Tuesday, 8 October 2019

(10.13 am)

SIR BRIAN LANGSTAFF: Particularly since we've lost a little bit of time this morning, for which I apologise, now isn't the time for many words from me. We have a full calendar for the next month with a bit of a break in the middle for half term but I would like to mention four matters, if I may.

First, those of you who follow the Inquiry as it has moved from place to place throughout the country will know how great an importance is placed on respecting the wishes of witnesses concerning the way they wish to give their evidence. Part of what makes it easier for many to give their evidence orally as best they would wish to do is having the protection of an anonymity order.

You will have heard me read out the exact terms of an order protecting a witness' identity against disclosure so many times that you may have begun to switch off. Here we go again. A bit like the reaction of the frequent flier who hears the cabin crew's safety talk so often that hearing it again becomes an irritation, without meaning, rather than something which is of importance.

In these weeks of hearing, there will be

a greater number of witnesses who will give evidence anonymously than we have had before. In one case at least the witness will not come into this room to testify. You will hear rather than see the witness.

I'm putting in a plea to each of you, and to the press, to listen carefully to the words of any anonymity order but, more than that, to take care yourselves, each of you, of what anonymity is really all about, and in this Inquiry what we need to be particularly careful about -- this Inquiry of all inquiries -- that is respecting a person's privacy. It's very easy indeed, for the press, media or public to take a photo of someone who is willing to be photographed but it's frighteningly easy too for someone who is not willing to be photoed or videoed to be caught in the background. If you must take photographs with permission, please do take care that such a person is not unintentionally caught.

Second, on a different note I was reflecting last week that it's just over a year ago that I met many of you at Church House for our preliminary hearings. With sadness, I note that some who were there then cannot be with us here now.

What became clear then, and remains clear now, is that a great many have lost what was dearest to

them and for some real financial hardship is the everyday reality and that is through no fault of their own. No-one could fail to have been moved by what they heard, whether politician, press or public, nor lose sight of the fact that some would not see out the Inquiry, however hard the Inquiry tries to work quickly. So I wrote to the Cabinet Office that October outlining the inadequacies and variation in financial support and suggested that decisive action should be taken.

A year on, evidence is being given by witness after witness which has underscored the point but also a year on some disparities remain. Of course, I'm not yet in a position to report final conclusions and make recommendations but I would hope that nonetheless there remains the will to take further meaningful steps forward.

Third, I'd like to say a word to those who have things to say to me but think it may be too late to make a contribution. It isn't. It really isn't. Every witness statement contributed between now and the end of the Inquiry will be read. Do not, please, think that because someone else has said much the same as you would say there's no point in your saying it too. Everyone is different.

Everyone has their own story to tell and if it is the fact that one witness statement says more or less the same as another, that itself is valuable because each of them is supporting evidence for the other.

It may be that there's a link between the reluctance of some perhaps to give a witness statement with what I said about anonymity just a few minutes ago. You may not yet have come forward because you are nervous about the reaction of others to what you have to say. If you feel like that, it may be that you have some particularly distressing experiences to relate and, if so, I acknowledge that that makes it all the more difficult to speak out. But at the same time, it makes it all the more important for the Inquiry to hear what has happened. Be assured the Inquiry will do what it can to respect your privacy if that is important to you.

Fourth, if you have given a witness statement and would like to be heard, do not please think at the end of this set of hearings that you have lost the chance, any chance, of that. I promised to put people who had been infected or affected by the suffering of others not only first but last.

I shall keep that promise.

Well, I shouldn't take up any more time since the schedule we have set ourselves for these next three weeks is challenging. The evidence that has been collected and needed to be explored orally demanded that we take three not two weeks as originally planned and many days within those weeks are closely packed. On each day we shall simply go on until we finish the witnesses scheduled for that day. If on an individual level you find it too long or too draining, then I'm sorry but I hope you understand the reasons for that because they reflect the sheer amount of material that you have already offered us.

So thank you once again for listening to what I've had to say and now, without any more taking of time, on to our first witnesses together who wish to be known as ...?

MS RICHARDS: Colin and Denise, sir.

DENISE TURTON, sworn

COLIN TURTON, sworn

Questioned by MS RICHARDS

MS RICHARDS: Colin and Denise, you are here to give evidence about what happened to your son, Lee. Your daughter Kerry sits with you. Prior to the Inquiry

you've not spoken publicly about Lee before; is that right?

DENISE: That's right, yes.

MS RICHARDS: But you felt you wanted to come and explain what happened to Lee.

DENISE: Yes, we did. It's the last chance.

MS RICHARDS: Lee was born in 1981 and he was the first of your four children.

DENISE: Yes.

MS RICHARDS: He was diagnosed with haemophilia A when he was a baby. How did that come about?

DENISE: At six months old he was having -- he was crying a lot with one of his hips so we called the local GP out who, they do the hip test and they sent him to hospital and because they couldn't find anything wrong with him and they kept him in for a week, a week, because they obviously thought we'd hurt him.

So every morning we would go in, we were pulled into a little room to be asked if, you know, what was home life like. After a week they done a blood test on him and his arm came up like a big balloon and that's when they realised that he had haemophilia.

MS RICHARDS: What were you told about the severity of his haemophilia?

DENISE: He was mild.

MS RICHARDS: But later on you were informed that his haemophilia was more than mild, was severe.

DENISE: He was severe, yes.

MS RICHARDS: Now Lee's care until 1989 was at Bristol; is that right?

DENISE: Yes.

MS RICHARDS: He was under the care of Dr Burman until 1987.

DENISE: Yes.

MS RICHARDS: The treatment that Lee initially received for his haemophilia was cryoprecipitate when he was a baby.

DENISE: Yes, he did.

MS RICHARDS: You would go to hospital for him to receive that treatment.

DENISE: Yes. I don't think he had many treatments with the cryo but, yes, we always went to the hospital.

MS RICHARDS: That changed to Factor VIII products when Lee was still a baby in about early 1982.

DENISE: Mmm.

MS RICHARDS: What were you told was the reason for the switch from cryoprecipitate to Factor VIII?

DENISE: Factor VIII, it would be easier because the cryo took so long to go in so the Factor VIII would be

easier with a small child to get into him.

MS RICHARDS: I think it's right, Colin, you say in your statement that you were also told that cryoprecipitate would no longer be available.

COLIN: That's correct, yes.

MS RICHARDS: We can see that from one of the documents. Paul, could we have on screen please 1575012. We can see the very bottom entry. This is a later entry from Lee's medical records, 1985, but the last two lines say:

"Swapped from cryo to Factor VIII around 1982 because cryo not available."

Were you given, either of you, and I think you used to attend the consultations together for the most part, were you given any information or advice or warnings about any risks of infection from the Factor VIII products?

DENISE: No.

MS RICHARDS: Had you been told there was any risk of infection with a virus to Lee, what would you have done?

DENISE: We wouldn't have given him the Factor VIII.

MS RICHARDS: The products which Lee received were NHS Factor VIII products, as far as you're aware.

DENISE: Yes.

MS RICHARDS: We can see that from a couple of documents.
Paul, could we have up on screen, please, 1574002. That's it. We can see this is a letter from the Avon Health Authority a number of years later, November 1997, the main paragraph says:
"I enclose for your attention a schedule of the cryoprecipitate and Factor VIII administered to Lee Turton between 1982 and March 1985. I am advised that all of this material was NHS product and none of it was commercial of American origin. I am also advised that this material was not heat treated as heat treated NHS products were not available until April 1985."
Then if we go to the next page please, Paul, we can see the schedule referred to. We see there it suggested, if you go towards the top of the page, please, Paul, under "NHS Factor VIII", it is suggested there that the first date that Lee received it was March 1982 but, in fact, his records show that he received Factor VIII first in January 1982. We can see that all the products listed there are NHS Factor VIII.
DENISE: Yes.
MS RICHARDS: Those products were all administered at Bristol with I think one exception when Lee was

treated elsewhere.
COLIN: Torbay.
MS RICHARDS: Colin, your statement says as far as you know that again it was NHS product that he received that one occasion in Torbay in 1984.
COLIN: Yes.
MS RICHARDS: You both recall, as I understand it, becoming generally aware of news reports about AIDS and the possibility of it affecting the haemophilia community, and you spoke to Lee's consultant, Dr Burman, and asked him if there were any risks to Lee. What did he tell you?
DENISE: He told us that Lee was only having British Factor VIII so there was no risk. He wasn't having imported American Factor VIII and he did say all the children were getting British Factor VIII.
MS RICHARDS: You don't, I think, recall when that conversation was but it was before Lee was diagnosed.
DENISE: Yes.
MS RICHARDS: Now, in the course of 1985 when Lee was four years old, you were called into the hospital to see Dr Burman to be told of Lee's diagnosis with what we would now call HIV. We'll look at some records in a moment but, first of all, what can both of you recall about that meeting?

DENISE: We were called in. I can remember going into the room and it was Dr Burman and there was another doctor in there and I can remember he stood by the doorway, the other doctor, and I'm not sure if it was Dr Oakhill or not, and he just told us they'd had a discussion, this is Dr Burman, they'd had a discussion between all of them and they weren't going to tell us but they decided they would tell us that Lee was HIV positive.
MS RICHARDS: You are both critical in your statements of the manner in which that news was broken to you, what you have described as the attitude as the doctor. You've described it as arrogant in your statements. Is that right?
DENISE: Yes, he was very arrogant. He was the professional person and you knew he was a professional. He always came across as, you know, "I'm in charge".
MS RICHARDS: Can you recall what, if anything, you were told about the prognosis for Lee at that time?
DENISE: We weren't actually told much at all. That day he told us, we asked -- because I was angry at the time and I did shout at him saying, "You told us it was British Factor VIII, you know, why has this happened?" And he said, "If you've you got any more

questions", he went towards the door, to open the door, and said, "If you've got any more questions make an appointment to come back and see us", and we also -- before we went he said we wanted it kept private.
MS RICHARDS: Were you given any practical advice on managing Lee's haemophilia in light of this news?
COLIN: None.
MS RICHARDS: Were you given any advice on possible risks to yourself or to Kerry who was about two years old at the time.
DENISE: No.
MS RICHARDS: Had you known prior to that meeting that Lee was being tested for HIV?
DENISE: No, not at all.
MS RICHARDS: Now, in your statements you've suggested that Lee was diagnosed in March 1985 but that you weren't told until August 1985. You didn't have the benefit of all of the medical records then and we've since looked at the medical records and we can see that it's likely that you were told in June 1985 and I think you accept that?
DENISE: Yes.
MS RICHARDS: We'll just try and look at some of the documents and try and get some of the dates as part of

your evidence.

If we have up on screen please, Paul, 1574002, this is the letter we have already looked at but if we can look at the last paragraph on the letter it says this:

"Lee Turton was known to be HIV negative in February 1984 and was found to be HIV positive on 8 March 1985."

That gives the date on which Lee first tested positive for HIV as being 8 March 1985.

If we can then have up on screen please, Paul, 1575004, we can see here again it's a later letter but it says that Lee was first found to be HIV positive in March 1985. The previous September he was negative, so the window within which Lee was infected is roughly some point from the autumn of 1984 to the spring of 1985. The March 1985 test results are not in Lee's medical records.

