne.

So it -- she said, "Well, we'll go to marriage guidance", and that did help. It did -- you know, we managed to sort of patch things up between us. But at the same time I was finding it increasingly difficult in my job. You know, you've got certain targets to meet, and you're trying to develop -- you're trying to look after your other staff, and all the time, you know, you want someone to -- you want to be able to talk to someone and maybe share what you're going through and there is no one.

Q. At the end of that year, the end of 1986, you decided to resign from work.

A. Yes.

Q. Yvonne returned to work and you stayed at home to spend time with Jessica, because you were still

preoccupied with the idea you wouldn't see her grow up and you wanted to maximise the time you had with her.

A. Yes. I mean, it's weird, but things kind of worked out quite fortuitously, because we had a childminder arranged for Yvonne to go back to work after six months of maternity leave, but the childminder we had didn't work out, she was -- we didn't take to her and she was constantly complaining about Jessica, so that only lasted about three weeks. I had already started looking for other jobs. I was having interviews with other consultancies. I was -- because of what had happened when I had taken time off work, there was -- you know, my relationship with my area manager and the director had kind of soured somewhat, so I thought perhaps if I move on, I'll be able to get my mo-jo back and start doing as well as I used to. Again, not thinking this had anything to do with HIV.

But -- so when the childminder didn't work out, and just -- you know, and I thought about this, I'm trying to do this job which I'm no longer enjoying, I'm not happy, I'm really struggling, and I'm not getting the time with my daughter, so why don't I look after Jess full-time until I feel well enough to go back to work? Yvonne earned more than me anyway, she's smarter than me. She was an accountant at that

time working for a merchant bank. So we thought that we could survive on Yvonne's salary.

Q. In March 1987 a letter was sent to you by the Royal Free. We'll just look at it. It's 2384023, please.

We can see it's dated 6 March 1987, addressed to you, and it's from Professor Kernoff, and it says this:

"As I am sure you know, a problem of concern for some years has been the transmission of non-A, non-B hepatitis viruses by clotting factor concentrates. Many people with haemophilia have abnormal liver function tests and, although the significance of these abnormalities is not known with certainty, there is a possibility of progressive liver damage due to chronic non-A, non-B hepatitis infection.

"Recent evidence suggests that a newly available drug, interferon, can be beneficial in the treatment of people with possible chronic non-A, non-B hepatitis by normalising LFTs and preventing progression of liver damage. We shall be starting a clinical trial of interferon in the near future and I wondered whether you would like to participate. The main problem so far as you are concerned will be the inconvenience of attending for blood tests at frequent intervals. I should also mention that in order to be sure that any benefit is due to interferon, some people included in the study will act as controls, ie not receive interferon, until the value of the drug is proved."

Then you were invited to respond.

Can you recall receiving that letter and what you thought of it?

A. I couldn't recall it until I actually saw it when I got my notes, and I did remember being asked to participate in a trial, but I can't remember having a discussion with them. I can only assume, because from looking at the letter it doesn't say -- doesn't tell me, "You have got non-A, non-B hepatitis"; it talks about the possibility of haemophiliacs developing this.

So as with any trial, it suggests it's a new drug, it's an experimental drug. I didn't particularly fancy the idea of being a guinea pig, so there was that reason for not wanting to go on the trial. And also, more practically and more immediately for us, we were just about to relocate from London down to south Wales, so I declined.

Q. But at that point, non-A, non-B hepatitis had not previously been discussed with you.

A. No, no. I mean, I'd never heard of it. I had no -- there had been no conversations with the doctors about any form of hepatitis.

Q. In May 1987 you moved to *[redacted]*.

A. Yes.

Q. And you then transferred your care to the Swansea Haemophilia Centre at the Morriston Hospital under the care of Dr Ismail.

A. That's right.

Q. Now, you already mentioned you'd planned a larger family.

A. Mm-hm.

Q. And so in 1987 you decided to try to conceive again.

A. Yes. We -- and, again, we sought advice, but there wasn't really any -- you know, the -- as a haemophiliac I kind of guess I expected, you know, the Haemophilia Society to be able to answer our questions. I remember phoning the Haemophilia Society and asking was there anyone I could talk to about this, about what was the risk. But, no, they didn't have anyone we could talk to.

This was before the Macfarlane Trust existed, so there was no -- and I didn't know any other group, so I didn't -- you know, I wasn't a gay man, so I wasn't in contact with Terrence Higgins or Body Positive or any of these, so the only person we could really ask was Dr Ismail. And I remember talking to Dr Ismail about it and Dr Ismail just being completely embarrassed, probably like teachers who have to do sex ed classes with a bunch of hormonal 14-year olds or whatever. It was just very awkward. But his advice -- to be fair to him, he gave us advice -- and his advice was: "No, don't do it".

But, you know, we investigated ourselves as best we could, and we thought, right, if we can work out Yvonne's cycle and find out when she was ovulating, then we would take the chance to have unprotected sex in the hope she would get pregnant, and that we'd do that. Once we'd done that, she would go and have a test, a HIV test, and then we would wait to see whether she'd conceived or not.

So my recollection is that we tried about three or four times -- for two months. So probably two cycles. Yvonne didn't get pregnant, and the kind of -- just the trauma that -- the fear -- yes, the fear rather than trauma of waiting for the test results on both those occasions was just too much. We couldn't -- you know, I've -- looking back, I think it was foolhardy, but I think it's just a measure of how desperate we were.

Q. By 1988 you had been suffering further infections and flu-like symptoms.

A. Yes.

Q. But the two of you decided to try artificial donor insemination at a local fertility clinic in *[redacted]*.

A. Yes.

Q. Yvonne did get pregnant but miscarried?

A. She did she got pregnant in -- was it late 1987?

Q. March 1988.

A. March 1988, yes, and for us at the time -- she had just been off -- she'd been for an interview for a new job. She was working for a small company as a company accountant and she'd applied for a job with the local evening paper as their accountant, and it was a step up, it was, you know, better salary, because I wasn't working at this time down in *[redacted]*. She got offered the job and then found out she was pregnant, and she -- you know, "What are we going to do?" She decided that she needed to tell her prospective new employers, which she did, and they withdrew the job offer, and then she miscarried, which -- it was all rather unfortunate.

Q. You describe it in your statement as devastating.

A. Yes.

Q. But you persisted with attempting donor treatments at a clinic in London at your own cost.

A. Yes. We -- yes, I should mention that when -- prior to Yvonne starting the treatment, we had applied to the Macfarlane Trust for funding, is that right? Oh, sorry, that was later on. That was for in vitro fertilisation later on, sorry. I'm getting that confused.

Q. Don't worry. What you say in your statement is you switched to a private London clinic, persisted with donor treatments with a substantial financial cost, but none of those resulted in pregnancy.

A. That's right. The reason we switched is because the clinician in *[redacted]*, the private practice in *[redacted]* that were doing it, they were told that they -- what ... yes, they were using live sperm, and they'd been told by whatever body governs these things that they could no longer do that, so it had to be frozen sperm. This guy stopped doing it altogether. That's why we had to go to London and so -- it was much more expensive and obviously travelling back and forth to London as well.

Q. By the middle of 1988 you returned to work, a small retail business in *[redacted]*.

A. I did.

Q. And you continued to have your care at the Haemophilia Centre in Swansea.

A. Yes.

Q. But over the two/three years that followed you were increasingly struggling because of your health.

A. Yes.

Q. What can you recall about that?

A. So we're into the sort of late 1980s/early 1990s. There were -- again, there was -- there was no medication for HIV as such. The front-line medications were to treat the sort of kind of opportunistic infections that would kill people, so things like PCP, Kaposi's sarcoma. To be honest, I don't even know if there was a treatment for that. But PCP was a big killer. It's a form of pneumonia. And there were -- the front-line treatment for that was a drug called Septrin. So I was -- Dr Ismail asked me would I go on Septrin and it will stop me getting this pneumonia, and I agreed. He didn't tell me that there were potential side-effects, he just said, "You need to be on this".

So I went on Septrin, I think it was late 1991 or 1992.

Q. Your statement suggests November 1992.

A. Right, which -- yeah, yeah. So -- and I think it was a matter of four or five weeks, and I suddenly developed fever, high temperature, skin rash, nausea, and I was taken to hospital, and we didn't know -- we assumed that it was something to do with HIV. And I was taken to hospital, admitted, again, the whole rigmarole of having to go through A&E. You know, you would tell them, "I'm a HIV positive haemophiliac". They wouldn't know what any of that was, and you'd have to wait until they got -- dragged out a haematologist from somewhere, and then you might not be familiar with that haematologist and, you know, I was ill, I was burning up and I'm trying to explain to them what -- you know, my symptom or my diagnosis.

Anyway, they started me on various different antibiotics, thinking it was something HIV related, but after I think it was a week, someone -- I suspect it was the GU clinic, the GU clinician, I think they consulted him and he said -- asked the question, "Is he on Septrin? Stop the Septrin". They stopped the Septrin and within a couple of -- within a day or two my symptoms had alleviated. So it was an extremely toxic reaction to Septrin.

Q. We've looked at that last letter from the Royal Free in 1987 about non-A, non-B hepatitis. You recall being told by Dr Ismail in the early 1990s that you had hepatitis C.

A. No, the first I knew of it was January 1993, I think, there's a letter.

Q. We'll have a look at that. 2384015, please, Henry.

We can see there it's 21 January 1993, addressed to your GP, and it says:

"I reviewed Michael in the haemophilia clinic today."

Then if we go to the third paragraph:

"I explained to Michael the fact that he has been exposed to hepatitis C through previous treatment with Factor VIII concentrate. His hepatitis B antigen test is negative. His liver function test shows mildly disturbed liver function."

And that's explained. Then it says:

"Currently there is no approved treatment for hepatitis C, but interferon may be considered as an option in the future."

So that would suggest that in the haemophilia clinic, 21 January 1993, that's when you were told you had hepatitis C.

A. Yes.

Q. Had you been aware you were being tested for hepatitis C?

A. No, no.

Q. Let's look at two earlier documents. So that's January 1993. If we now have 2384016, please.

We can see this is a letter just over a month previously, so 10 December 1992, to your GP again, referring to a review in the haematology clinic that day.

It says in the last paragraph:

"I have arranged to review Michael in the haemophilia clinic in due course. We will need to follow up the changes in his liver function tests with raised aspartate transaminase and gamma GT. These may well be secondary to the hepatitis C infection which he had."

Were you told in December 1992 that you had had hepatitis C?

A. No.

Q. And then we'll have 2384018, please.

We can see this is dated September 1991. There are two date stamps: 9 September 1991 and 13 September 1991:

"Hepatitis B surface antigen negative. Antibody to hepatitis C: positive."

So autumn of the previous year, September 1991, a positive hepatitis C result. Was that communicated to you?

A. No.

Q. Were you aware you were being tested in the autumn of 1991?

A. No.

Q. You didn't learn that test result until January 1993.

A. That right.

Q. In the course of 1993, you started an Open University degree.

A. Mm-hm.

Q. And you've said in your statement you think it was that year you received an ex gratia payment from the government.

A. That's right.

Q. But you had to use that because of the financial difficulties relating to your ability to work as a result of your health problems, you had to use that to wind down your business.

A. Yes.

Q. And you had to remortgage the house as well.

A. Yes. I had a video shop, and I bought it as a going concern. We -- when we left London, we didn't sell our house in London straight away because I didn't know whether I'd settle in *[redacted]*. But after -- so we rented it out while we were in London and we were renting in *[redacted]*. Then after a year we decided we would stay there. So we sold our house in

London and we used that to buy a house in *[redacted]*. And the -- we made a profit on the house, so some of that we invested in the business, but we still had to take out quite a substantial loan to buy the business.

And I suppose the older ones of us here can remember the video boom in the early 1980s and 1990s, so I came in on the tail end of it, and within a year of opening my shop or taking over that business, Blockbuster had come in, which were a big corporate business. I was a single independent shop. Also Sky TV had started and they were showing all the new movies. So I couldn't -- you know, it became increasingly harder to be competitive and to be successful in the business.

So, again, I -- you know, I had no treatment for HIV, you know, I was still alive and probably amazed that I was still alive, but still aware that this going to catch up with you eventually.

So I always attributed any sort of concerns that I had to more immediate things, recognisable things, like financial pressures, rather than to HIV, but I think that -- because again around that period our relationship deteriorated, and I think again because I was bottling things up I wouldn't talk about my diagnosis, and that again manifested itself in anger

and various other things.

Q. And there was a period of time in the early 1990s when you separated.

A. We did. We had a disagreement about this the other day, but I think my wife was right. She usually is. It was in 1991 we separated for six months, and I moved out of the family home and lived in a one-room flat in central *[redacted]* for six months.

Q. In late 1993 you were increasingly experiencing opportunistic infections.

A. Yes.

Q. Skin rashes -- you can't remember, your statement says, whether you required hospitalisation, but you certainly required treatment.

A. Yes, yes, I forever seemed to be on different regimes of antibiotics. I think it's there in my notes, references to ciprofloxacin -- I can't pronounce it -- erythromycin.

I think basically they didn't know what to throw at these illnesses, so it would just be a whole range of broad spectrum antibiotics, and half the time they would make you feel worse than you were.

My biggest problems, and I'm sure these are common to all of us who were, you know, struggling with HIV in the early days, were I had seborrheic dermatitis. It -- I mean, I got used to it, but this wasn't a skin rash that was around for a week or so; this rash lasted the best part of three or four years, and it was there and I was very self-conscious about it. Don't forget I was working in a shop, I was meeting people, face-to-face with people every day, and I had this really, really noticeable horrible rash, big red splotches all over my face, and tried various different creams and compounds for this and nothing seemed to be able to clear it up.

I also suffered with a lot of oral infections, oral hairy leukoplakia, thrush, and again these things, they affect your sense of taste. I do all our cooking and I've always enjoyed food and I like food, and so when you lose the ability to taste food, it's kind of strange and I found that hard to deal with.

So, yes, you know, fatigue, chest problems, but, you know, I just got on with it because there was nothing that they could really do.

Q. You say in your statement that it was in probably late 1994 Yvonne went to see a consultant to the discuss the possibility of IVF treatment.

A. Yes.

Q. But you weren't able to proceed with that because of the cost.

A. Yes.

Q. And you did see whether you could get it funded by the Macfarlane Trust.

A. Yes, I found in my records a letter that Dr Ismail had wrote on our behalf, because I'm sure you've probably heard this from other people who've given evidence, the Macfarlane Trust -- so they made monthly regular payments, but they also had a pot of money where you could apply for funding for specific things, and it was usually to do with your house if you needed home improvements. We did access this, we got a grant to put a new boiler in our house. We had a coal-fired boiler, so we changed that. We needed a new bed. And, anyway, we thought we'd apply for funding for this.

And we -- Dr Ismail wrote this letter saying that our inability -- you know, he was telling the truth, our inability to have a family was directly attributable to my infection with the HIV.

But anyway despite his letter and despite them -- us sending sort of various quotes from different organisations who were providing that service, they declined, they said it wasn't within their remit and they wouldn't -- they wouldn't fund it.

So we -- but we just couldn't afford it.

Q. You also in 1994 started a course of treatment with interferon.

A. Yes, yes. So this was just over a year I guess after I was diagnosed, and Dr Ismail asked me to come in, and he probably brought up at one of our regular three-monthly monitoring sessions, that -- he told me about this drug, interferon. I had no memory of the previous offer of a trial in 1987. I had no memory of that.

So I asked him about the drug, you know, what's the success rate, and the -- I was genotype 1, so I think they did tell me at the time that the chances of it being successful were much less than with other genotypes, but that he felt it was still worth giving it a go. I asked about side-effects and was told, well, mild flu-like symptoms and that was it.

So -- but, you know, on that basis I decided, well -- you have to understand as well that with hepatitis -- to me hepatitis was nothing. I -- it didn't -- I don't say that to demean anyone who is only mono-infected, but my main concern -- I didn't know anyone who had become ill of hepatitis or who had died of hepatitis. I knew I had friends who died -- who had died of HIV, so it was a much realer thing to

me.

So I thought, well, I'll -- I don't know if I've had any symptoms of hepatitis C because all of my illnesses that I had I attributed directly to HIV, so I didn't know, but I thought, well, look they're not treating me for HIV, there's nothing else they're giving me, I'm not taking Septrin anymore. They wanted me to go on to nebulised pentamidine, but I didn't want to. I did later but at that stage I didn't want to.

So I decided, well, I'll give it a go, and I went on the treatment, and it was just -- it was just ordinary, boring old interferon in those days before it became pegylated interferon. I never really understood the difference. And it was just -- it was a mono-treatment, subcutaneous injections, I think it was three times a week, and so, yeah, I started the treatment.

Q. What side-effects did you experience?

A. This is difficult because I already had all this anger inside me which I wasn't talking to anyone about.

At the time I thought, you know -- I had flu-like symptoms, but I was expecting that, so I didn't think that there were any side-effects. It was only later when -- I think I was on the treatment for 10 months, and it was only after the cessation of treatment and it had been unsuccessful that Yvonne tells me that I was a completely different person, that I was a monster, and, you know, looking back, I can see that I was.

For me -- I mean, I don't remember, but, you know, I know that I was -- I used to go through periods where I was -- where I was a monster to anyone around me, just wouldn't -- either wouldn't talk, would shut people completely out, or if I was talking to them, it was to scream and rage at them.

But when you're going through this, you don't suddenly think, "Oh, I'm this person that day and a then I'm a completely different person the next day", you don't know it, you don't realise it, at least I didn't realise it. It was only months after I stopped treatment that, you know, that we started -- we talked about it and Yvonne told me, you know, "You weren't yourself, you were just a different person". A person that she didn't know, that my daughter didn't know.

Q. You say in your statement that the failure of that first course of treatment upset you much more than you'd anticipated.

A. Yes. A few other witnesses that I heard over the

course of the Inquiry have talked about emotional resilience, and I think that's something very common to haemophiliacs of my generation, that as I said earlier, you grow up where you're -- when you're a child, you know, you're under the care of a physician and because they treat you throughout your childhood into young adulthood and tend to have a paternalistic attitude to you, you tend to go along with what they say because they know best, and you go along with your mum and dad and you go along with what your teachers say to you at school, so you can't play football, you can't run about with the other kids, you can't rough and tumble, all of these things. And I never had spontaneous -- well, I did have spontaneous bleeds, but not much as a kid. Usually if I had a bleed as a result of trauma. So I kind of resented this being wrapped in cotton wool.

So I made that decision (inaudible) that I was going to take control of my own life and make my own decisions, and I became every resilient. In a kind of perverse way, I think when I was diagnosed and living -- those first few years of living with the diagnosis, that resilience that I'd learned through being a haemophiliac carried over and helped me to cope with it. One of the ways -- clearly one of the

ways I coped was compartmentalising it, so that I wouldn't think every day about HIV, I'd put it into that one part of my mind and just forget about it. Obviously it was coming through then later in anger and these really dark moods.

But I think because I had -- I'm generally an optimistic guy, and I think even though I didn't know much about this medication, I thought, well, I'll give it a go and perhaps I'll be one of the lucky ones that, even though I've got genotype 1, it will have a good effect and it will get rid of the virus. Even though I wasn't -- we weren't talking or anything about it saying, "Oh, this is going to work", I think deep down I expected it to work, I really wanted it to work. I didn't think consciously about it, but it was only when I was told after 10 months, you've been through this really shitty period of going through all of this and then you're told, you know -- in effect you're told that it was a pointless exercise and you've gone through all of that for nothing, so it was fairly crushing.

Q. In 1995 you were hospitalised with a severe bacterial infection, and your condition was so serious that Yvonne was told at one stage that if your condition didn't improve there were no more treatment options

and they thought you were going to die.

A. Yes. Yes.

They didn't -- again, they didn't know whether I had some form of pneumonia, they didn't know -- again, just firing all these different antibiotics at me. I can remember -- we've talked about this a few times -- for the best part of a week I -- my temperature was in old money in the hundreds, and I was just in a constant fever, I couldn't sleep. There were three or four -- I was in a separate room, which any time I had hospitalisation after my diagnosis you were usually put in a separate room, and particularly in the early days if any nursing staff or ancillary staff came in, they were always wearing -- they were gloved and gowned and masked, which kind of really made you feel special.