I think it's right you had some difficulty obtaining Lee's medical records. What happened when you tried to get them?

DENISE: The medical records we did apply for them but obviously they just didn't want to send them out. We had to wait so long for them but we also applied for the GP records from the PCSE. We waited 11 months and that was only because we asked our solicitors and they had to do it. They sent -- we sent it off, done what we had to do, we had a letter back to say they were dealing with it, we had to wait 40 days, give them 40 days. We kept phoning them back up and they saying they were with the clinician and every time we phoned they were with the clinician but they could not contact the clinician and then we had a letter through to say they either wanted a grant of probate or his last will and testament for the child.

MS RICHARDS: How old was Lee when he died?

DENISE: Ten. I phoned them up and I said he's ten and they said you have to do one of them.

MS RICHARDS: When you were trying to get his medical records, that was when? Was that a long time ago or was that recently?

COLIN: Last September.

DENISE: Last year, last September.

MS RICHARDS: So we don't have the March 1985 test result. There is one from early May of 1985, a positive HTLV-III result.

If we look next at 1575008, please, Paul, we can see here -- oh, can we take that down, please. Sorry there's a name, someone else that's not been redacted. I am going to read out the relevant parts of the letter.

This is a letter that was sent by Dr Daly to Dr Burman 31 May 1985 and it says this:

"Dear Dr Burman, I enclose the results of the anti-HTLV III antibody testing on the haemophiliac children. As you will note both Lee Turton who was a mildly affected Factor VIII deficient patient and [another child] who is a severely affected Factor VIII deficient patient are both anti-HTLV~III positive. These patients are now high risk patients. I would be grateful if you could see them and counsel them and their parents appropriately as they are so young the main problem with these patients will be in the injection of Factor VIII concentrate to them, which would put the parents or whoever the administrator is at slight risk of contamination and they obviously ought to wear gloves."

Denise, you looked after Lee full time, but you looked after him in particular when he had a bleed.

DENISE: Yes.

MS RICHARDS: And you had a two year old toddler at home. Were you and Colin told of the need to wear gloves?

DENISE: No.

MS RICHARDS: The letter continues:

"If you want I can arrange for the parents of both these children to be tested. I am going to look through their records to see whether or not these children ever received commercial Factor VIII concentrate or whether they were, in fact, contaminated by British Factor VIII concentrate. I will let you know the results of this. I regret to have to give you what must really be tragic results in the light that these samples were taken prior to the commencement of heat-treated British Factor VIII concentrate."

So that's the letter Dr Daly wrote to Dr Burman, 31 May 1985.

If we have up on screen please, Paul, 1575006, this is a later letter, November 1988, to Dr Daly again. We'll just look at the last sentence please:

"It is almost certain that he [that's Lee] acquired his HIV infection from one particular batch of NHS concentrate just prior to the introduction of heat-treating."

If we then have up on screen please 1575010 this is a letter of 14 June 1985. If we just look at the second page please, Paul, we can see it's from a Dr Donaldson, senior registrar, to Dr Burman.

If we go up to the top of the page, please, the first page, we can see it's a letter to the GP. It's dated 14 June 1985 and I think you now accept this is in all likelihood when you were first told of Lee's infection.

DENISE: Yes.

MS RICHARDS: It says this:

"I saw Lee's parents recently following a report from the laboratory that he is positive to HTLV-III virus. This retrovirus is, as you know, implicated in the cause of acquired immune deficiency syndrome, AIDS. Whereas a significant number of homosexual subjects who have raised antibodies in the HTLV-III virus go on to get clinical AIDS the risk appears to be far lower in the haemophilia population. To date there are 5,000 haemophiliacs in the UK, approximately 50 per cent of whom are antibody positive to HTLV-III. Only four cases of AIDS have been described in haemophiliacs in the UK and a comparable number in the USA."

And then it says this:

"The chance of Lee developing AIDS is therefore extremely small and I stressed this to his parents."

Do you recall that information being given to you, that you were told that it was unlikely he would develop AIDS?

DENISE: Yes.

MS RICHARDS: Then if we carry on with the letter, please, it says:

"He has obviously met the virus through receiving human Factor VIII pooled from multiple donors, but from now on there should be no further exposure since the Factor VIII obtained is British not American and is heat treated."

Then again we see a reference to the importance of wearing needles (sic) as a precaution, the haematologists recommend -- sorry, wearing gloves, that anyone taking blood from or administering blood products -- I'm sorry, can we take that down. We have the wrong name in there again. In any event, it is a letter being written about you and it has the name of the other child in there who was not yours, but it was again a reference to the importance of wearing gloves and you were not told that.

DENISE: No.

MS RICHARDS: Then if we can have one final letter up please 1575012 -- sorry, my apologies. It is the third page of that. Thank you.

This is a letter, if we go down to the last page, thank you, 22 July 1985, and this is from Dr Burman who you remember having the conversations with:

"I saw the parents of Lee Turton in out-patients here on 16 July and it says however it is now known that at least half the haemophiliacs in the country have this virus, yet very few of them have AIDS."

It refers to him giving you the analogy of polio. Do you recall that? Any discussion about an analogy with polio.

DENISE: I think there was actually, yes.

MS RICHARDS: Then it says in the next paragraph that:

"We really do not know the significance of the finding. Quite clearly it's worrying for them. I pointed out the low risks. I have told them there is no point in worrying about things as we did not know what to do about it at the moment but if in the future there is some change in policy we will be the first to let them know. I hope I have been reassuring but I have told them that honestly I cannot promise that Lee will not get AIDS."

Other than the meetings that we've seen described in these two letters in June and July 1985, do you recall any other meetings in which you were given advice or information about how Lee's illness might develop?

DENISE: No, never. They always used to say, "You know as much as we know".

MS RICHARDS: Lee was only four when you had this news and you didn't tell him because of his young age. Just tell us a little what he was like at that age as a four year old boy.

COLIN: He was a bright, intelligent child, joking, always joking, wasn't he?

DENISE: Happy little boy.

COLIN: Yes, happy little boy.

MS RICHARDS: When was it that he started to become unwell?

DENISE: About '86 he started really going downhill.

MS RICHARDS: You have described in your statements he started to lose energy.

DENISE: Yes. He would get tired. He didn't want to eat, did he? He was just not himself. He was just really, really low. He just wanted to go to bed.

MS RICHARDS: In about 1988 your statement suggests he started to acquire a number of infections.

DENISE: Yes.

MS RICHARDS: The impression your statements give is that he was never really well after that.

DENISE: No.

MS RICHARDS: There's one further letter I want to put on screen and you have seen it this morning. It's 1575009, please, Paul. It's dated 21 December 1987 so Lee was not well by this time but before he'd started developing the serious infections you describe in your statements. It is written by a locum consultant paediatrician to a senior medical officer with the DHSS and it says this:

"Lee has acquired from one of his batches of Factor VIII HTLV-III positive status. He is asymptomatic at present but will sooner or later develop full-blown AIDS syndrome from which he will die."

Were you ever told that?

DENISE: No.

MS RICHARDS: When Lee was about seven, he was started on AZT. What can you tell us about that?

DENISE: They told him about his virus because we had to tell him because obviously AZT and AIDS and everything was on the news and he wasn't stupid. He knew something was wrong, so he was told why he was taking AZT and we tried to do it as basic as we possibly

could. But from then he just went downhill, didn't he?

COLIN: Yes.

DENISE: He just went downhill so, so quick and he was on a very high dose of AZT.

MS RICHARDS: You were particularly worried about the high dose.

DENISE: Yes.

MS RICHARDS: You knew of another child who was HIV positive being treated at the same hospital, also haemophiliac, who was not receiving AZT at all.

DENISE: Yes.

MS RICHARDS: As I understand it that led you to question whether Lee was being given AZT for the purpose of research.

DENISE: Yes.

MS RICHARDS: In April 1989 you moved to Cornwall. Lee transferred to the care of Dr Daly at the Royal Cornwall Hospital. What was it that led to that move?

DENISE: We'd had -- when Lee started school in '85 and somebody had leaked it to the school -- well, I don't know if it was the school it had been leaked to but they'd leaked it to the press that Lee was starting school and he was HIV positive, so we'd had a lot of problems with the press. Parents didn't want him at

the school. There was a teacher at school that wouldn't teach him. He ... sorry.

MS RICHARDS: Take your time.

DENISE: Yes, we had the press knocking on the door, banging on the windows when he was small and the school would phone up and say the press were outside the school so I'd have to go and get him and take him out the back entrance. Parents wouldn't stand by you. He wasn't invited to friends. He wasn't invited to parties, which was very hard, not only for him but for Kerry as well because they were both at school. So we decided once he started on AZT and he started getting worse we decided to move from the area to give him a childhood the best we could without nobody knowing who he was.

MS RICHARDS: Kerry's described in her statement her recollection as a child of having to keep the curtains closed in the house because of the press being outside, of having to go in via the back entrance to school escorted by a teacher because of the press and press knocking at the door.

In terms of Lee's own schooling, Denise, you have said in your statement it was really a very isolating experience for Lee at school.

DENISE: Yes.

MS RICHARDS: Your statements describe after the move to Cornwall Lee's physical deterioration and ill health. What is it you feel able to tell us about that? I can take it from your statements, if you would prefer.

COLIN: Eyesight, his chest.

DENISE: He couldn't walk far, he couldn't breathe, he couldn't eat, he was fed eventually through a tube. He had intermittent ... where he couldn't hear and some days he couldn't see properly, bloated stomach. It was just infection after infection. We spent most of the time in hospital, in and out of hospital with him and they never -- could never found out what was wrong with him, what infection it was. Or they didn't tell us what it was.

MS RICHARDS: He would stay awake at night and have night sweats.

DENISE: Yes.

MS RICHARDS: He was frightened.

DENISE: He would say, "I'm frightened".

MS RICHARDS: He was in pain and you would take it in turns to sit up with him and give him reassurance through the night.

DENISE: Yes.

MS RICHARDS: You largely tried to keep his illness, particularly after the move to Cornwall and what had happened with the press where you previously lived because of the stigmatising effect of AIDS but one consequence of that and of your move to Cornwall was you yourselves as a family felt alone. You didn't have relatives and friends around.

DENISE: No, we didn't have the support.

MS RICHARDS: Lee's health continued to get worse and on 12 January 1992, Denise, you found Lee on the bathroom floor fitting.

DENISE: Yes.

MS RICHARDS: What happened after that?

DENISE: Well, he just -- he was continuously fitting so we called the ambulance out because we'd gone to stay with Colin's Mum and Dad at the time so we were at their house in Bristol so the ambulance took him to the children's hospital in Bristol. They took him off for a scan but they didn't tell us the result and Lee wanted to go home so we insisted that he went back to Cornwall because that's where he wanted to go.

So they took him back in an ambulance and you drove back in the car and Kerry stayed with our in-laws and then, when we got back to Cornwall, they actually told us he had between -- they called us in, didn't they -- two and ten days to live.

They said he'd an infection on the brain, so

we insisted that he went home that day because that's what he wanted to do. He kept asking to go home, so we took him home. They didn't want him to go home.

COLIN: No.

DENISE: They sent out a nurse with us and in the next few days we were told we couldn't have him buried, while he was dying, he wouldn't be allowed to be buried because of the virus. He would have to be cremated. He died on the eighth day.