But in this room I was there on my own, and you would just be there for long periods on my own until Yvonne -- don't forget, my wife is working. She's changed careers. She's now working as a teacher. Jess is 9 years old I think at this time. We had a dog. We had all these things. So my wife's life then was get back from her own job, pick up Jess from the childminder, come home, feed Jess, drop Jess off at childminder, come see me in hospital, stay with me until 9 or 10 o'clock, go home, go to bed, get up in the morning, back to work. Being told that, you know, "If his condition doesn't change soon then the outlook is pretty bleak".

I was completely unaware of this, I didn't know, but I have vivid memories of -- I can't remember which particularly antibiotic I was on, but there was one particular antibiotic and they stopped it, and I think this antibiotic was making me worse. And they had stopped it, and I remember Singleton Hospital looks out over Swansea Bay, so you can see the lights of Mumbles on the water across the bay you can see Port Talbot Steelworks, which look quite pretty at night, all the flames coming out -- I know that's strange -- and I can just remember lying on my bed, burning up, and then suddenly -- and it was very quickly -- this fever broke, and I just began -- my body began to cool down, and it was like this rush of relief going from my head down through my body, and I thought -- I said to myself, "Christ, you're going to live". And that -- because, you know, I thought -- I was so ill that I thought I was on the way out.

Q. In 1997 Dr Ismail, your haematologist, referred you for management of your HIV to the GUM clinic.

A. Yes, that's not -- I know -- I put that in my

statement. That's not strictly true. What happened was by this stage I was actively involved in two support groups: one was Birchgrove, which was for HIV positive haemophiliacs; the other one was a HIV group in *[redacted]*, a self-help group set up by gay men and drug users. I'd become heavily involved in both groups. The guys at -- the *[redacted]* organisation was called SWISH, which is obviously a gay term, but it also stood for South Wales Immunodeficiency Self-Help group. I started asking these guys about where they were getting their treatment, because obviously my treatment or my lack of treatment was happening or not happening at the Haemophilia Centre, and they told me, "We go to see Dr Yoganathan at the GUM clinic", and he was also one of the patrons of that organisation.

So I asked Dr Ismail about him and he was very reluctant to -- you know, "We know what's best for you because he doesn't know anything about haemophilia", and I said, "You don't know anything about HIV clearly because you're not offering me any treatments. Can you make a referral?" And fair play, he did, he made the referral.

Q. You had started on AZT and DDI and the pentamadine, but you describe again side-effects: diarrhoea,

fatigue, loss of appetite and skin rash.

A. Those side-effects, and again most of us used to -- most of the guys that I know started treatment around 1997, and I think it was because up until then the only sort of monitor they had of health was measuring of CD4 counts, but -- and obviously with CD4, the lower it was, the more likely you were to have a disease progression.

1996, 1997, they developed viral load tests so they could actually measure the amount of virus in your blood, and the more -- the higher the figure was, the much more -- you know, I think it was just more accurate, it was a more accurate diagnostic tool than the CD4 count.

So the first thing that Yoganathan did was to take a viral load, and on my first viral load count his strong recommendation was that I start treatment, so I did.

But, yes, sorry, I missed the point, you asked me about side-effects.

We all changed medications many times over the course of the following years. I had side-effects, the same side-effects, skin rash, bad skin and severe diarrhoea, for probably the next 15 years. So they weren't -- you know, whatever combination I went on,

those side-effects were always there and you just lived with them. You managed it. That became your sort of life.

Q. It was in 1997 that the two of you decided to explore the idea of adoption.

A. Yes.

Q. What can you tell us about that process and what happened?

A. So in 1997 I'd been living with HIV for 12 years from diagnosis, and we still hadn't given up on the idea of enlarging -- expanding our family. We tried AID, we'd investigated in vitro, we'd taken the chance of conceiving naturally and none of that had sort of worked out, so we talked about it and we said, well, okay, let's try adoption.

We kind of knew my HIV status and hep C as well would be problematic, so I decided -- what they initially do when you -- you don't start training straight away. You have to be approved as a candidate for training. So you go through a series of interviews to see whether you're suitable.

So we just decided, well, look, I'm not going to mention my HIV or hep C through the interview process. Let's see how we get on with that and whether they think we're good candidates as adoptive parents, and then we'll make a decision about what we say. So that was it.

So we had a series of five or six interviews, which was the same social worker from *[redacted]* adoption came to see us, came out to the house, you know, they come and look around your house and where -- "Which room would be for the children?" Talked to us about our outlook on life, our, you know, our morals and ethics and all of this. And clearly at the end of that process, you know, we were told, yes, we're good candidates, "We're going to recommend you forward for training".

So at this last meeting that was -- there were two social workers, so there was another social worker came with her to give her seal -- probably her boss wanted to come and meet us, so, yeah, they told us, "Yes, we're going to recommend you go forward", and I said, "Well, there's something I need to tell you. It's not an issue for us, and hopefully it won't be for you, but I'm HIV positive and I've got hepatitis."

Straight away you could tell by their reactions that, "Oh, Christ, you know, what's this?" Where do we go from here? You know, I'm not -- they had probably never encountered this before, they probably hadn't had people with HIV, you know. I suppose -- I

mean, I don't know. But clearly they were shocked and they didn't know what to do, and they left it with us that they'll have to take it further up the line and get advice on how to proceed. So, fine, we understand that.

So a week goes by, we don't hear anything, and then another week goes by, and then we are starting to chase them. "What's the decision?" And they were very reluctant to give us a decision, and then they did say it, but verbally over the phone, that, "I'm sorry, you know, we've decided that we can't proceed with it. Because of your diagnosis, the prognosis would be that, you know, you would be dead and we don't want to be putting a child into that situation."

I explained, you know, that I'd been living with this for 12 years. I know it better than you, what my prognosis is, and, you know, I'd started on treatment, but, no.

So we said, "Well, can we have that in writing?" Yvonne was very insistent she wanted it in writing. We were both very upset. We were actually devastated because this seemed to be the last crushing blow on our hopes of expanding our family.

So we did eventually get a letter explaining what I've just told you, the reasons why. We looked

long and hard for that letter, I cannot find it, but that was the decision and that was the end of that.

Q. You were subsequently approved as foster carers.

A. Yes, there was a social worker called Tim Hunt who was -- I met through Birchgrove. He was the guy that introduced me to Birchgrove. And he was a great guy. If I was making an application to the Mac Trust for funding, for, you know, the boiler, whatever, Tim would -- he was very good, he would write letters of support, help me get quotes.

So Tim knew that we were going through this process of adoption, so he asked us about it, we told him what had happened, and a little later down the road he was visiting us at home and he said, "Have you thought about fostering?" Because they do long-term fostering. And we hadn't really considered it, and we thought, okay, well, let's investigate further, and Tim put us in contact with an agency called Tact, The Adolescent and Children's Trust, a private fostering charity based in Neath, *[redacted]*, and so they came and met us, and I thought, well, I'm not going to mess around, I told him straight out: "This is -- you know, I have HIV and I'm hepatitis C, I've had it this long, I'm on medication, you know, I get periods of illness, but I'm still here and we would like to do this". So

we had a couple of interviews and they said, "Right, that's great, we're happy for you to come on the training programme."

So Yvonne was still -- Yvonne was teaching by now, so I was going to be the main carer. So Yvonne did do some training, but I did the bulk of the training.

Q. You did have various foster placements.

A. We did. We had -- I think over the years we had about six or seven different kids that we fostered. We had a boy for two years. We had another young girl who was sent to us because she herself was HIV positive, but that placement didn't last very long. You know, it was just -- it was a very difficult -- you know, there were lots of problems in that placement, so that didn't last. And then we took on two sisters in about 2003, and they were to be long-term fostered. The older sister, that placement broke down after about two-and-a-half years, but the younger sister stayed with us, and eventually she told us she wanted us to be her permanent mum and dad.

We applied for what's called special guardianship, and it's like -- it's a halfway house between fostering and adoption where you don't have full parental authority, you share parental authority with the local authority. So we went down that road, and Jamie, my second daughter, she changed her name to O'Driscoll and she's still part of our family now.

Q. Returning to your medical history, there's a curious letter from 1998 in your records we're going to look at. It's 2384022, please.

It's not a letter that was sent to you. It's a letter that appears in your records dated April 1998. It's addressed to Dr Ismail and it's from Professor Lee. It says:

"Thank you very much for sending the update on Michael O'Driscoll."

It talks about it being very nice to see you are doing well. Then it says this:

"We will acknowledge your collaboration in any publications that we make following our cohort."

Did you know, first of all, that updates on you were being sent by Swansea Hospital to the Royal Free?

A. No.

Q. Do you know what is meant by the "cohort" or "possible publication"?

A. Well, I know what the word "cohort" means, and it suggests a specific set or group of people for some purpose or other. Given that it's medics, I presume it was something -- some sort of trial, perhaps. But

I had no knowledge of any particular cohort and I didn't have any idea that Dr Ismail was collaborating in some way and would be named as a co-author in any publication. I've no idea what -- I've no idea. I hadn't seen that letter until I saw my notes.

Q. You completed your Open University degree.

A. Yes.

Q. Degree in humanities. Then in 2003 you embarked upon a second course of treatment for hepatitis C.

A. Yes.

Q. This time pegylated interferon and Ribavirin.

A. Yes.

Q. What was that course of treatment like?

A. This -- so at this time there was a new consultant in Cardiff -- my treatment had always been in Swansea, but through Birchgrove a lot of the positive haemophiliacs were being treated still at the Haemophilia Centre there and there was a new physician there, new head, younger guy, a lot more progressive in his attitude, a lot more -- he treated you like an adult, not like a child. I had never met Professor Bloom, I was never under him, so I don't know anything about him. But I did meet Peter Collins, who was this particular physician. I met him

at some Birchgrove social events and he talked to me -- he was asking me about what treatments I was on. They told me that there was a new drug that they were using in combination with a new form of interferon, and perhaps if I wanted to come up and meet Dr Dasani, who was running the programme. So I said I'd give it a go.

It had been nearly ten years since my previous experiences of interferon. So I thought, well -- you know, again, I talked with Yvonne, and said, well, hopefully there will have been a lot of progress made in terms of the medication. So I met with Dr Dasani, and he told me about pegylated interferon and this other drug Ribavirin.

Again, there wasn't a great emphasis on the possible side-effects. Flu-like symptoms, mild depression. So I think that -- I agreed to start treatment and I think before I did -- did I take antidepressants then, the first time? Right, okay, I didn't take antidepressants, I think it was the third time I took antidepressants.

Again, because I never saw myself as -- you know, even when I was going through all these rages the first time around, I never thought that was depression, and I never saw myself as a depressed

person. So I thought, yeah, no, I can deal with this, I can handle it, I'll get through it. So I embarked on the treatment.

Q. That was a shorter course -- or rather it was suspended after 12 weeks.

A. Yes, yes, by this stage there -- so they developed a viral load measure for hepatitis C as well as HIV, so they were able to -- you were monitored. I would go up to Cardiff every -- I think probably once a week for monitoring. They would do blood tests and after 12 weeks -- what they were looking for was what Dr Dasani called a log drop. So if you can all remember your maths, sine and cosine and logbooks and all that. So a log basically if you drop -- if you can cross off a 0 -- if it's a million, you get rid of a 0 and it comes down to the hundreds of thousands, that's a log drop, and that's what they were looking for to show that the treatment was making progress against the virus.

After 12 weeks he called me in and said, "We haven't had a log drop, we don't think the treatment is working, therefore, for your health and wellbeing, we think it's better to stop the drug", and so they did.

Q. In 2004 or thereabouts you received communication about vCJD and potential exposure to vCJD.

A. Yes.

Q. Can you recall receiving it and what you thought of that?

A. Even before I received the letter we were expecting it. Myself and other people involved in Birchgrove, we were pretty clued up at that stage so, you know, before this letter came out, we -- you know, I was expecting it.

Having said that, you know, amongst ourselves we would laugh and joke about it and say, "Oh, another bloody -- another virus", even though it's not a virus, "another thing they're throwing at us, but we've beat this and we've beat that, so bring it on."

That was, you know -- amongst ourselves that was the kind of attitude, but obviously in the privacy of your own thoughts you're thinking: shit, you know, what is this? And how -- if it turns out that I have been exposed to it, because vCJD was very much in the news before this, and there were no treatments, and then again it was another death sentence. So there was that worry about whether you had been exposed or not.

Q. You had not, as far as you're aware, received an implicated batch.

A. Yes, I was told that I hadn't received an implicated batch, but for purposes of public safety I was on some sort of register.

Q. We can see that that had some practical implications for your care. If we look at 2384020.

This is a letter that was sent by Dr Ismail to the Singleton Hospital. If we go down into the body of the letter, dated 10 January 2006, then it says this:

"He is a patient with severe haemophilia A who is also hepatitis C and HIV positive. He was treated in the past with UK pooled coagulation factor concentrate and has been designated as being at risk for public health purposes with regard to variant CJD. This does not mean that he will develop the disease, but certain specific actions are needed in case he undergoes endoscopy or invasive procedure, particularly in the nose and throat. The instruments used for these procedures cannot be used on other patients and have to be quarantined."

And we can see that someone has added there also:

"Or ENT examination."

That was a letter sent in January 2006 to a consultant at the Singleton Hospital.

Then we can see the effect that seems to have had if we look at 2384019, please.

We can see the top entry is 13 January 2006. So three days later:

"Patient theatre cancelled due to ..."

Then:

"Theatre people had to arrange for another set of instruments as we cannot use the instruments again. Discussed in detail with the patient. Happy to wait."

What observations do you have on that entry?

A. That I remember the -- because I was already in hospital, they'd said, "Come in in the morning and we'll get you a bed up on the ward". It was only -- it was quite -- I had started teaching, I was a secondary school teacher at this time, and so I think it was in -- yeah, it was just before -- just before or at the start of the new term, and I had developed -- my voice had gone really, really hoarse, it was just a croak, and they'd found this nodule or something on my vocal cord, so the procedure was to remove that. So it was pretty straightforward procedure. But nevertheless they had to have Factor VIII cover and whatever.

So, "Come in, check yourself in" -- so I was in hospital, and then they came and they told me --

nothing was mentioned about it being cancelled because of fears about using the equipment with CJD. My understanding was that it was something to do with the HIV and -- or hep C, but nothing was mentioned about the CJD.

Q. Were you happy to wait?

A. No, no, no, because I was due back at school and I wanted this -- because, you know, otherwise you're standing in front of a class of kids, you can't talk -- it's no good, you can't do your job if you can't talk, and I literally could barely talk at that stage.

Q. We talked earlier about your request for referral to Dr Yoganathan for your HIV care.

A. Yes.

Q. There's one letter I omitted to ask you to comment on. It is 2384017, please, Henry.

We can see this is June 2001. It's from Dr Dasani to Dr Yoganathan. It just picks up on the theme of what you were talking about. So if we go further down -- thank you -- the first main paragraph, it says this:

"I saw Michael in the Haemophilia Centre today. He came mainly to discuss treatment of his HCV with me."

Then it says this:

"As you know, there is a very limited experience and no clear guidelines in terms of treating co-infection."

You had been talking earlier, Mike, about haemophilia and HIV care; here we have an acceptance by Dr Dasani that was very limited experience and no clear guidelines in terms of treating those co-infected with HIV and hepatitis C.

A. Yes. That was my experience, that, you know, they -- any infection that you picked up or any problem, which I tended to always attribute to HIV, but of course it could've been hepatitis, I didn't know, I'm not a clinical expert so I didn't know what caused these things. But it was always kind of the same -- the treatment was the same response: let's bombard him with antibiotics. And most of the time when I took that, you know, those broad spectrum antibiotics, they made me ill.

So, yes, it's funny to see it there, that admission that, "We don't know what to do, we don't know how to treat these people".

Q. By April 2007, you were becoming exhausted, stressed and depressed.

A. Mm-hm.

Q. You ended up giving up teaching.

A. I did, I did.

Q. You say in your statement that you attribute that directly to the hepatitis C?

A. Yes. I mean, I had finished an MA. At that time I was doing voluntary work with a mental health charity teaching adults literacy, numeracy and computer skills, and I was doing that two days a week. I really enjoyed it and I thought -- my wife said to me after I completed my MA, "You seem to enjoy teaching adults, why don't you do a PGCE and become a proper teacher", as she calls it, and I thought, okay, I'll give it a go. I did my PGCE and I loved it. It was very demanding. Sometimes you were in university and the rest of the time you were actually out teaching in the schools, not really knowing what you're doing. But I did that. I loved the challenge of it. I was excited by it.

And this is -- I started doing this not that long after my -- the failure of my second hep C treatment. But I felt -- well, I felt up for the challenge, and then I got a job. My first job was a nine-month contract for -- to cover an English teacher while she was on maternity leave, and I went in. I was fine through most of the first term up

until Christmas. But -- my wife is a teacher, I presume there are other people here who are or may have been teachers. It's a very, very demanding job. I was in a secondary school teaching 11 to 16-year-olds. I was in a very working class district of *[redacted]*, a very socially deprived area. The kids were very challenging. So you really had to be on your toes, and I would be in school -- the school day was 8.45 to 3 o'clock, but I would be in school usually by 7.45, so an hour beforehand. I never left school until 5 o'clock. I would get home, cook dinner for me and Yvonne, and then into the study doing work, lesson prep, marking, whatever it was, until 9 o'clock at night.

By the time we got into the post-Christmas term, I was drinking every day. It was the only way I could cope with the pressure. So as soon as I finished work at 9.00 at night, I would open a bottle of wine and I'd drink most of that myself. That was the only -- the -- it was such a stressful job, I just needed to kind of blank it out. So -- you know, obviously with hepatitis that wasn't good for me. It just became more and more pressure, more pressure.

My long-term contract came to an end. I did maybe a couple of other supply jobs short-term, and

then it was after Easter I said, "I don't want to go back". We talked about it, me and Yvonne. I said, "I can't go back. If I go back, I'm going to die or I'm going to kill someone", because, you know, it was that tough.

Q. You have worked since, you worked in the voluntary and care sector, and then most recently, until 2014, for a mental health charity.

A. It was the same charity that I worked for voluntarily before I went teaching. They were a charity who had a number of different projects. They did social housing, tenancy support, they had a drug and rehab centre, a homeless hostel. The project that I'd done voluntary work in was a day centre for adults with alcohol dependence.

So after I had given up teaching, I ran into my old boss from my voluntary days, and she asked would I come back doing voluntary work. I said yeah, I'll be happy to, because, you know, it's not pressure, you know, you're a volunteer, you can come and go as you please more. You know, obviously you have to make a certain amount of commitment, but it's not like teaching.

So I went back on a voluntary basis, and then I started getting paid work there as cover for other tutors when they were on holiday or off sick. Then a vacancy came up in general care work, so kind of moving away from the tutoring into general care work, within the same project at the day centre, and then -- so that -- this was 2007.

And then in 2010 or 2011, the manager stepped down and I applied for her job, and I became the manager of the project. I stayed working there until 2016.

Q. In 2013 you started your third programme of treatment for hepatitis C.

A. Yes.

Q. Pegylated interferon and Ribavirin and telaprevir.

A. Yes.

Q. What were the side-effects, if any, of that?

A. So by this stage -- I mean, I wouldn't have gone on treatment if it had just been interferon and pegylated interferon. There would've been no point. But by this stage this was -- this all happened in Swansea I'd been referred to Dr Chin Lee, a gastroenterologist, it was his speciality, and I met him and the senior nurse clinician who was managing the treatment -- I've forgotten her name, I think it's in my notes -- Lisa Hodge-Johnson, they were very open about side-effects and much more honest with me than

anyone had been before. And also they were very -- quite positive about the chances of success because of this new drug telaprevir. They said, "It's going to be hard, but you'll only be on that for 12 weeks and then you would continue with the other two drugs for 48 weeks".

They recommended that I go on antidepressants before I start, so I did. It was -- citalopram. So I took citalopram and I started the treatment. The telaprevir was 12 weeks. And, you know, they were monitoring me I think it was every fortnight, or maybe even every week, I would go and I'd have a blood test, and, you know, they were sharing the information with me all the time, saying, "Your actual viral load now at the end of 12 weeks is zero". So I knew then it was having a really good effect.

So I stayed on the treatment for the 48 weeks. It was tough. I think because I was mentally more prepared, I knew what to expect -- citalopram is quite a mild antidepressant. It did help to some extent, but I stopped taking it. I think after maybe three/four months I thought, I'm going to try and get through this on my own. I had all the flu-like symptoms.