MS RICHARDS: Lee himself told you that he was very frightened.

DENISE: Yes.

MS RICHARDS: He died on 22 January 1992 when he was ten years old.

DENISE: Yes.

MS RICHARDS: As you have said, you were told he couldn't be buried.

DENISE: Yes.

MS RICHARDS: You insisted.

DENISE: We insisted. He died on the Wednesday and we insisted he was being buried and we found out on the Thursday the vicar would bury him but it had to be done on the Monday so we had two days to organise a funeral and get relatives and get -- because we got

Kerry back early because he was dying.

MS RICHARDS: You felt the whole thing was very rushed.

DENISE: It was very rushed. When you're grieving you can't -- we couldn't do what we wanted to do funeral-wise. It was just a rush. You're grieving. You're just not thinking straight.

MS RICHARDS: It was after Lee died that you became aware from his medical records some, I think many years after, that he also had been infected with hepatitis C.

DENISE: Yes, we didn't know.

MS RICHARDS: The impact on both of you of losing your son you say in your statements is still to this day and every day extremely painful for you both and when you're asked how many children you have you sometimes simply say three because you don't want to explain what happened to Lee.

DENISE: It's just easier.

MS RICHARDS: You've both found it hard to trust people and make new friends.

DENISE: Yes.

MS RICHARDS: You have become very wary.

DENISE: *(Nodded)*

MS RICHARDS: You find it very hard to trust medical professionals.

DENISE: Definitely.

MS RICHARDS: You've remained very private in the years that have followed.

DENISE: *Yes.*

MS RICHARDS: In terms of your own health, you Denise have had physical health problems yourself.

DENISE: Yes.

MS RICHARDS: You've both been on antidepressants.

DENISE: Yes.

MS RICHARDS: Which you attribute to the events you have just been telling us about.

DENISE: Yes.

MS RICHARDS: You also say this in your statement, Colin, that you blame yourselves and each other and you say, "We let it happen".

COLIN: Yes. We trusted professionals, believed in them.

MS RICHARDS: Were either of you ever offered counselling or psychological support?

COLIN: No.

DENISE: No.

MS RICHARDS: Was Lee ever offered anything?

DENISE: No. I think Kerry was once.

KERRY: *(Nodded)*

MS RICHARDS: You had given up your job, Colin, for the move to Cornwall and although you found a new job you had to give that up because of the amount of time that Lee was in hospital.

COLIN: They laid me off because I wasn't there, basically.

MS RICHARDS: In 1993 after Lee's death you moved again to find work and you have said, Colin, that you have worked, consultancy work, since Lee's death but you have never felt able to concentrate on your work in the way that you used to be able to.

COLIN: No.

MS RICHARDS: In terms of the impact upon your other children, Kerry's provided a statement to the Inquiry and she's explained in that that after Lee died she was bullied at school, she was beaten up and she was told to die like her brother, and she still has flashbacks.

You feel that all your children, Kerry and Robin who was only a few months old when Lee died and Jack who was born after Lee's death have all been greatly affected. They grew up, those two, not knowing their elder brother.

DENISE: Yes, and also Jack has severe haemophilia as well.

MS RICHARDS: You had some involvement with the HIV litigation and you felt pressured to accept the

settlement that was offered. What can you tell us about that.

DENISE: Lee was ill at the time. It was '91, he wasn't very well and we'd been asked to sign the form to say that we would not take anything any further and we refused, we kept refusing and then we had the solicitor kept asking, saying, "If you don't sign -- you need to sign because if you don't do it nobody else will get anything", and in the end we only had three days in which to sign it because we kept saying no, so we signed it because we were told that if we didn't nobody would get anything and then they told us afterwards that Lee's money, even though he was dying, would be put in trust until he was 18.

MS RICHARDS: So you weren't able to spend it for his benefit.

DENISE: We had to go through and fight to say he needed it because we wanted him to have what he wanted because he died the year after. He was ill and they were putting it in trust.

MS RICHARDS: You had some dealings with the Macfarlane Trust and, Colin, you have said in your statement that some payments were received but all assistance stopped after Lee died.

COLIN: Definitely true, yes.

MS RICHARDS: Was there any financial assistance for Lee's funeral?

DENISE: I think we paid for it. I don't think we had any help with anything. It might have been Lee's money that we had left.

MS RICHARDS: What was your experience of the application process?

DENISE: We used to have to apply and we used to have to get a quote. We didn't actually have much from them. I think we had a washing machine.

COLIN: We had a washing machine and sheets and blankets.

DENISE: And sheets because of the night sweats.

COLIN: Yes.

DENISE: We didn't actually apply for much at all.

MS RICHARDS: What Colin said in his statement is:

"The application process seemed unnecessarily problematic. Whenever we asked for assistance [and you said that wasn't very often] we had to wait for a very long time to get a response and then there were meetings to discuss it. All the time our son was dying. The application process took ages and it made us feel like we were begging for money."

DENISE: Yes.

MS RICHARDS: Because of that, you didn't apply for help very often, regardless of the fact that you needed it.

DENISE: *(Nodded)*

MS RICHARDS: Those are the questions I have for you. We have a video we're going to play in a moment but before that is there anything else either of you would like to say?

DENISE: I just want to say just a little bit. All I want to say is the pain of reliving what happened to Lee is nothing compared to the pain and suffering he had in his short life. We lost our beautiful son and brother, as did so many parents like Colin and Jan, who lost their little Colin at seven. We listen to MPs shouting about fearing for their safety. Haemophiliacs were fearing for their lives and the safety of the Factor VIII that they were using. The Government knew the Factor VIII being used was infected, as did the pharmaceutical companies, and did nothing.

MS RICHARDS: Just before we play the video, I am going to ask Mr Snowden if there's anything else he wants to ask.

Paul, could we play Lee's video, please. I should just say, you wanted me to explain that this is Lee's last Christmas and he died four weeks later.

(Video played)

DENISE: Can I just thank Jason Evans for doing that for us and the Factor VIII Group.

MS RICHARDS: Thank you.

SIR BRIAN LANGSTAFF: I would like to thank you myself. It's obviously so very raw all the more I think shows that you have a special something that brings you here to tell us more or less for the first time something which is inevitably going to be difficult particularly for a young lad who was so obviously loved as he was. Thank you very much.

We'll take a break until 11.35. If those if you who are downstairs if you can begin to move up probably five minutes before it avoids the problems of congestion with the lifts. Sorry to be so mundane after what we have just heard.

(11.04 am)

(A short break)

(11.38 am)

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

MS RICHARDS: Yes, sir.

SIR BRIAN LANGSTAFF: Sue, please.

SUSAN THREAKALL, sworn

Questioned by MS RICHARDS

Q. Sue, you are here to talk about your husband, Bob, and

can we have up on screen please, Paul, a photo of Bob with your son, David -- thank you -- and we're going to keep that photo on screen apart from when we have other documents or other material displayed.

That was a photo taken in 1985.

A. About 1985, yes, on our holiday in Aberdovey.

Q. Bob was born in 1943.

A. Yes.

Q. And diagnosed with severe haemophilia A. How was he treated during his childhood and young adulthood and how did his haemophilia affect him?

A. I think it needs to be remembered that Bob was actually ten years older than me so he was -- had he survived he would be one of the oldest surviving haemophiliacs. He would be nearly 80 and when he was a child things were very, very different. There was no treatment, basically, other than bed rest, hot and cold compresses. They tried things like snake venom, I think some of the older men remember that. Goodness knows what that was supposed to do but they tried it. It didn't work.

So, as I said, it was mainly bed rest and he spent, apparently, according to his Mum, who was a really great friend, she was lovely, many, many days and nights just lying in bed and so she, like

most haemophilia mums was a fabulous advocate, really strong and she would sit with him night after night when he was in pain and bleeding and no treatment.

Bob as an adult became a very, very good chess player. He was actually a chess champion for the DHSS and the reason for that is she sat up night after night teaching him how to play chess. He also made apparently a little hole in the wall by the side of his bed where his imaginary friend the mouse lived and when his Dad would redecorate the room apparently he had to paper round the hole. So, yes, it was an unusual childhood.

As far as education went, he was denied an education initially. They just couldn't find a school to have him. Mainstream schools wouldn't look at him so again his Mum went into battle and got him into Wilson Stuart special school in Birmingham, which was and remains one of the finest special schools in Birmingham. It's fantastic.

There he became head boy and head of the scout troop because, as he said to me afterwards, he was the only one there really capable of doing it because he was basically a normal little boy but with haemophilia.

Q. His haemophilia didn't stop him being very active, very busy and leading a very normal full life.

A. No, not at all. I mean, he came out from Wilson Stuart with no qualifications because they didn't take them at that school and he took himself off to night school, got whatever he needed to get into the civil service and made a pretty good career out of that.

He got married, had two boys, had his own home, to all intents and purposes leading a normal life. I mean, when I met him we used to do things like play badminton believe it or not and to see a haemophiliac playing badminton is quite an interesting spectacle, but then I'm rubbish at badminton, so I would run up and down in front of the net frantically trying to find the shuttlecock and he would do this kind of giraffe walk at the back and, you know, manage to actually hit them because he got much better co-ordination.

As I said, he played badminton. You know, we had active holidays.

Q. It was when he was about 21 that he started to receive cryoprecipitate.

A. Yes.

Q. You have said in your statement that that transformed the treatment of his haemophilia for a number of years.

A. I think it did for all haemophiliacs, yes, because until then there wasn't any treatment. Yes, it was time consuming and they had to go to hospital to have it administered but it worked most of the time and, yes, they got used to it. He was fine.

Q. Could we have up on screen please, Paul, 1564003.

This is a chronology you have put together from Bob's records. We can see from this, 1968, being given fresh frozen plasma and cryoprecipitate and then 1977 being given cryoprecipitate in April of 1977. November 1977 notes that he doesn't have many severe bleeds and misses little off work.

Then we come to October 1977, 23 October, when he was admitted to hospital with a bleed in his thigh. This, as you understand it, was when he was first given not cryoprecipitate but Factor VIII products.

A. Yes, this was probably around about the time I first met him. I met him in the late '70s so I think he'd just started on it when we met.

Q. He was treated at the Haemophilia Centre at the Queen Elizabeth Hospital in Birmingham throughout this period. He was under the care of Dr Ian Franklin and Dr Frank Hill?

A. Mainly Dr Franklin but yes.

Q. His medical records show that following that first administration of Factor VIII in October of 1977 he received Factor VIII in January of 1978 and November of 1979.

Can we just have up on screen please, Paul, 1564002.

We can then see, and this is an extract again from Bob's medical records, that box there shows in 1980 and 1981 Bob receiving Factor VIII BPL on three occasions and Factorate on a fourth occasion.

Then if we can have up please, Paul, 1564011, turn that round, these are from the UKHCDO database records and if we look from the bottom of the page please, Paul, up, we can see 1977 onwards and if we look to the right-hand column we can see that Bob received a range of different products, sometimes the BPL NHS Factor VIII but he received a range of different commercial Factor VIII products.