The worst things for me were things like loss of

appetite and everything tasting bland. I completely lost my taste. You have no interest in food, therefore you're eating less, which is not a good thing if you're immunocompromised. You need to sort of -- kind of have -- you know, to be eating well and be eating healthily. And I wasn't. But I just always kind of had this hope that this time, you know, third time lucky, that it's going to work.

So it -- for me, it was something worth going through, and that's how it proved, you know. At the end of the 48 weeks, they said, "Well, your virus is undetectable, you're virus free. We'll measure you again in seven months after the cessation of treatment", which they did, and, "You are still virus free".

So I was still virus free, back then anyway.

Q. And how is your current physical and mental health?

A. Pretty good, I would say. I don't know -- because I've had no follow-up on my hepatitis, which is not something that ever occurred to me until I started coming to these hearings, and the question was raised -- and I think it was asked today of one of the witnesses -- did -- when people had cleared the virus, were they -- was there any follow-up? And in my case, the answer is no. And it just hadn't occurred to me

because I thought, well, I've been cleared of that.

Clearly damage had been done to my liver. I had been told my liver had scarred. And, you know, maybe that's my fault, I should've been more proactive in speaking to the doctors and saying, "Look, can you just do a liver function test to see how everything is?"

But, again, I would've thought that they would do that, knowing that you've had this illness and knowing that it's done this amount of damage, that they would as a matter of course follow you up at least once a year to give you that test or maybe an ultrasound scan, none of which I've had since I cleared treatment.

So your question was how am I physically and mentally. I eat healthily. I do all the cooking. I exercise. I go to the gym. My main passion is cycling. I cycle a lot. I joined a cycling club three or four years ago and I go out and ride with them nearly every Sunday. Me and Yvonne together, we both like hiking, so we do a lot of hiking.

I'm lucky with my knees. I've had two knee replacements, both of which have been very successful and gave me a new lease of life on both occasions. My knees had, because of various bleeds over the years, severe arthritis. My first knee was done when I was just turned 40 in 1999, and the second one was done in 2016, which is when I gave up work. I took time off work for recuperation and decided that I didn't want -- you know, political stuff going on at work and I just decided I didn't want to go back.

So, yeah.

Q. I'm going to ask you in a moment about your experiences with Birchgrove and the question of support and counselling, but before I do that, can I just ask you about your personal, direct experiences of making applications to any of the trusts or schemes.

A. Yes.

Q. You've told us about the Macfarlane Trust and the request for assistance with the funding for IVF and that being rejected.

A. Yes.

Q. In your statement you've said you did receive help for some things, you've given us some examples, but you found the process quite arduous.

A. From the early days, so we were given an ex gratia payment, I think it was around 1990 or 1989, I can't remember exactly when, of £20,000, and then a few years later there was a payment of £60,000.

But for us personally, that was lost in the black hole that was my business. But the main thing that helped us survive was that they made regular payments, monthly payments, and these were more or less means tested depending on your circumstances, how many dependents you had. So because Yvonne was working and had quite a decent salary, well, we would get less money than perhaps people who weren't working. And I'm -- you know, I question the kind of morality of that, but, you know, that's the way the scheme was.

But then they had this separate pot of money to make -- that people could apply to when there was a specific need. So, for example, in my case we applied for a new boiler, we applied for a new bed. Other things -- so I applied when I started my OU course. I can't remember what the fees were but I couldn't afford to pay the fees, so I made an application and they turned me down, "We don't do that sort of thing".

So I enlisted the help of Tim Hunt helped me and I argued that, look, HIV has had a direct effect on my career, and on my life, my ability to continue in the job I was in, and I said that I can't be the only person this has happened to. We have periods of

wellness when we can cope and maybe can work, so I said, you know, "I want to retrain and reskill myself, so, you know, this is why you should fund this". The government are always -- were always propagating this message about people reskilling and continuing in education. So eventually I was successful in getting funding for that.

Now, I don't know, but I think I was one of the first people to get funding for education from the Mac Trust, and I think they changed their policy because of that. But when I came to do my MA, they said they wouldn't fund that. They said, "We've spent that budget", so they wouldn't do any more.

But more specifically on applying, it was kind of an embarrassing process because, for example, with the boiler, we already had a boiler, but it was an old coal-fired boiler. "So why do you need a new boiler?" Well, because it involves me, with my dodgy knees, going out into the middle -- going out to a bunk house in the middle of winter and bringing in a bucket of coal, and it's just not practical with my health, my knees, my HIV, so we needed a more modern boiler in the house.

Then you would have to go away and get quotes, and, you know, anybody who has dealt with builders or

people like this, trying to get people to come round to your house, unless they're sort of like sure they're going to get the job, a lot of the time they'll make an appointment, say, "Oh we'll be around", and they don't show up.

So it was hassle, and that happened time and again. Whatever it was you were applying for, it was -- you know, other people have said the same thing. You feel as if you're being judged, you feel -- it's a very demeaning process that you're looking for a handout.

The way I looked at it, it was that we had been -- you know, we had been infected with this blood, which as far as we were concerned, people who were making purchasing decisions about blood products knew these risks, and so the government was culpable, as far as we were concerned. The government have set up this fund to help us, they've given it this pot of money, and yet the people administering the fund are acting like government gatekeepers and an extended arm of the DHSS.

So -- well, it was very humiliating, you know. At that time -- when I first started making applications, I wasn't on any benefits, and that was also the perverse thing. If you weren't on benefits, you got less money from the Mac Trust. If you were on benefits, you got more money from the Mac Trust.

In the end, when I gave up my shop, that's when I -- so I had to go through that whole process with the DHSS, applying for Disability Living Allowance, which is a pretty humiliating and arduous exercise itself. So then having to go through it again with the Mac Trust is just compounding things.

Q. I wanted to ask you now about Birchgrove.

A. Yes.

Q. And the role of psychosocial support.

A. Yes.

Q. Drawing both on your own personal experiences and, indeed, on the professional work you've done working in the charitable and care sector.

I just want to start with referring you to a letter. We don't have it to put on screen. I think it may have been tucked into your witness statement. But you know the letter that I'm going to talk to you about and the chair has a copy. It's dated 13 August 2001. It's from Dr Collins and Dr Dasani. I need only read three sentences from it, which you've seen. It's addressed to the GP. It says:

"Treatments of HIV and hepatitis C infections involve a complex combination of potentially toxic

antiviral drugs. It also involves providing lots of psychosocial support for the patients their partners and family."

Then it goes on to say:

"Patients on treatment for HIV and HCV infections attend the centre every month, and patients on no treatment are reviewed at least once every three months."

It's a request for views about whether to reorganise the way in which care is provided.

I wanted to focus upon the statement that treatment of co-infection involves providing lots of psychosocial support for patients, partners and family, and ask you about that.

You have described in your witness statements the years before you were introduced to the Birchgrove Group as being years in which you lived in fear and isolation, waiting to die.

A. Yes.

Q. There was no psychosocial support available to you during that period.

A. No, none whatsoever.

The Birchgrove had been founded in I think it was about 1987 by a group of patients at the UHW in Cardiff. I think they might have had some help in --

from a social worker, not -- the predecessor of Tim Hunt and I think she might have brought them together and introduced them to each other and said, "It may help if you talk to each other about your experiences", and that's how Birchgrove got started. So they existed, and by 1993, when Tim Hunt got in contact with me and said, "I think it would be really good for you to come and meet these guys". But they'd already done a lot of work by that stage.

So, to me, Swansea Haemophilia Centre would undoubtedly have known about them because Dr Ismail and Dr Bloom were in contact all the time. The mailing list for Birchgrove was held at and administered -- overseen by the social workers at the Heath.

So it's impossible that Dr Ismail couldn't have known of their existence, yet not he nor any of the nurses at the haemophilia unit in Swansea had ever told me such a group existed.

Q. So in those years again before you were finally introduced to the Birchgrove Group, you've painted in your statement a picture of absence of support. You've described how such organisations as did exist that you were aware of were focused upon HIV and gay men.

A. Yes, yes.

Q. And then you say this of the Haemophilia Society, of whom you are, its fair to say, very critical in your statements.

A. Yes.

Q. You say:

"It had washed its hands of us."

A. Yes.

Q. What do you mean by that?

A. I referred earlier on to phoning them -- speaking to them for advice about whether we should take the risk of having unprotected sex when we were -- they didn't know anything.

No -- you know, we were members of the Haemophilia Society. You paid -- I can't remember, £5 a year subscription at that time and you got their magazine. In the early days, they would cover it, and there wasn't a lot of information but, you know, they were aware that haemophiliacs were getting infected. But over the course of time, and certainly when the Mac Trust was set up in 1990, it was almost as if, "Right, okay, the government have set this up now, that's to take care of you, now we can get back to our real cohort", to use a word that was mentioned earlier on, and being on the outside of that cohort, we could see that the cohort was non-infected haemophiliacs, particularly children. It was a nice image, the -- we were seen -- because of the associations of HIV with drug users and with the gay community, we were seen as somehow dirty, and we -- the Haemophilia Society, we perceived it as they didn't want us contaminating the innocent little kiddies, and parents of these innocent children didn't want us mixing or associating with them. So it was -- they would keep us over there, "You're the Mac Trust, stay over there, don't get involved".

They had a page in the -- their magazine was The Bulletin, I can't remember how often it was published, but they stuck a little page towards the back called the red ribbon page and there would be a little bit of information to do with HIV in that.

But on the whole, you know, there were no workers in the early days in the society dedicated to helping, advising, giving information to people with haemophilia. So -- and as I said in my statement, there were organisations like THT and Body Positive. I lived in *[redacted]*, those organisations weren't in *[redacted]*. There was nowhere for me to go. Later on -- and, again, it was through Tim Hunt -- I found out about SWISH, but that was in 1993. That was the same time I found out about Birchgrove.

If someone told me -- I didn't care who they were. If there was someone who knew how to live with this disease, how -- you know, what were your treatment options, what -- whether it was safe to take this drug or that drug, I would've gone to them. I didn't care who they were. I had no problems mixing with drug users, mixing with the gay community. If they had something to offer in terms of support, we would've been -- we would've been grateful.