A. He did. Can I just make an observation about that?

Q. Absolutely.

A. I have applied to the UKHCDO for their records probably two/three times. I phoned them up and all I've been provided with is a sheet about, you know, that long *(indicated)*, four or five treatments for his entire life. It is so wrong that we, as the victims, cannot get co-operation from these official bodies and have to rely on solicitors and legal people to do it. You know, I'm so impressed that you got that because I battled for ages and couldn't get anything.

Q. If we just look at one further document which is 1564012, we can see there this is a letter that was sent by the West Midlands Regional Health Authority to Bob in May 1990 and we can again see a number of treatments listed there which show us the range of different products.

Now, they don't entirely tally, as I understand it, the two documents we have seen, the UKHCDO and this.

A. No.

Q. They are not entirely compatible.

A. And I'm not entirely surprised but ...

Q. But what they do show is that Bob received both NHS and commercial products over the period from 1977 onwards.

A. Mmm.

Q. Now, you and Bob married in 1981 but you had known each other as friends and work colleagues since about 1977.

A. Yes.

Q. Was Bob, as far as you know, given any advice or warnings or information about risks, any risks associated with the Factor VIII products?

A. Well, obviously I wasn't there at the time but based on conversations with Bob over a long period of time afterwards, no, none at all.

He didn't want to transfer to it. He got a sort of natural suspicion about it. He used to -- I could never understand in my naiveté then why he was reluctant to treat a bleed and, apart from the fact he could never find a vein, he just didn't want to use the product. I said, "Well, for goodness sake, if it stops bleeding why not just use it", and he said, "Because you don't know what's in it".

Q. Was he ever, as far as you know, given any advice or information or any choice about the different Factor VIII products?

A. No.

Q. In 1981, approximately 1981, correct me if I'm wrong, Bob was infected with hepatitis B?

A. Yes, it was before we got married, definitely. I noticed yesterday the dates in his hospital records are actually wrong because they refer to it at one stage.

Yes, he got -- he said he got hepatitis B. He was very jaundiced, really quite unwell and

I remember the only advice we were given was dietary. The reason I remember that is because, I mean, my culinary skills are not actually legendary but I did learn to make this vegetable pie because apparently he couldn't eat meat. I remember at the time as I was still living at home with my Mum and we ate it round there, so that's why I knew it was before we got married.

Q. What was he told, if anything, about the hepatitis B and how was he told about it?

A. You know, it will go away in time, won't do you any harm. You know, just get on with it, get better and live your life basically.

Q. It was information that was given to him on his own at regular clinic appointment.

A. Mmm.

Q. What was the effect of the hepatitis B? Did it pass?

A. It did but retrospectively I mean, you can look back, I mean, hindsight's a great thing but I think the damage to his liver began then. As I said, he was clearly very unwell while it was active. But then based on the information we were given we just kind of forgot about it and got on.

Q. Now, your witness statement explains that Bob tested positive for HIV, HTLV-III as the records then refer

to it, in 1985 but wasn't told about it until the summer and was told alone at a regular clinic appointment?

A. Mmm.

Q. We will look at the records in a moment but what can you recall about how he learnt and how you learnt about it?

A. I recall that we were waiting to hear what the result was and that that day he was going into the clinic to get it. I was working as a teacher at a local school at the time and I recall he came round at lunchtime to see me. I don't know whether we went out or whether we just sat in the car but I do remember sitting on the driver's side so we might have popped out or he might just have gone over into my car, I don't know, and he said, well, it was positive.

I said, "Well, what else did they say? What advice, did they give?" And he said, "Well, they said I've got to use protection when we have sex and tell Sue not to get pregnant for a couple of years", and that was it.

Q. Any advice about prognosis?

A. No. He was told at one stage that he might be fortunate, the haemophiliacs might be fortunate because they may actually have been inoculated against

it.

Q. Any advice about practicalities other than in relation to sexual relationship, any advice about the practicalities of managing the infection?

A. No, not a thing. The press did a better job of that actually because they were always saying, "Do you share toothbrushes?" No, why would anyone share a toothbrush regardless of HIV, but other people seemed more conscious of it being passed on. I think partly due to the Government advertising campaign which was catastrophic for haemophiliacs.

Q. We'll just look at a handful of records to look at the dates of tests and appointments, Sue. Paul, can we have up on screen please 1564008. We can see here, top of the page, 23 January 1985, there's a reference to Bob attending:

"Had venipuncture for HBV and HTLV-III."

So blood taken for testing in January 1985.

Then if we look at, please, 1564014, if we look here, the first half of the page, again we can see the date of the blood specimen 23 January 1985. The examination, the purpose of it is HTLV-III and hepatitis screen. We have a date stamp of 25 January 1985 but only a result there in relation to the hepatitis B. Nothing on this document in relation

to the HTLV-III.

But if we then look at 1564015, we can see here PHLS, Public Health Laboratory Service, virus reference laboratory request for HTLV-III investigation. Again, the date 23 January 1985 there faintly and if we go down to the bottom of the page, please, Paul, we see the result there, positive. There's no date of the actual result.

The first test result we can see in Bob's records is 1564016 and we can see the bottom of the page positive for antibody to HTLV-III 4 March 1985. So whether or not there was a delay between January and March, by the beginning of March there's a result in the medical records.

As far as you can recall, Bob wasn't told until the July of 1985.

A. No, definitely not.

Q. We can see that -- we can see actually if we put 1564010, please, up on screen, that should be -- is there a second page to that? Thank you.

We can see there there's an entry for 6 April 1985, so this is after the test result that we've just looked at. There's no reference there to the diagnosis being communicated to Bob. Then if we go to 1564021 -- we can see at the bottom of the page in fact it says:

"Check HTLV-III antibody."

Then if we go to 1564021, please, Paul, this is not a terribly easy copy to read but it's a letter 5 July 1985. It's sent by Dr Hill to Dr O'Brien, the GP --

A. Who wasn't actually Bob's doctor. He hadn't actually been Bob's doctor since before we got married, so I assume our GP never saw this.

Q. So it was sent to Bob's former GP but it says this:

"This man has severe haemophilia and has been trained to administer his Factor VIII concentrate at home but like 60 per cent of our haemophiliac patients who have been treated with American Factor VIII concentrate, has developed antibodies to the HTLV-III virus. We are still unsure what significance to place on these results other that he has been exposed to the virus."

Then if we just go further down the page it says this:

"I have therefore advised him to wear a sheath during intercourse and the virus can be --

SIR BRIAN LANGSTAFF: Contracted.

MS RICHARDS: -- "contracted", thank you, sir, "through sexual intercourse. I have also advised him and his wife not to have another child in the near future."

So that would suggest your recollection of July 1985 was born out by this record. This is when Bob was told.

A. Yes.

Q. You don't know what, if any, is the reason for the delay between the blood sample being taken in January and Bob being told?

A. I've absolutely no idea but it seems to have been a very common practice at the time.

Q. Then we can see 1564010, please, if we can go to the next page.

The top entry is 25 July 1985. It says:

"Seen with wife to discuss AIDS. Current situation is they wish to have further children", and then there's a reference to you being tested and "to be seen by me when result known".

Can you recall anything about that subsequent consultation and you going along to be tested?

A. I recall being tested, yes. I do recall writing to Dr Franklin after Bob had had his positive result, you know, basically saying we needed more information but then I think this was the point when I started off into campaign mode really because as well as writing to Dr Franklin I wrote to all sorts of people, including, you know, the National Federation of Haemophilia and the Haemophilia Society and, you know, the Birmingham Evening Mail and lord knows who else. I imagine that that meeting was just a response to me saying we need to know more.

Q. We can take that down thanks, Paul, and put the photograph back up.

Now, in 1985 when you received this news you had been married for just four years and you had a two year old son. What was the impact of the diagnosis on your lives together at that point?

A. It put tremendous strain on our relationship. It changed I think people's perception of us. We were very fortunate in that we got a close-knit circle of friends and a good social life that revolved round friends, you know, and good jobs and the people that we interacted with on a daily basis appeared to accept it, appeared to be supportive. But you see you never know what's going on quietly in the background.

It was interesting to hear the lady earlier on say about her son not being invited to many birthday parties. David wasn't. He was a very, very quiet child but still at the back of your mind you think is that because we were the AIDS family, and that's how we were known.

Suddenly, as I said earlier on, all these adverts on the television, you know the crashing tombstones all the rest of it, whenever they came on you would be thinking, well, that's us. It didn't feel like us because we didn't feel any different, you know. People started dying, Rock Hudson we were talking about earlier on, various other people, and it became more and more real and more and more scary.

You know, people were told don't die of ignorance. A letter to Birmingham Evening Mail suggested that everyone with HIV should be instantly rounded up and put on an island somewhere off the coast of Scotland I think was the preferred venue and, you know, we were suddenly dealing with all this.

I told my amazing boss at work. He was one of the best people I've ever worked for, he was fabulous, but even he said, "Sue, be careful who you tell", and I thought, "No, we've done nothing wrong. You know, I'm not going to be careful who I tell. If people don't like it and can't deal with it that is their problem".

I'm glad we took that approach but, yes, it changed us as a family. It changed the interaction between us, between obviously him and his Mum, because she was worried to death, you know, his sister. Everyone was very protective of Bob and there was this non-information. There was this void of information, you know, people just floundering around, not helped by the fact that haemophiliacs, generally, I know Bob certainly and I know a lot of others were stuck in a haematology unit when specialist AIDS units were springing up round the country, so they never had that specialism that was developing. They just sat with haematologists who were learning as they went along, basically.

Q. You have described in your witness statement the impact in particular on Bob of his whole life becoming defined by the infection.

A. Mmm.

Q. And his plans and dreams crashing down around him.

A. Yes. I mean, Bob's first marriage had fallen apart I think through no fault of his own. He gained full custody of his two boys, which was unusual in those days, had to give up his own home and then move in with his Mum who helped bring the boys up, and when he met me it was kind of a new start. We bought this beautiful old Victorian house, strictly speaking actually he bought it, if I'm being completely honest.

You know, a lovely garden. We had nice holidays. We both got good jobs. Then David came along to complete the picture. The boys always lived with us, the step-sons, from day 1.

So he got this kind of second chance and then the whole thing was ripped away, you know. The rug was pulled from under him.

Q. You, prior to the diagnosis, you had been wanting to try for a second child but Bob was desperate not to infect you.

A. He was and he is quoted as saying I was desperate for a second child but obviously he'd already got three so there wasn't the same yearning for another baby really. I wanted one so that David had a sibling closer to his own age, because obviously the other two were quite a bit older and I must admit I got a bit like a dog with a bone, you know, because I'm not very good when people say you can't do that.

So I kind of pursued that and -- we investigated everything. I remember Paul Hooper, who you have heard from or you will hear from, Paul and I were, independently of each other I have to say, investigating sperm washing techniques. That was just in its infancy, you know, but we did a lot of research into that, and I wrote to the Oxford

Haemophilia Centre, you know, to see what they knew, knowing that they were the reference centre, the biggest centre in the area, and we were eventually offered an appointment down there.

Do you want to hear about that now?

Q. Yes, absolutely.

A. Well, we saw Dr Rizza at Oxford and he gave different advice, in my opinion, to everybody else. He was kind of saying, well, if you want to go for it, yes, there's a risk but -- and then he went on to say that people don't like discussing their sex lives and there's obviously -- there's clearly a bigger risk with anal sex and people don't like to tell you if they've been indulging in anal sex. He was basically saying that the heterosexual transmissions were probably through anal sex, so as long as you don't do that you should be okay.

That didn't go down very well with the Queen Elizabeth.

Q. Were you getting different advice from the Queen Elizabeth Hospital?

A. Yes, totally different. It was basically: don't.

Q. Bob's physical health started to deteriorate. What can you tell us about that?

A. He wasn't too bad until he was put on AZT and after

that it was just catastrophic. It was like slipping off the side of a mountain. He got multiple infections. They were constant. It was tonsillitis or it was a urinary tract infection or he'd have a chest infection or something would be wrong somewhere. He was never free of infection. He lost a tremendous amount of weight. He started looking like an AIDS victim, but that didn't happen until AZT was started. Then the huge doses they were giving people in those days, he was on 1200 milligrammes a day in two divided doses which I said at the Archer Inquiry is enough to kill a horse and I think it probably is.

Q. He started to have night sweats, fevers, bouts of diarrhoea, he always felt cold, and he had difficulty swallowing.

A. He did. He had oral thrush, which was more than likely straight down his oesophagus, yes, and he was having problems swallowing. Yes, I just have this vision of this man, cold all the time.

Q. We have a picture of Bob at the beach on his very last holiday in August 1990 which we'll show.

Paul, it's 1564018, please.

We can see how much weight Bob had lost.

A. When he saw that photograph -- I should probably get struck down by something in a minute because when he saw that he was horrified. You shouldn't have taken it, you know. He was appalled himself.

The background to this is yes, it was our last holiday. It was in Pembrokeshire and we booked a holiday cottage which turned out to be completely unsuitable for various reasons that I won't go into. David had his seventh birthday during that holiday. I contracted campylobacter food poisoning which is like norovirus times two. I was just so ill.

If I look back -- and this is not me being dramatic, I promise -- I should have been in hospital on a drip. You know, I'd got uncontrollable vomiting and diarrhoea. Bob ended up with a bleed. We both ended up at the local GP and then the Public Health Department came down to check me over when they found out what was wrong and Bob's attitude was, "You're just being so difficult and look at the mess you are making". This wasn't the man I married. It was like why can't you drive ... you know, it was so hard.

That beach is actually Pendine Sands in Pembrokeshire. It's the one where they do the world speed records and in those days you could actually park on the beach and that's why we were there

because he could barely walk. I could barely walk. I was just about upright again. That was his one venture out of the car.

Q. Paul, we can take that down and put back the photo of Bob and David, thank you.

You described Bob to the Archer Inquiry in these terms, Sue. You said:

"He was just an ordinary man living an ordinary life. He was a great dad, partner, brilliant friend. He was good fun. He was practical, dependable, reliable and as honest and honourable as it was possible to be."

A. Yes, I stand by all that. I would also and that he was very old fashioned I suppose because of his age and his upbringing. He would refer to me as "my good wife" or he'd say -- he'd write in letters "your good self". You know, it was very archaic but very sweet, you know.

Q. What was the effect on Bob emotionally, psychologically, of his increasing ill health?

A. He just changed. His personality changed. I remember one day when, it was probably a couple of months before he died, I went to get my hair done, mainly to get out of the house, I've got to be honest. I came back in and David, as I said, was seven. We had

a long sort of living room joined on to the kitchen, you know, all the walls had been knocked down and things, and David he wasn't running but he came down from the kitchen to the television at the other end of the living room as a seven year old would and Bob said, "Will you just stop him running around", you know, and I remember thinking this is so unfair on me, on David, he was doing nothing wrong at all. But he just couldn't cope.

I can't remember what he was like with the two older boys but I think they generally kind of kept out of the way and, in fact, Paul had left home anyway by that stage so ...

Q. You described in your statement Bob becoming very, very frightened.

A. He was frightened, yes. He was terrified particularly of PCP pneumonia which he knew he was susceptible to and the slightest cough or sneeze -- you could see the terror just etched on his face. Again, this is like confession time but one night he'd been going on all day saying, "I think I might have PCP. Are you sure it's not pneumonia", and he just basically had a little bit of a tickle, you know, and this sounds awful. He wasn't actually ill that day and in the end I just couldn't stand it anymore. I just walked out

and went up to my friend's up the road and spent an hour up there and crept back with my tail between my legs later on.

But you get to the stage where it doesn't matter how much you love and care for someone, you can only put up with so much criticism and so much negativity, you know.

Q. It got to the stage where he didn't want you to go out or go anywhere. He wanted you to be there with him.

A. I was talking to the milkman one day, we have had the same milkman for years, and it was probably, "Rubbish weather. Do you think it will snow, and I'll have a couple of pints of semi-skimmed", or whatever. I went back into the living room and Bob said what were you talking about? It's the milkman, you know.

Then on another occasion I booked to go on an art course at the local library. It only lasted a couple of hours. It was just a one-off. I remember we were given pastels and we had to recreate this I think it was a renaissance type picture, that one with the women in the bar, you know, and I was really pleased with what I'd done. The tutors were excellent and I absolutely loved every minute of it and it was just a break for me. I went outside and Bob was standing there with

David, "Do you know how long you've been? What have you been doing?" You know, and it just makes you feel what else can I do. I try and get everything right for everybody. I try and keep all the balls and -- is it balls or plates in the air -- I don't know -- but either way there weren't any in the air because they just kept crashing down around me, you know.

Q. Bob was also very angry and he was angry in particular your statement says because he had not been given the opportunity to make his own informed choice about the treatment he had received.

A. But you see, there wasn't a choice because what they did, the UKHCDO deliberately phased out the production of cryoprecipitate and, as I said yesterday, that doesn't happen with anything else. If I went to my GP and she said, "Oh, Sue, we've got this really great anti-inflammatory that's just come on the market. I think it would be ideal for you. It's XY and Z and everything", if I decided to start taking it and it didn't agree with me, I would expect to go back and she'd say, "Well, never mind we'll go back on whatever you're on now", but that didn't happen because they took away all choice. There was nothing left for them to go on to.

Q. Was Bob ever offered or were you ever offered during the time you are describing any psychological support or counselling of any kind?

A. No. We had a couple of people, Mary Fletcher and another lady called Mary from Oxford, who talked to us in Oxford and they came up and talked to us in Birmingham. But they weren't proper counsellors. They were lovely, but they were just social workers -- I don't mean "just" social workers. You know what I mean.

Then we pushed and pushed and pushed as a patient group to get somebody appointed at the Queen Elizabeth and they eventually appointed Shirley Mallon as a social worker and Shirley was magnificent. She was great but, again, it wasn't counselling.

No. The only time I've ever got close to having counselling was when three or four years ago the Government allocated a pot of money to the Hep C Trust and you could apply and I thought about it for a couple of weeks and I thought, well, actually, yes, for me and David. So I applied and it's no easy thing to admit that you need help, you know. They sent the forms out and I filled them in and helped David fill his in. We got them sent off and

after a bit I phoned them up and they said, "Oh, we've got no money left".

Q. Despite everything you've described about Bob's health, he carried on working as the DHSS executive officer until about six months before he died.

A. He was determined to work for as long as possible, yes, he loved his job.

Q. But the point came when he could no longer work.

A. Yes.

Q. What can you tell us about the last weeks and days of Bob's life?

A. Before I go on to that I'll just say that I actually gave up work in the summer of that year because things were intolerable at home and at work. I had a new boss who, although he knew about Bob, had no empathy or understanding at all. I would tackle it differently now. I'd get in touch with the union, try and get compassionate leave or something, but he clearly thought I wasn't doing my job probably, which I probably wasn't at this stage, and he used to say, "I need you here early in the morning". Bear in mind I'd run the school as an acting head for two terms before he came, so I think I knew roughly what I was doing but, "You need to be here earlier. You need to be here later. I'm sending you on management

courses", and he sent me on management courses that involved me going away from home for -- only for days but a long distance to travel back. I remember one day breaking down on the M5 and just -- and I don't do this but just sitting sobbing on the hard shoulder. It was awful.

So, yes, I gave up work then. Bob's last Christmas 1990/1991 was very difficult. We've got photographs of him sitting at a neighbour's house and you look -- at the time you think it's normal in a way, you are kind of living with this day-to-day and you don't realise how bad it is. You look back at photographs and think, "My God, how could you not have realised how ill he was", but we were never told. We were never told he was terminal. Our GP was told. There's a letter in Bob's notes saying it's palliative care only. We were never told, so I certainly wasn't expecting that he would die then.

He deteriorated very rapidly. It was a horrible, horrible winter. We had an awful lot of snow. It was very cold. We'd got a big house. I kept the heating on full plus, you know, gas fires and stuff but he could never get warm. He started to go kind of blue tinged, you know, that's the only way I can explain it, nails, lips and so on. What we didn't realise was his chest was so bad that he just wasn't able to get in the oxygen that his body needed. It wasn't just the cold. It was a physical thing.

The reason we didn't realise it, was he'd had an x-ray at the QE I think early January which apparently showed shadowing on both lungs and they did nothing. This is a man who is at very high risk of PCP pneumonia and they did nothing. He may well have had antibiotics from our GP, I can't remember, but certainly as far as the hospital goes they had obviously given up on him and decided he was going to die anyway so they just let him go home.

In contrast to that, a few years ago I had really bad chest infection, ended up coughing up blood and all sorts of nasty things. I had a chest x-rays immediately. I had a CT scan. I had to have regular CT scans every six months for the next two or three years, and that is standard treatment. Well, it's gold standard treatment, but he wasn't even allowed that, you know, shadowing on both lungs, okay, go home and die, basically.

He did his last piece of television work. He used to enjoy doing the press work but he really didn't want to do that final one because he was so

poorly but he got up and did it. He was due to go into hospital on a Monday because they were going to fit a nasogastric tube to try and give him some nutrition because he was so emaciated. I didn't know at the time they had also ordered a whole battery of other tests. Why would you do that on someone who is clearly dying, you know.

By this Sunday, the day before he was due to go in, he was so poorly, I mean, so desperately ill, I was just absolutely frantic. I just didn't know which way to turn. I made various calls to the Queen Elizabeth Hospital and their attitude eventually was, "All right, if you insist, bring him in then". So my best friend and I managed to get him into the car. It didn't occur to me to ring an ambulance but I don't know A&E wouldn't have been the best place anyway. Got him into the car, took him to the back entrance at the QE. I had to pester a porter for a wheelchair because he couldn't walk. We got him into the wheelchair, got him up on to the ward and the doctor turned round to me and said, "Well, he doesn't look as bad as you made out he was on the phone".

They then did a series of tests. They x-rayed his chest and did loads of bloods and everything and

all of a sudden there was all hell let loose. I got taken into a small room with three doctors, I think, and they were showing me the chest x-rays and clearly trying to tell me that the Bob was dying and I just wasn't having any of it. You know, it just wasn't going in.

He said, "But he's got no -- do you realise what we're trying to tell you. He has no or relatively no normal lung tissue left. It's all been destroyed". So by this time Bob was on 100 per cent oxygen and still blue. He then started to hallucinate and get very, very agitated and confused. Apparently, all his electrolytes were out of sync. I'm not quite sure how that works.

They changed his drip. I remember I went to shut the curtains in his room because it was late afternoon early evening. He went mad, "What are you doing? What are you doing?" I said, "Well, it's going dark".