Q. You described the Birchgrove Group in your statement as filling a vacuum left by the Haemophilia Society. It was the Birchgrove Group, you say, asking challenging questions, providing support and information and providing a forum to meet and share experiences.

A. Absolutely. It was -- when I was first introduced to them, Tim Hunt came and told me about them and said they were holding this event, they were trying to get new people involved in running it, because the people who ran the group were all positive haemophiliacs, so it was a self-help organisation, and I was very, very reluctant to go along because I thought I had -- you know, I had a very kind of -- I thought it's going to be bunch of haemophiliacs sitting around whining and feeling sorry for themselves, and it was completely wrong. This is when I met people like *[redacted]* and Paul Jenkins and others. And they were, you know -- a shot of fresh air. They had so much energy. They weren't guys who were lying down and taking the diagnosis and being dictated to by their doctors and told, "This is what you need to do, this is what you need to do". No, it wasn't at all like that. They were asking questions, you know, so they'd already had quite a considerable history behind them by the time that I got involved.

So I went along to this meeting and I met up with a couple of other guys, a guy who became a very good friend, *[redacted]*, went along for the very first time that day, and I think both of us had lived -- had been living in isolation. So to meet these other men who -- we were all around the same age, and, you know, some of them had families, some had children, so we all had very kind of similar experiences, and to -- it was a shock to me, but a good shock, to know that you don't have to accept this kind of life, that you can actually start asking questions, start being more challenging. So, yeah.

Q. You've described in your statement some of the work that Birchgrove did. It held conferences, national conferences.

A. Yes, yes.

Q. Seminars, workshops. It raised awareness of treatments and of the risks of treatments and side-effects of treatments.

A. Yes.

Q. You were getting information from Birchgrove you say that you weren't getting from clinicians.

A. Absolutely, yes. Paul and *[redacted]* and -- so Birchgrove, it started in Wales, but simultaneously other support groups had started, particularly in London, under a guy called Cady Khudabux, and then Birchgrove arranged to meet with these guys and then form a national Birchgrove, and Cady was involved in that. And this guy Cady was a very intelligent guy. I think he was a biochemist who I think just coincidentally had done some work -- part of his research work, I think, was in looking at some aspect or other of HTLV III. So I met these guys, and they were an inspiration.

When -- you mentioned a conference. So the first conference that I went to, the first national conference was in Manchester, I think December 1993. So I already met the people in Wales. Then I began to meet a lot of other people, some of whom are in this room, at that conference and became really good friends, and we all started working closely together, and these people from other parts of the country went away from that group empowered themselves and set up their own Birchgrove groups in their local areas.

I've forgotten the question.

Q. You're answering it. The activities of Birchgrove again you've described in your statement, and we've heard some of these from others, the establishment of the Woodland Memorial.

A. Yes, yes, that was -- so there were 1,243 haemophiliacs who were infected with HIV, and I think the original idea came from Paul Jenkins and Cady that it would be -- wouldn't it be wonderful to have a memorial to these people to all of those who got infected and many of whom had already died by this stage. So this would've been 1993/1994. So Cady and Paul and later Alan Burgess was involved in negotiations with the Woodland Trust to -- for them to give us a plot of land in one of their forestries while we could plant 1,200 birch trees, and the idea was that infected haemophiliacs or their families would sponsor a tree, or -- I can't remember what it was, like £10 a tree.

So, you know, that raised so much money. We

didn't have money to complete the project initially. We got hold of a big sandstone rock that we wanted to put there with a plaque on it with an inscription. All of these -- you know, we had to transport the rock there.

So we went -- the people involved -- I wasn't directly involved in that project, but the guys who were involved with it went to the Haemophilia Society and told them what we were doing and, you know, "We've got a shortfall, can you donate some money to help us get over the -- you know, get over the line?" And the answer was no, that they were -- they had their own AIDS memorials which, as far as we were concerned, was a once-a-year service on World AIDS Day at a church up in London and that was it, that was their lasting memorial. It wasn't anything -- we wanted something that we had managed, that we had organised, that we had set up, and they refused. So we had to get it -- we managed to find someone who did a sponsored cycle from John o'Groats to Land's End and raised £12,000, which I think finally got us there, and we had an opening day, I think, a day when we unveiled the plaque on the stone, and many of the surviving people -- not necessarily all involved in Birchgrove, but people who had sponsored trees, were there for

that ceremony.

Q. And you also describe other activities of Birchgrove as including the establishment of an outreach post.

A. Yes.

Q. What was the function of that?

A. Yes, the -- again, this was another project initiated by Paul Jenkins, who -- I can't speak highly enough of the guy. He became a very close friend. Sadly no longer with us.

He -- excuse me ...

We were aware -- I mean Birchgrove had been going for six years at least before I got involved, so we were aware or Paul Jenkins was aware that there were other people out there, haemophiliacs in the community who weren't getting the level of support that we now were getting and giving to each other, because when I talk about psychosocial support, I'm talking about -- my support were some of the people in this room, we supported each other. But we were aware that not everyone had -- you know, was in contact with Birchgrove or even knew about this. Some haemophilia centres in north Wales were very protective of their patients. They didn't want -- "We don't want you getting in contact with this rowdy bunch of people asking awkward questions."

So Paul, he discussed it with some Birchgrove -- let's see if we can get some funding for an outreach post to find a position where rather than being based in the office, this person would be out on the road, contacting other subcentres, the -- not the main comprehensive care centres, but places like *[redacted]*, down in west Wales, north Wales, mid Wales, finding out how many infected haemophiliacs were out there in the community who weren't getting that level of support and then provide them with that support. So they would go and visit them in their homes, talk to them about treatment options, tell them about Birchgrove and maybe introduce them to us.

So Paul put the funding bid together, drew up the bid. Sadly he became ill himself and passed away, and myself and *[redacted]* took it on, and we put the bid into the Lottery Wales, and the bid was successful and we had three years' funding for the post, and we employed initially two people on a job share, then one of them didn't work out and other person became full-time, and that person was in post, working out in the community, travelling to people's houses for three years.

Q. Birchgrove also involved itself heavily in campaigning and advocacy.

A. Yes.

Q. One of the mechanisms for that, one of the tools that was used, was the newsletter.

A. Yes, yes.

Q. We'll look at some examples of the newsletter that you have drawn to the inquiry's attention in a moment, but one of the things that Birchgrove was keen to advocate for was in respect of the Macfarlane Trust.

A. Mm-hm.

Q. Better financial assistance and a more transparent process; is that right?

A. Yes, yes.

Obviously because we were seeing -- you know, the people who were active in Birchgrove we would share horror stories about our applications for various grants and reasons why we were getting turned down, and there seemed to be a great measure of inconsistency. I might have been successful in applying for this thing, and the guy over here is applying for exactly the same thing in exactly the same circumstances but for whatever reason was turned down. There was no rationale to it.

At some stage they did publish or set up a checklist of things that you could -- that they would and wouldn't fund. If it was outside that, then

tough.

Basically what we wanted was them to be pressing government for more funding, because we knew it was inadequate, and we wanted a level playing field. So it didn't matter that -- the fact that I was, you know, perhaps more articulate than this guy and could write a better application, and maybe someone who was struggling to write, you know, that shouldn't come into it, you know. And the process of going out and getting quotes -- the other thing they would do is they would insist on writing to your doctor to get a medical report on you every time you applied for something. And, well, the people we're talking to, I can't even remember the names, I can remember a couple of names, but they weren't medical professionals, they didn't know any better about the complications of living with HIV than Joe Public. So it was -- you know, you resented it.

So we were trying to get a change in the way the organisation was run and in its funding.

Q. You've summed up in your statement the effects on you of involvement with Birchgrove and SWISH, and you say:

"It was through my involvement with these organisations, particularly Birchgrove, that I discovered I was not alone in my situation, that it

was legitimate to challenge the decisions made by clinicians about managing my health, that I could take back some measure of control over my life, and that by working together with others who experienced the same ill-treatment and neglect, we could make ourselves heard."

A. Yes.

Q. You've drawn to the inquiry's attention and provided us with copies of a number of the newsletters produced by Birchgrove, and there are a number of specific references you wanted to highlight.

A. Yes.

Q. We're going to go to some of them, but I can assure you that all of the newsletters have now become part of the inquiry's record and they contain an enormous amount of incredibly valuable information and insight.

A. Yes. Can I just say that those newsletters -- obviously, you know, we would reprint articles from medical journals with permission, but the bulk of these newsletters, the articles, the personal stories, were written by people -- infected haemophiliacs themselves and we did this without any payment, we -- you know, we put an awful lot -- because this was our main tool to reaching the wider community. We were sending this to haemophilia centres. We knew

haemophilia centre directors and clinicians were reading this and had access to this. We knew that the Macfarlane Trust was seeing it. We knew that the Haemophilia Society was seeing it.

Q. If you have other newsletters beyond those you've already supplied, please do provide them to us.

A. Okay.

Q. The ones we're going to look at, just selected a handful of the references you flagged up.

Henry, can we have 2384003, please.

This is a Birchgrove newsletter, issue number 4. It's from 1994, and it's that first column, it's not terribly clear, but it's "The PAS Interview - Washes Whiter", is the heading, and it says this:

"When the Birchgrove Group discovered that the Macfarlane Trust was willing to undertake research into the needs of its registrants, we began waiting with eagerness and anticipation. We have always advocated that the needs of those involved in living with haemophilia and HIV are many and varied, and we have always felt that the provision has been random and at times limited. We were pleased to discover that the Macfarlane Trust had decided to use an independent body to carry out this needs-led research, and we were happy to participate in talks with PAS, the research company carrying out the survey."

Then skipping a few lines, it says this:

"So it was with not a little disappointment that we have become aware that this research may not be as competent as we had hoped."

Without going into the detail of the rest of the article, it talks about this research commissioned by the Macfarlane Trust being undertaken by those with little or no background understanding of HIV, let alone haemophilia and HIV.

A. Yes. I think the reference to the "washes whiter", it -- this company who were carrying out the survey had done work in advertising and had done research work for Persil, I believe. So I think Paul Jenkins, who wrote the article, is being quite witty, "washes whiter" and it's just going to be another whitewash.

Q. Then if we have, please, 2384004.

This is issue number 5 of 1995. There's an article by you, "What price blood?", but that's not the one you've drawn to my attention. It's the right-hand column that you flagged up.

A. Yes.

Q. And it reflects something that had been said at the Birchgrove conference, and it's this:

"Frustration and anger was again forcefully expressed by people who are affected with haemophilia and HIV at the Birchgrove conference. Registrants believe that it is the role of the Macfarlane Trust to provide adequately for those who are affected. The conference believes that the trust is failing to respond to many of the existing identified needs. The Macfarlane Trust has failed to tackle or examine the wider range of problems or concerns which face those people who are affected with haemophilia or HIV."

Then there was a call for an open letter to be sent to the chair of the trust. Henry, could you go within this same document, please, to page 6.

We can see there the open letter addressed to the Reverend Tanner, chair of the Macfarlane Trust at that time:

"We the undersigned are very concerned about the manner in which the Macfarlane Trust is interpreting its role. We believe that the government, in awarding haemophiliacs with HIV financial recompense, were recognising a unique case which involved considerable and very particular needs. We feel that the current focus of the trust is one of means-related financial assistance. It fails properly to address many of the specific concerns of those that are affected by

haemophilia and HIV. The Macfarlane Trust offers financial assistance in a manner which poorly recognises the effect of HIV on an individual's life and does not adequately encourage or support them in their continued fight for survival."

Then the letter sets out three specific concerns: the inappropriateness of means-related financial assistance, which you've already referred to, Mike; the failure to meet the changing needs of long-term survivors; and the lack of support for bereaved wives, partners and families.

We've heard a lot from witnesses about that third concern.

A. Yes.

Q. Can I ask you a little about the second, the failure to meet the changing needs of long-term survivors.

A. It was probably -- I -- this is my personal view, we used to talk about it in Birchgrove, in the office in Cardiff -- that we thought -- we came to the conclusion that the reason it was so inadequately funded -- and anyone who thinks the Mac Trust was adequately funded, they're living in a different universe to me. But the reason for that was because the government thought that we would probably be all dead by 1995, so there wouldn't be any long-term

survivors. So they hadn't planned for that eventuality.

Of course, even by the time the Mac Trust was set up, we'd been living with it for five years, so they must have known or -- not that they must have known, but they should've anticipated that the disease progression was different amongst different people, different individuals. It was different if you -- depending on whether you were co-infected or mono-infected.

But there was no -- there was no -- there were -- I saw -- someone said something about them being a very reactive organisation, and that's exactly what they were. They weren't proactive at all. There was no anticipation of people's needs.

I'll give you another example. In one of their surveys, and I -- Birchgrove had been putting pressure on them, asking them, "You need to do a proper needs survey, what is it that people -- registrants need?" Anyway, so they came up with this survey which wasn't at all what we had asked for. It was kind of a tick box. "On a score of 1 to 10, how well do you rate Macfarlane Trust? On a score of 1 to 10, how happy are you ..." So it was that sort of exercise. It was asking us to say whether we approved or disapproved, and obviously it was no surprise what sort of answers they were going to get, but they weren't -- the questions weren't designed to ask -- to elicit what we actually needed.

Q. We can see that view expressed in this same document. If you go, please, Henry, to page 3, another reference you have flagged up.

It's, "Open the box", the right-hand column, again by Paul Jenkins.

A. Oh yes, yes.

Q. It refers to this very issue. Second paragraph:

"The Birchgrove Group worked on a report called 'Living with haemophilia and HIV', a document which attempted to describe the special need that existed in our haemophilia and HIV community."

I don't know whether you have a copy of that, Mike, or anyone else. If so, again, the inquiry will be very grateful to receive it.

A. Okay, I'll try and dig it out.

Q. Thank you.

It goes on to say:

"Its main proposal was to demand that more resources be put into the psychological and social needs of those who were affected."

So that's what Birchgrove was calling for.

A. Yes.

Q. It talks then about a meeting with representatives from the trust, and Paul this says:

"I was surprised that the opinion of the trust was that if there were needs that were not being met, then registrants were certainly not expressing this. We pointed out that we were registrants, we had needs that were not being addressed and that we were expressing this on behalf of many other registrants who had similar opinions."

Then there's a reference to the survey. If we go a few paragraphs down, it refers to a customer satisfaction survey:

"I am worried that the original needs-led survey has been overwhelmed by a new type of research, a customer satisfaction survey, ie what do you think of the trust's response times? Are they friendly? Would you use brand X? I am no expert, but I can't see how questions about existing services are going to reveal what my needs are."

Then he says this:

"I am concerned that this research is looking for an answer to a different question, what do people think of the trust? Whilst this may be very interesting it's not going to move the issues forward. Should there be a greater range of services for those with haemophilia and HIV? What about advice for those wishing to start a family? What about help for people to remain active and involve members of society? What about support for the bereaved? I can see only one question in the survey which does relate to developing services: would you still like the trust to spend more on services if this meant reducing the amount spent on regular and single payments? Or, in clear words: you know that money which goes into your family finances every month, the bit that helps with the gas bill, why don't you give it up, or some of it anyway, and then maybe you could have some unspecified services from the mystery box."

A. That was Paul for you. He could tell it very succinctly and very clearly.

The other thing -- the thing to remember, because it refers to the Macfarlane Trust say if there's anyone out there who has these needs they certainly haven't expressed them to us, when we were expressing, because we used to have meetings with Macfarlane Trust staff, we used to go up to London once every couple of months to say this is what needs to be done. But they wouldn't accept us as speaking on behalf of registrants.

And, you know, not every registrant was involved in Birchgrove, not -- maybe not actively, but the majority would -- they would come to our events, they would take our newsletter, so we felt we did have a legitimate voice. Because it was a voice they didn't want to hear they saw us as this antagonistic bunch of people making all these demands, they didn't really want to talk to us or negotiate with us, certainly not in the early days. Things did change later on down the road.

Q. Henry, could we have, please, 2384006.

This is again from 1995. If we go to page 7, please. We'll just pick it up, this part of a much longer article, but it's just part of an article about sperm washing.

A. Yes.

Q. We see this in the first paragraph, it refers to an article on sperm washing having been published back in November 1994, first in this newsletter and subsequently in the Haemophilia Society's bulletin:

"Out of the blue the Macfarlane Trust stopped funding any forms of fertility treatment from November 1994."

That was your direct experience as well, yours and Yvonne's?

A. Yes.

Q. Then on this same document please, Henry, page 15. It's the column headed "Access to Information and Service Provision" that you flagged up, Mike.

It refers to:

"The Haemophilia Society and Birchgrove Group have commissioned a short term study into the provision of information and services for people directly affected by HIV and haemophilia."

You were asking, or the newsletter was asking for help in this stage of the study.

And then it says:

"We've identified key areas which it seems sensible to investigate."

These are the areas that are identified:

"Firstly, it appears that there's very little printed information available which reflects or is targeted at HIV positive haemophiliacs or their partners, families or carers."

Two areas of concern which have been mentioned are the information needs for long-term survivors and information for those who wish to have children.

Then it says:

"This is part of the project we would like to ascertain, if and how care in the community is

working. We realise there may be discrepancies between the theory and people's own experiences and there may be problems with effective and sensitive service provision.

"It has been said that some haemophilia centres are not fully conversant with all HIV-related treatments and care issues."

Again, a point you have made from your own direct experience, Mike:

"There appears to be reluctance in some areas to coordinate or consult with HIV specialist, bearing in mind the long and particularly intense relationship between people with haemophilia and haemophilia centres, this area is likely to be complex."

And then a final area of concern is the role and contribution that HIV-dedicated voluntary organisations are making and/or could make in the provision of information on services for those affected by both haemophilia and HIV.

A. **(Nodded assent)**

Q. Do you know what the outcome of the study was, or what it showed?

A. No, no, I can't remember it, it's so long ago.

Q. I'm sure we can ask others.

Then just two further references of the various

ones you've identified, Mike. 2384007, please. This takes us forward to 2003, and if we could go to pages 8 and 9, please, Henry.

This is about the Macfarlane Trust Partnership Group, and you've talked about that in your statement. Can you just tell us briefly what that was and what its function was.

A. The -- so what we wanted was a forum where we could meet -- so rather than it being the Birchgrove, because our relationship had -- had become very fractious. So it was a partnership group, so what we would have is representatives from Birchgrove, the Haemophilia Society, and registrants who weren't -- necessarily had any connection with Birchgrove, but to be able to meet on a regular basis, discuss the needs of the registrants, so that it would be a less antagonistic forum.

I myself didn't get involved in it, I -- I was in favour of it, but I -- because of my own experiences with particular individuals in the trust, I chose not to get involved. I do know a lot of the people who did get involved in the partnership group.

Q. If we look at page 9, please, Henry, which is part of this article, there's one particular bit that you've -- I think this is one of the bits you flagged

up, it's the second main paragraph:

"One issue bugging many of us was that we could sound off to MFT, write to our MPs, hassle the Hemophilia Society, and generally moan at anyone we could get our hands on. But no way did we have access to the people who matter, the officials and ministers at the Department of Health. We feel that it's important that the government at least know how we feel. Personally I'm not happy with the status quo and find the very existence of the MFT ridiculous in its current format. I am not happy that 20 years on I have to go cap in hand to MFT for financial help that may well be turned down, or that, should I die, my family will have to sink or swim after six months, or that I've not been able to work for ten years and worry about finances constantly. And that's just me, what about all of you, your worries and concerns?"

And that view, expressed here by a particular individual is, as I understand it from reading the full range of Birchgrove material you've given to us, a pretty near unanimous view from those involved in Birchgrove?

A. Oh yes. I mean, I think a lot of the time they must have thought that it was just the same bunch of individuals. But by this time I was no longer involved in the newsletter, I would still write articles for it but I had no editorial involvement at this time. It was a completely new set of individuals, but reiterating the same problems as the writer there says, 10 or 20 years down the road.

So these problems hadn't been resolved, the partnership group itself didn't -- in some ways it was a positive thing, but it didn't resolve all the issues, and I believe that things became worse again later on down the road.

So, yeah, these were widely held attitudes by people towards the Macfarlane Trust.

Q. And then the final reference, 2384014, please, Henry.

I'm not sure I know the date of this, but if we go to pages 10 and 11. You've flagged up an article called Centre Spy.