"No, no, no, it's daytime, it's daytime." I remember saying but look Coronation Street or whatever it was was on the television and he wouldn't have it. He was so frightened because he thought it was daytime and we were shutting curtains and doing evening things, you know.

I have to apologise for the next bit because it may be all completely out of sync because the next two or three days just blurred into one. He was put in charge of -- Dr Franklin was in Scotland on some sort of conference. He was put in the charge of a junior doctor called Dr Rousseau. She was very sweet. She was very Greek or Cypriot and her English wasn't particularly good but the main thing was she was exhausted. She sat there going, "So tired, I'm so tired", and she said she'd done a 72-hour shift and she was now covering for someone else and, "I didn't want to do this. Oh God, I don't know what I'm doing".

Now I would be jumping up and down screaming for a decent consultant, any consultant, anyone that knew what they were doing but in those days we were all just being dragged along, you know.

Anyway, one of the things that, apparently, was supposed to be done had he been admitted normally was arterial blood gasses which basically means puncturing an artery and getting some blood out of it and finding out how much oxygen is in it. The haemophilia sister was sent for to give him some Factor VIII. She was crying, sobbing, she said, "Please, don't do this. You can see what his blood gases are like. He's blue, even on oxygen".

"No, no, no, I have to do this. Dr Franklin's written it down. I need to do this." Now, again, now I'd launch myself in between Bob and her and there would be no doubt that she wouldn't have got near him but I wasn't that person then, you know.

So we stood back, both haemophilia sisters in floods of tears. They had to take the oxygen mask off Bob to find out what his normal oxygen levels would have been, so they let him -- he was struggling for breath at that point and she insisted on doing these blood gases. They treated him for TB. They treated him with erythromycin which we told them would give him diarrhoea. They gave him -- oh, I can't remember, some other antibiotic, but then they also decided that they would give him pentamidine which is the sort of second line treatment for PCP because he was allergic to Septrin which at that time was the first line.

The doctor brought me the leaflet in the middle of the night, you know, the leaflets that go with the drugs and she said, "Can you read this through and tell me what side effects I'm supposed to look for. I don't understand it", so I did and it was basically they had to be monitored, they had

to lie flat, they had to have their blood pressure regularly checked because the main thing was a catastrophic drop in blood pressure.

That afternoon he had appalling diarrhoea. Luckily I had a friend with me who was a male nurse and we cleaned him up. There was not a nurse in sight. We sorted all that out.

His Mum came along and we gave him a bed bath. This is all quite biblical really. It's weird looking back on it, you know. His sister came and then we realised how poorly he was so we started making phone calls. We got his son back from university in Brighton and his oldest step-son came. David was poorly himself and also only seven and it was night time and he was in bed, you know. Bob had perked up a little bit.

He had actually had a little bit to eat, a bit of jelly or something like that and he was able to swallow it and he was quite lucid and then all of a sudden his blood pressure absolutely hit the floor and there were doctors and nurses flying round all over the place.

Oh, incidentally, one other thing was I was convinced he was seriously dehydrated because his drip ran out, the one with the pentamidine in, and

I was interrupting hand over meetings, attacking every nurse that I could find, "Will you please come and put some more fluids up".

"No, no, no, we'll do them when we give him the next dose", and it is recorded in his notes post-mortem dehydrated. They wouldn't listen. It was really at that time that he deteriorated very rapidly.

Anyway, it suddenly at that point occurred to me that actually this was really happening. He was dying and I remember Paul, my step-son, standing behind me with his arms around me, Bob in the bed. Bob's last words were, "Is everything sorted", and I know he meant financially, so I lied and I said, "Yeah, it's all fine", and he then just crashed and this young doctor, terrified, the look on his face I'll never forget, pulled him up the bed, I've no idea why, somebody said it might have been a technique to raise the blood pressure but I would have thought you're better off lying down for that, I do not know why he did it, but his arms flopped out, it looked like he was being crucified and, actually, that's exactly what was happening to him if you think about it.

I don't remember getting home. I remember

being taken to the room. I remember going back to see Bob in the room that he was in and they put these horrible -- why do people do this? Why do they treat people with so little respect, this horrible, horrible quilt over him that, you know, my nan would have thrown out and I think they thought they were doing something nice but he's lying there dead with this horrid thing over him.

Anyway, we went home, don't know how I got home, no idea. I remember it was full of people crying but trying to not to because we didn't want to wake David up. I remember my sister grabbed a bottle of wine and hauled me off to bed with a couple of glasses and bottle. You know, it's whatever gets you through the night sometimes I suppose.

The next morning we phoned the hospital to say could we come and see him in the chapel of rest and they said, "No, because he is in a body bag and we will not open the body bag", so then the Chairman of the local group of the Haemophilia Society got involved and eventually after a few calls they agreed to open it but only to chest level. So we all trouped along to the -- well, it's a mortuary really, isn't it, at the hospital and, again, we were met by Carey Howells, the haemophilia sister who was in floods of tears again, and she said, "Sue, I've tried. I've really tried. I can't shut his eyes. His eyes aren't shut". What do you say? We went in and Bob was lying there from the chest up. I don't believe he'd been washed. I don't believe he's been dressed -- I don't remember really what he was wearing but I do remember that round his neck they put this ghastly horrible cardboard ruff, you know, like clowns wear. Why would you do that? I mean, you know.

His eyes were open and in his right eye there was a little bit of cotton or fluff or something and he'd got the same expression on his face that he had when he died the night before.

Now, if you look back into ancient history, every culture respects the dead. Look at what the Egyptians did, burying them with artefacts and so on for the after-life. You know very ancient people, prehistoric people respected the dead. They looked after their dead, and we just didn't. Not with haemophiliacs with AIDS, we didn't.

Q. Bob died on 20 February 1991?

A. Mmm.

Q. He was 47 years old?

A. He was.

Q. It was only after his death, some time after his death, you learnt he had also been infected with hepatitis C, you found a post-mortem reference to non-A non-B but you haven't been able to find anything else about hepatitis C.

A. No, we knew nothing.

Q. What was the effect of what you described on Bob's Mum who he and you were very close to?

A. She was an amazing, amazing woman. I mean, a week or so after he died she gently suggested to me that I really needed to do something about the funeral. I was just walking around -- I didn't know whether it was day or night, let alone organise funerals.

She was always there for us. She was amazing. But she'd lost her only son. She'd fought for him since he was a tiny baby. She'd fought to get him an education. She'd fought for treatment for him. She'd watched him through three -- two marriages, not three, and to lose him was devastating and she never recovered, and two or three years later I was at work and I got a call to say the fire brigade had had to break into her flat and they found her dead headfirst in the china cabinet with a brain haemorrhage.

Q. Bob's three sons, without going into any detail about their lives, Bob's three sons, your own and your two step-sons, all struggled with the loss of their father.

A. They did, all in different ways but yes.

Q. Bob's eldest son in his written evidence to the Archer Inquiry described Bob as:

"My Dad was the glue that held our family together."

A. Yes. I mean, I tried but it's the difference between Gorilla Glue and wallpaper paste, you know.

Q. As you have described, you had been a deputy headteacher. You had given that up to care for Bob.

A. Yes.

Q. How were you after Bob's death?

A. I was a mess, absolute mess. I did try and go back to some teaching. I mean, I loved my career, absolutely loved it. Even now I will dream about children in a classroom two or three times a week, all the things that I used to love doing with them. I think I was good at my job but I could never get it back. Yes, as I said, I was a mess. I lost weight, I just -- I couldn't cope with being a mother anymore. I couldn't cope with being a sort of homemaker anymore. It was just so difficult doing all that on

my own.

Some women have been a lot stronger than me, some women have managed to hold it together but it was just so, so -- the things that I was proud of, I loved being a mum. I adored it. When David came along it was that unconditional love, you know, and still is, but I think I'd found something I could do, something I was good at. My own I family background is quite dysfunctional I suppose, weird. I never felt secure at home but I did once I got my own home but then it all just fell apart.

Q. Your best friend has provided her view in an email that you are both happy for me to quote from.

A. Yes, it's only your very best friend that could write this.

Q. She says this:

"In the early years" -- you have been best friends for nearly 40 years.

A. 40 years.

Q. "In the early years Sue had an extremely responsible job as a deputy headteacher and was an aspiring headteacher. She was also a wife to Bob and mother to David and two step-sons. As Bob became increasingly unwell Sue found all her responsibilities overwhelming and was forced to resign from her deputy headship.

Once it became impossible for Sue to care for Bob at home he was hospitalised. Sue was at his side constantly. She lost all sense of day and night. A friend or myself would go to the hospital at perhaps midnight or 1 am and insist she came home for some rest. During this time, David was looked after by Bob's mother, Hazel, and friends. Following Bob's death Sue ceased to be the person I knew. She rapidly lost weight. She was constantly dashing in and out of the house dealing with legalities, being interviewed by the press, going to gigs until the early hours of the morning, something she had never done before. When she was at home it was a constant round of phone calls and a house full of reporters, and cameramen. All David wanted was his mum but she was reacting to Bob's death. It often fell to me to read him his bedtime story or bring him to our house to eat with our family."

That's her perspective.

A. Which I think is probably very fair.

Q. You have not been able to return to full-time teaching. Your own health has suffered over the years and you've attributed that, in part at least to the stress of everything you've described?

A. Possibly. I think it could be. I mean, in last ten

years I've had a hysterectomy, a hip replacement, a knee replacement and breast cancer.

Q. In terms of your financial position, Bob had had to give up work, you had to give up work, so two solid incomes lost.

A. Yes.

Q. How after Bob's death have you managed financially?

A. I'm embarrassed by how bad it's been. I mean really embarrassed.

It's been really, really difficult. I mean, I've moved house, I've taken on various jobs. I have done teaching. I've done short-term contracts but, as you say, quite rightly, never full-time work again proper.

I've worked in care homes. I've helped run a sub post office. I've done work in the Crown post office in our local town. I've taught foreign students English. I've done home tuition. I've done all sorts of stuff. I've been a ward clerk at two different hospitals, but I've never, ever been able to make up that solid regular income again and I think this is what's lacking and I think it's where the Government is undeniably cruel in that they throw money at people and then go to the press bleating about how awful we are and, you know, how

we scrounge from them and in the last few months we've given them this, and we've given them that and we've given the other.

Now, yes, £20,000, £10,000, 50 or whatever it is sounds an awful lot of money to the man in the street, but if you then look at it in terms of lost income, lost pensions and so on, and you get this one-off payment and what you do then is you replace everything that's broken and you try and save some to keep you going for the future and then it's gone again and you've still got no regular money coming in.

Q. I am going to ask you in a minute about your dealings with the Macfarlane Trust but before you do that you have given three examples in your witness statement of quite how awful things were in terms of your ability to manage financially, not having enough money to get the car put through an MOT so as to be able to continue to get to work.

A. Mmm.

Q. Going through your pockets, bags and drawers to find 50 pence to use for enough petrol to get home.

A. That did happen one night. Various people since have said why didn't you say? Because it's embarrassing, that's why.

Q. Small but important practical things like not being able to afford new glasses?

A. My glasses are just an ongoing nightmare. I've got very poor sight anyway and I've got a really complicated prescription and I think the Macfarlane Trust paid for a repair or a new set of glasses at one stage but they wouldn't help again and I broke my glasses and for two years I was going round with an old prescription which was giving me ocular migraines, which are horrible, it's like you're having a stroke, it's awful, everything's like a kaleidoscope, you know. I couldn't see. I got continual headaches and so on until I could afford some new glasses.

They flatly refused to pay for them. I think you'll demonstrate why in a bit or their reason why, and I have to say the EIBSS have been exactly the same, if not worse. Since I had breast cancer last year the radiotherapy has caused very dry eyes and it's also exacerbated cataracts in both eyes. I have had three lots of glasses in the last 18 months. I'm blind as a bat at the moment and I can't afford another pair and they flatly refuse to pay.

Q. In general terms before we look at some specific correspondence, in general terms what have been your experiences of dealing with the Macfarlane Trust?

A. Right at the beginning they were okay. I mean, there were people like Ann Hithersay who was very kind, she was lovely. She used to phone us up at home and say, "Are you okay? What's going on? Is there anything you need, anything we can help you with", and that continued for some time after Bob died but then I think they were beginning to realise that as people were dying they weren't actually getting rid of the problem. They were inheriting a new one in terms of widows and children and they started to tighten up and become very difficult.

I always had a policy that if I did need some help, I would approach them because after all that's what they were set up to do and I just tried to, I don't know, encourage them to do their job really and I would also advocate on behalf of other people and, in particular, David I would always try and get him help.

I was told by a trustee a few years ago that because all these requests would have to go in front of a committee, I was told by a trustee that the minute they know you're involved they turn it down on principle.

Q. You were also I think told that the Macfarlane Trust had given you more than any other widow but you then learnt that other widows had been told the same thing.

A. Clair Walton looked at me and laughed and said, "Oh you as well. They told me that too".

Q. You had a loan from the Macfarlane Trust secured on your house.

A. Yes. I applied for a grant and they flatly refused and this was a point when I was paying the mortgage on credit cards and buying food on credit cards and you get pushed into this corner and you have no choice. They offered it as a loan and I took it and they then said, "Well, we'd like £300-odd a month in repayments".

Now, if I had had £300-odd a month spare I wouldn't have been asking them for a loan or any assistance. So we settled eventually on £25 a month which came out of the top-up payment I was getting at the time and that was deducted at source.

So you go to them or you went to them, and I see no difference now, in financial distress, you are already in debt and all they do is give you another debt and not only that they have then got a share of your house as well.

Q. You expressed your view in your witness statement of

what you describe as a fundamental problem of no money ever being paid to widows in their own right?

A. They've never recognised the widows' losses. To be fair, they haven't recognised anybody losses particularly well because they have never done a proper assessment of impact or loss.

So what they did was to pluck this sum of money out of the air and there is a pot, and they said, well, we'll distribute it between the different groups that we have created and oh goody that will set you off one against the other and you can spend the next couple of years arguing about who's getting what and that lets us off the hook for a bit. I'm certain that is their logic.

Q. A number of years after Bob's death you began a relationship with a new partner?

A. Mmm.

Q. How did that affect the Macfarlane Trust's dealing with you?

A. Well, basically, they suddenly decided they'd come up with a policy, until I actually asked to see the policy, when they started referring to it I think as an unwritten policy, that they do not give grants to women who have moved on, for example, finding a new partner.

Now, my argument there is it's threefold really. First of all, the only reason we found a new partner was because the old one had been murdered by the treatment. I don't use the word "murdered" lightly.

The second thing is it makes two assumptions, first of all, that any new man in your life is perfectly happy to take on full financial responsibility for you and is able to do so, and the second assumption is that the widow or the woman is equally happy for this man to waltz into her life and say, "Don't worry, dear. You just sit at home and knit or something and I'll deal with all the finances".

You know, this is not the 1800s. I had a really good income. I'm not even talking about Bob's income. I'm talking about my income which was lost, my pension which was lost. It should be a really substantial pension and it's about 8,000 a year.

Q. You had a letter after you to moved to Devon from the Macfarlane Trust which started, you described in your witness statement, with these words:

"When you moved to Devon with your new partner leaving your son behind in Birmingham."

A. I will never, ever forgive *[redacted]* for saying that, ever, and I'm a very forgiving person, but no.

Q. We will just look at the letters or emails that deal with the policy that you have described. Paul could we have up on screen, please, 1564004.

We can see it's a letter dated 8 December 2006. It refers to a clothing grant being agreed for David but then says that the NSSC have declined additional assistance to you for the following reasons, three reasons given, and then the fourth is this:

"Although there is no firm policy the Trust takes the view that after ten years following bereavement and where a non-infected widow has the good fortune to establish another relationship, that individuals should be afforded every opportunity to move forward in the context of that relationship and enable the Trust to provide support to others in less fortunate circumstances."

A. Yes, how very generous of them.

Q. Your response, Sue, we can see at 1564005. If you go down, first of all, to the bottom of the page, please, Paul, this is your email of 12 December 2006 and if we go on to the next page, please, Paul, we can just pick it up where it says:

"Good fortunate to establish another relationship."

You say this, Sue:

"'Good fortunate to establish another relationship', words fail me. Why do you think I did this? It was not easy, believe me. If Bob had not died I wouldn't have had to. My partner as you well know is not able to contribute financially. If he was I certainly wouldn't be begging for money. It is impossible to move forward as you put it when I am facing financial ruin."

Then we see the response, if we you go back to the first page please, Paul. We see the response in an email of 20 December 2006. The penultimate bullet point says this:

"The ten-year cut-off plan is not formulaic. It is an approximate time-frame that the Trust applies to those who have been bereaved but have managed to gain some sort of independence (i.e. embarking on a new relationship being just one component of that phase)."

The issue then came up --

A. Then they wished me a merry Christmas at the end.

Q. I should say in the context of you having said in your email:

"I should like to ask that you reconsider your decision and ask that you afford me a grant at least to get through Christmas."

A. Mmm.

Q. Paul, could we have up on screen next 156006, please. This is 16 June 2008:

"Dear Sue, the NSSC met on 12 June 2008 and considered your request for financial assistance towards your glasses. Unfortunately, they have declined a grant for this purpose as the Trust does not give grants to widows who have either remarried or are in a new relationship. I would like to draw your attention to my earlier sentence about a new relationship. The Trust has to make difficult choices and one of our concerns are those widows who do not have (as the Trust would see it) the advantage, which I appreciate is not necessarily financial, of the support that comes from being in that position. I am well aware that this may not be acceptable to you but it is a policy of the Trust."

You've not ever seen a written policy to that effect?

A. No, I did keep asking for that but no never. But then they used to change the trustees with such alarming regularity without actually consulting with anybody

about it who knows.

Q. Then for the sake of completeness there's one further communication that deals with this particular issue 1564007. It's the 3 July 2008 so you have obviously I think gone back again and, "Just, please, could I have the money for some glasses":

"The NSCC met yesterday and considered your appeal for financial assistance towards your glasses but unfortunately they have upheld their original decision."

Then it refers to a query you raised about support to those in new relationships. It says this:

"They asked we relay the following to you, that it's long been known that widows who have remarried or are in a new relationship are no longer eligible for financial assistance from the Trust unless they have children by the primary beneficiary who are still dependants of the Trust. However, in exceptional circumstances the trustees may agree financial assistance at their discretion. It has become clear that some widows in new relationships wish to disengage themselves from the Trust and we take the view that respect for a widow's privacy is paramount."

A. The last bit's irrelevant. Other widows may well wish to disengage from the Trust. I chose not to. I don't know. As I just said to Andy, it's the gift that keep on giving, isn't it.

Q. We can take that down, please Paul and put the photo back.

SIR BRIAN LANGSTAFF: Ms Richards, just before you move on, those letters appear to penalise Sue for her marital status. It occurs to me that certainly by the time of the Equality Act in 2010 discrimination on marital status was unlawful.

MS RICHARDS: Yes, not in fact -- indeed marital status but any kind of further relationship, yes.

SIR BRIAN LANGSTAFF: Effectively, the same point. Perhaps, some enquiries can be made as to what the legal position was actually in 2008.

MS RICHARDS: Certainly, sir.

Sue, in your capacity as a member of the Tainted Blood committee you saw a number of emails from the Macfarlane Trust --

A. I did, yes.

Q. -- a few years ago. You have drawn the Inquiry's attention to three that you recall. You don't yourself have copies. Three examples, I wonder if you could tell us what those are.

A. Yes, we were given the emails by Gareth as chair. He

sent them round to a few of us. I don't know how they were obtained but they've stuck in my memory. After a time, I know that Martin Harvey and I believe his wife, would travel down to South Wales to give a formal apology to Haydn because, if I remember rightly, Gaynor didn't actually want to let him in.

And after the apology Gareth asked that we should all delete these emails from our hard drives which we did and I was quite surprised when I went searching for them a few weeks ago that I really did delete them and they weren't on any other hard drive.

But there were three, there are three examples. The first one refers to Gareth and Haydn and those of us that knew them well love them to bits. They were like chalk and cheese but they were fantastic men, fantastic advocates for the campaign and, you know, we miss them daily and they were referred to in an email, an MFT email, as "the Welsh terrorists".

Second one, somebody's marriage had broken up. We've had a lot of relationship and marriage break ups in our community and it's quite obvious why, the strains and the stresses and so on. When someone finds a new partner I think it should be a cause for

rejoicing, you know. It should be something good that's come out of it. One gentleman had done that after his marriage broke up and the name of the new partner cropped up and somebody said, "Oh, who is so and so", and the reply in an email was, "Oh, that is X's latest squeeze".

The final one, I think most people in this room have heard this bounced around but I've actually seen it in the email, we as a community, that means people who have sat here, talked to you, me, Andy, Jan, Colin, all these people Ade, Mark, are referred to as "the great unwashed".

Q. We touched in your answers a few moments ago on your view that under the Macfarlane Trust's replacement, the EIBSS, things haven't greatly changed or improved from your perspective?

A. No.

Q. You have given some examples in your witness statement of particular issues that you have had with EIBSS. You can't get your travel costs in relation to the travel you had to undertake for radiotherapy for your cancer.

A. Yes, it was 120 mile round trip to Exeter every day, five days a week for three weeks, and I approached them to see if they would help with the travel costs

and they said, "No, we don't give grants to widows, travel expenses grants".

Q. The assistance of a benefits adviser who had been funded by the Macfarlane Trust and who had provided practical support and assistance to your son, that isn't funded under the EIBSS.

A. No, they wouldn't continue it. I mean, the work was continuing so I have had to fund it. In fact, it got so bad that he agreed I could pay him so much a month and I've still got one payment left.

Q. You have said that as widows you are entitled to little more than a funeral grant and retraining for a new career, "a joke when most of us are in our 50s and 60s", you say?

A. Yes.

Q. You have referred to the discrepancy in your witness statement between the position of widows outside of Scotland and those within Scotland?

A. Yes, I think it's a disgrace. I mean, I make no judgment on the amounts of money that have been awarded to groups. That is not my responsibility but what I would say is if something has happened to you under the same circumstances then you should be afforded equal and fair treatment and for a widow in my position in Scotland to receive 27,750 a year and for me to receive nothing when both our husbands were infected and died under the same Westminster Government is abhorrent. It's just grossly unfair.