A. Mm-hm.

Q. Again, it builds upon things that have emerged from your evidence, Mike, from your own direct experience, and it says this:

"How are things down at your local Haemophilia Centre? Are you satisfied that you're getting the best available treatments for your HIV and your hepatitis C related problems? Are you happy with the information provided on CD4 cell counts? Liver

function tests, viral loads, you have been offered a viral load test haven't you? And drugs, I assume that all the various types of drugs [and it lists them] have been explained and offered to you - yes? Very good. But is this actually the case for HIV and haemophiliacs? Whilst I'm not sure or at least I hope that some centres are providing a good service to their clients, there does seem to be at best a lackadaisical attitude, at worst an almost complete ignorance of the latest developments in HIV treatment and care among a number of haemophilia centres up and down the country.

Then if we go to the very bottom of that column, the author says this:

"Which brings me back to where I came in. The quality of service offered by haemophilia centres to their HIV positive patients -- oops, I mean clients -- a case history:

"Client: Doctor, When do you think you will start offering viral load testing?

"Dr Blood: What's that then?

"Client: It's a test developed to ascertain the amount of viral activity in the blood. Been around for a while now apparently. Supposed to be a more accurate indicator of disease progression than just a

CD4 count.

"Doctor: Yes, I think I've heard of it. Still, no worry to worry yourself about that. We'll take good care of you.

"Client: But, Dr Blood, some friends who go up to the GUM clinic are already being offered the test. Why can't I have it?

"Doctor: Oh, you don't want to be listening to those people. You're a haemophiliac, not like them.

"Client: You mean we're still dying?

"Doctor: We're doing everything we can. Trust me."

Then it goes on to say this:

"Don't fob me off with a six-monthly gawk at my tongue and a quick grope under my armpits. Talk to me about combination therapy, about what a viral load test result means for my future health and when and what drugs I should take to stay relatively healthy. Discuss with me, don't dictate to me, what my options are and whether I need to make any changes in my lifestyle. Should I drink less, smoke more, eat less spicy food, have more sex, develop an interest in outdoor pursuits, take up trainspotting, do more or less, any volunteer work for Birchgrove, travel to Tibet, meditate, start pumping iron, cultivate more

esoteric sexual habits, campaign for the legislation of crack cocaine or admit that the game is up and lie down and die.

"Monitor my health, let me know how I'm doing, advise me on which drugs might best suit me, let me know their side-effects and how you might counter them. If I'm seriously ill or the immediate prognosis doesn't look too good, tell me. Don't treat me like a child by assuming I can't take the bad news. I can. Do ask about my partner, my family, my friends. Do be human. And if I decide to experiment with alternative therapists, such as aromatherapy, acupuncture or amaroli, don't start taking the piss, but encourage me or at least support my efforts to take control of my health.

"Outrageous, you say? Can't be done? You're already getting the best care money can provide? Pull the other one.

"There are, I'm sure, some centres that do provide a good level of service such as I've described, but I'm just as sure there are many haemophiliacs up and down the country whose quality of service leaves much to be desired."

You've described that accurately I think to me as a satirical article, but it talks about something which you directly experienced and indeed led to your request for a transfer of your personal HIV care to a different clinic.

A. Yes. Mine wasn't an isolated case. I mean, that was what was happening to me, the lack of treatment, the lack of advice from centre doctors was typical of most of the guys that I got to know.

Q. Mike, those are the questions I have for you. I'm just going to ask Mr Williams if there's anything further he wants me to ask.

No, nothing. But I think there's something further you would like to say.

A. Yes, this won't take long.

I'd like you all to go back 34 years and imagine being 25 years old. You've lived with haemophilia all that time and have managed not to let it dominate your life and define who you are. You're married just under three years. Your wife is four months pregnant, both of you having good careers, a house and mortgage in north London. You have in effect everything to look forward to.

And then what happens? HIV happens.

Like most haemophiliacs who are infected with HIV, I was totally unprepared for the way in which it would change the course of my life. From having

everything to live for to having to come to terms with what was initially a death sentence, the next ten years or so were the most difficult of my life. It impacted not only on my physical and mental health, but on my own and my wife's careers, our plans for having a family, our home, social lives and our relationship.

I'd spent the first 17 or 18 years of my life having to cope with the day-to-day reality of haemophilia. To a large extent this meant I was always being told by parents, teachers, doctors, what I could and couldn't do. I was always resistant to these voices and wanting, like most people, to find my own way in the world. By the time I was a young adult, I was determined that I would make my own decisions and shape my destiny as best I could. I thought I was following this path, and then HIV took it all away.

There was nobody to tell us how to cope or how to go on living. There was no post-test counselling, and for the next ten years there was no psychosocial support of any kind. We were on our own.

Having got over the shock of my initial diagnosis and come to terms with having to live with HIV, the only way we could go on was by living what

was in fact a double life. Although our immediate families were aware of my diagnosis and were supportive, even they weren't aware of the full extent of the problems we faced, largely because we wanted to protect ourselves from confronting the reality of the situation. I talked earlier on about repressing stuff. That's what that's referring to.

To the outside world we presented as a regular couple living a normal life, never revealing or discussing with friends or colleagues the truth about my health. The stigma around HIV meant we were living a secret life. We were terrified that if people found out, we would be ostracised and our daughter shunned by her school friends. More than anything, we wanted to protect her. It's impossible to convey the strain this put on our relationship.

It was only within the confines of the relationship that we were able to talk openly about our hopes and fears, trying to adjust to the new reality and the plans for what had become a more circumscribed life. Although we tried our best to adapt, the truth was the curtailment of our hopes and dreams had a shattering impact on our marriage.

Despite all this, we're still together. Yvonne has stuck by me through everything: health crises,

financial difficulties, and in particular dealing with my erratic mood swings, my anger, bitterness and dark moments, and for this I'll always be grateful.

The isolation came to an end after eight years, when we became involved with Birchgrove. It was through the friendships we made, the support and camaraderie and most of all the purpose it gave me that we were able to get through the pain and fear of living with HIV and hepatitis C.

Many of those friends, men like Paul Jenkins, Cady Khudabux, Paul K, Paul Hooper, *[redacted]*, had their lives cut brutally short, but in founding Birchgrove and empowering so many other, they began a process of advocacy and campaigning that contributed to where we are now with this public inquiry.

There's two things I'd like to say to those individuals.

Cady Khudabux was a Buddhist. He knew he was dying. He was getting lots of infections and he was in very poor shape. He was married and his wife, Deborah, I think had given up her job to look after him through his final days. *[redacted]*

Cady had had no interest on going on any medications. He was very, you know, against medication and he decided, "I'm not going to go on".

When they got Deborah's diagnosis, Cady made the decision that he would go on drugs to keep him well enough to be able to look after Deborah whilst she was going through her final days.

She died -- I can't remember how long it was. It was a matter of months. And as soon as she had passed away, Cady stopped all his medication. He didn't believe in suicide. He knew what it meant, but, you know, he didn't believe in suicide, but more than anything he wanted to be with Deborah, and slowly and surely over the next few months Cady deteriorated and he passed away. But that's the kind of guy he was. Very strong beliefs. But, you know, he did that for Deborah, to be there for her, and this is a man who had his own terminal prognosis.

I'd also like to say something about Paul Jenkins. Really inspirational figure for me. I worked very closely with him on the newsletter and lots of different projects in Birchgrove, and he was just a really inspirational figure for me.

He got to 39 and he had a birthday party in the Vale of Glamorgan. He wasn't a big drinker, but they did food at this pub and it was one of his favourite places to go. We had a birthday party for him. It was his 39th birthday, but he called it his "I almost

made it to 40" birthday. We had a lovely meal. He became very, very ill later that year with AIDS-related illnesses. He rallied a little bit in the December to the extent that -- because he wasn't coming into the office anymore, he was just too ill, he was in and out of hospital. He rallied a little bit and he said he wanted us all to go to a meal to his favourite Chinese restaurant in Swansea. This was in December 1996. So the usual crew from Cardiff, we took him out -- I think Tim Hunt was there as well. So myself, Gareth, Martin and another couple of people, and we went and we had this Chinese, and he was on great, great form, really good form. We thought, you know, perhaps he's going to get through this.

So then Christmas came and went, and then in January I'd been out, Yvonne wasn't home from school. I came home and my daughter was there, and she said, "Dad, I've got some bad news". And I said, "What?" And she said, "Paul is dead". And I said, "Stupid idiot, don't joke about things like that", and of course you don't joke about things like that. But, yeah, he had passed away suddenly early in the new year. And that was -- he was dead before Cady, so he was the first really close friend I had who passed

away, and that just became a common thing over the next few years, having to go to funerals of people who, you know, were dying in their thirties and forties, and they shouldn't be dying then.

I'll just finish this.

I turned 60 this month. It was a day that 34 years ago I didn't think I would live to see. Nor did I think I would live to see my daughter Jess grow up and have children of her own. I'm very lucky to have done so, and like so many HIV positive haemophiliacs whose futures were stolen from them, I'm one of the lucky ones, one of the 20 per cent or so of infected haemophiliacs who have survived. I hope that my evidence today and these closings words will help us to remember those who fought so hard to make a difference but are no longer here.

Thank you, Sir Brian, and to the inquiry team for listening. Thank you.

MS RICHARDS: Thank you.

Sir Brian.

SIR BRIAN LANGSTAFF: I can see why Yvonne encouraged you to become a proper teacher and why you became a writer, because you so obviously enjoy communicating, and you've given us freely a wealth of information about what happened to you, your life,

your thoughts, your views on the Birchgrove and the Macfarlane, I had thought repressing almost nothing, despite having been repressed in times in your life.

But it's obvious that there is still more which you, for perfectly proper reasons, haven't shown us, and indicated by the catch in your voice at the end, which I think everyone will have noticed and made us realise that you've offered us an awful lot.

Thank you very much. You must be tired.

A. Just a little bit.

SIR BRIAN LANGSTAFF: So thank you.

Well, tomorrow, 10 o'clock.

MS RICHARDS: Yes. We have evidence from Ms Jryna Batters, Myles Hutchinson and Paul Hutchinson, and then from two anonymous witnesses.

SIR BRIAN LANGSTAFF: So 10 o'clock tomorrow.

(5.15 pm)

(Adjourned until 10.00 am on Thursday, 31 October 2019)

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