I don't know what it is with the widows with Westminster. They have clearly been trying now for some years to get rid of us. There was a review, one of many reviews, two or three years ago, and one of the options they looked at was to taper off support to widows with a view to exiting them from the scheme and I believe that's more or less what they have done.

Q. You have described in the statement the EIBSS has been nicknamed "the last chance saloon".

A. One of many.

Q. "... as people have to first prove they have tried every other avenue for support, if necessary provide several quotes and even then get turned down."

A. Yes. I mean, do they know how hard it is for some of these people who are so poorly to have to approach -- I don't know who they approach, the Social Fund or whatever, you know, to try and get money for whatever it is and then you've got these other ridiculous anomalies. They don't give money for white goods. Why not? What is likely to go wrong in your life? The washing machine will break down or the fridge

freezer to something.

I know a haemophiliac who went without a fridge in his home for about three years. Do you know anybody without a fridge? And they wouldn't pay for it because it counts as white goods and I've never been able to get any rationale behind that either.

Q. You've spent many years since Bob's death campaigning, involved with Tainted Blood. You've described it as an unpaid full-time job?

A. Yes, I think it is, not just for me but for a whole group of us, yes.

Q. That's involved you -- your statement describes attending meetings, demonstrations, giving interviews, asking questions, continuing to ask questions when dissatisfied with the answers you've been given, providing support to others.

A. Mmm.

Q. You gave evidence to the Archer Inquiry. Can you give us a sense of what it's been like over the years for you, this dominant factor in your life in terms of the campaigning that you've done?

A. Yes, I've written down here for 30 years they have kept us, deliberately I think, dancing on the end of strings. You know, we make ribbons, we make

bracelets, we commission T-shirts and, you know, ties and we turn up suited and booted and trying to look respectable and we write letters and we go to Parliament.

You know, I must be one of the few people in the country, well, apart from people here, that can walk into Westminster Hall and think, "Yes, again". You should be walking into Westminster Hall thinking, "Wow", but you know we've done it so many times and we go over the same thing. We've had politicians crying in the House, please sort this out.

I entirely blame what's going on behind the scenes in the civil service. There is some -- I don't know what it is.

But, yes, I mean, every now and again we manage to put the Government in a little bit of a corner because we come up with some sort of evidence that they can't argue about and so they say, "Oh, okay, well we'll have a review and we'll get you to fill in some forms and, yes, we know you're filling in information which we already hold, but we need -- we need to find out what, like, everybody in your household is earning and we need to find out what your problems are, what you would

like, and here's our three preferred options, and you can't go beyond that".

I think the campaigning itself and everything else that's gone with it, even for those that don't actively campaign has been as big a scandal and as big a tragedy as what happened in the first place because it's taken people's lives. I mean, look at us today again and we always turn up, don't we? I mean, we're always here.

Q. You in your evidence to Lord Archer said this:

"We will only be able to move on and truly live our lives when we know the truth has come out and everything possible has been done to address this catastrophe."

Does that remain your view years later?

A. Yes, it does.

Q. Sue, those are the questions I have for you. I know you have some more you want to say and there are some photos and some video footage we are going to show.

Before we do that let me just ask Mr Snowden if there's anything further. *(Pause)*

Just one thing and it's the perspective of your step-son Paul in his evidence to the Archer Inquiry, just one small passage that Mr Snowden asks me to draw attention to:

"I never saw my Dad as outside people did. Although disabled by haemophilia he was a very active and involving person. He loved life and tried to make the most of what he had. He taught me DIY, chess, table tennis, badminton and too many other things to mention here. He tried to teach me to fish and failed much to his disappointment, but most of all he was my Dad."

A. Yes.

Q. Sue, there are -- I think you have some closing observations.

A. I do but there's one other thing if I may before I do that.

David Cameron's apology, we're fed up with him and people saying how sorry they are. To me an apology only means something if two things are in place: one is a full understanding of what you're apologising for and I don't believe he'd got a clue and the second thing is a willingness to actually act and put right what you can and that wasn't in place either. After that apology we've had a flurry of people telling us how sorry they are. It goes right over our heads.

Q. You've got some observations you want to make. After that there are some photographs that you want to show

and then after that there is a video of Bob so that we end your evidence with Bob.

A. Yes.

If anyone had told me in 1985 that I would still be campaigning in 2019 more than 34 years later I probably would have said they were stark raving mad. That I am still campaigning demonstrates to me that there is something fundamentally wrong in this country. Time after time after time we have seen victims having to fight for many years in order to achieve justice. Most recently the Hillsborough families whose campaign like ours went on for decades. There has to be a better way.

One clear reason for this is that people are having to do battle directly with the perpetrators. In the case of Hillsborough it was the football club and the police whereas with us our campaign has been aimed at the very heart of Government as well as prominent members of the medical and scientific community and the giant, all-powerful pharmaceutical companies.

All of them have held more power and financial clout than we could ever muster and they know it. On most occasions we have had to finance our

campaigning ourselves although one notable exception to this, the judicial review in 2010, proved to us that with properly financed legal representation we could win through.

Our ongoing battles have been compounded by the fact that financial support for victims has been set up by the very Government department at the heart of the scandal in the first place. Hence it has never been compensation, despite the word still being in regular use by some members of the press.

Instead, it has been *ex gratia*, meaning no liability support, and therein lies the true shame of successive governments who have used this very support system to divide and rule its victims. Many years ago in Ireland, a system of no fault compensation on compassionate grounds was instituted; so it can be done if the will is there. Clearly, in Westminster it is not.

Following on from that, I would like to commend the campaigners for their tenacity and their courage in the face of such abject cruelty from those whose actions and inactions caused this and who should have helped and supported us. Many of those I knew at the beginning are no longer with us and I am sure that suits the Government perfectly

for when one day, hopefully not too far away now, they are forced to provide proper compensation their bill will be very much smaller than it would have been had they done the right thing at the start.

Not of course that they will shed any tears over this or, as Mr Kenneth Clarke said in January 1985 when he was Minister of State for Health "as only haemophiliacs have died" -- "only haemophiliacs", I am completely convinced that from the outset haemophiliacs were viewed as expendable. Not by all the doctors (as we have heard many of them were excellent) and certainly not by most of the nurses. But the UKHCDO, the unknown (as yet) civil servants, the pharmaceutical companies, and members of the British Government (some still serving) truly have blood on their hands. Haemophiliacs in the early days were a compliant, finite, trusting group that was well used to hospitals, blood tests and so on. They readily co-operated with their doctors, believing them to be acting in their best interests. I make no apology for saying that the majority of our community are not like that now.

There were so many warnings in the early days, including two from the World Health Organisation.

We should and could have achieved self-sufficiency in our blood supply and raised donation standards before any damage was done. But then, as now, the health and safety of our population proved to be a very low priority in terms of Government spending and attention to detail. I've always maintained that this is not about affordability. The money was there for self-sufficiency and it is there for compensation today. What is lacking is what Haydn Lewis used to call political will. We have simply never been important enough. We are still not important enough. We are not a priority.

Or in the now familiar words of Edwina Currie: your haemophilia patient might die three weeks later and, hey presto, you've got a very wealthy family. They haven't got haemophilia. They haven't got AIDS but they've got a million quid of public money.

There was a timelag of around three years between HIV infection in haemophiliacs in the US and those in the UK. Three years. What would the average person in the street have used those three years for I wonder? I suspect that the vast majority would have put urgent measures in place to protect haemophiliacs over here from suffering the same fate as those in America. After all, we knew

perfectly well decades before this time that blood can carry viruses, particularly hepatitis, and we knew that we were importing vast amounts of American plasma products. It really shouldn't have been that hard, should it? They had three years in which I believe most of the infections to haemophiliacs could have been avoided. Three years.

Instead, they did the opposite. Effectively they sat back and monitored the spread of AIDS into the UK. I'd like to make one other thing clear. I said to my evidence to the Archer Inquiry that this scandal was wholly avoidable and I stand by that. A child could have made better decisions over haemophilia care.

Many times over the years I have heard campaigners say that there have been breaches of the Human Rights Act and the Nuremberg Code. Following much research, I have to say I agree but then I'm not an expert. I do hope, though, that the Inquiry team will look at these claims and make some kind of judgment on them. If our assertions are incorrect, then so be it. But please tell us why. If we were right all along, then of course we would expect the perpetrators to be identified and to face appropriate action.

I want to say a few words about HIV infection. We've all heard the utterly devastating testimonies of those who were infected with hepatitis C. The virus and its treatments are undeniably horrendous. It is a slow, creeping, insidious taker of lives and it is taking more and more. It should be remembered that haemophiliacs have been exposed to multiple viruses, prions and other contaminants through their treatment. But for those with HIV, there is a greater burden than is often acknowledged. There are very few survivors today from the co-infected group. Less than a quarter remain with us and the way they have been treated by the Department of Health and the support schemes has been utterly despicable. I am absolutely certain that in the early days when there was no treatment whatsoever and when life expectancy was so low that the Government believed that this particular problem would soon be out of the way. Fast forward three decades and the treatment of the co-infected has been appalling throughout. The extra impact of the two viruses has never been openly acknowledged by Government, despite the fact that studies commissioned by them have proved it conclusively.

The fact that this small group has acted as

guinea pigs for every HIV medication as it comes on the market has been ignored. I'm sick to death of people telling me it's okay now, is AIDS, it's treatable, just like diabetes, in fact. No, it certainly is not. Those who are still alive contracted the virus around 30 years ago and by the time any treatments came along, their immune systems were shot to ribbons. They all faced daily a nasty drug routine which, if they are lucky, keeps the virus at bay. If the drugs stop working or they stop taking their meds, they will die.

The first drug that game along, AZT, was initially prescribed in such high doses that the majority of people who took it did not survive. Haemophiliacs, along with other early victims, have been guinea pigs or pioneers for every treatment for HIV as it came on the market. Because of them, and in particular the small group alive today, we are now able to treat HIV provided it is detected early. This country, and indeed the world, owes these people a huge debt of gratitude.

It's often been said that the Government is stringing this out until we are all dead and I believe that could well be the case. Over the years, I have often said confidently to the press and to politicians that even if when this happens, the campaign will continue thanks to the children of victims who will carry on our fight. I have to be honest and say that often as I said that I was thinking "Will they really or will we all be forgotten when the last one dies?" I am so glad to be able to say that I was right. Over the last few years, the grown-up children have risen like a flock of phoenixes and they are awesome. They have built on what we've tried to do and their sheer energy and determination is quite formidable. I would like to take this opportunity to thank them all for their courage.

Thanks must go to Sir Brian and the Inquiry team, including the technical squad, and to Collins Solicitors, all of whom have been incredibly supportive throughout and have granted me the privilege of giving evidence today. I'm sure we haven't been the easiest people to deal with on occasion. Indeed, we have probably driven you mad at times, but hopefully you will realise why we're like we are. It's truly not personal, I promise. To be frank, it's all been a bit bewildering as we're really not used to the sort of treatment you have given us. I looked around this room earlier in

the year and thought: all this for us? So thank you for treating us with kindness and dignity.

To the victims who have given testimony, we applaud you for your bravery in telling your story. To the haemophilia community. You are astonishing. You are kind, protective of each other, generous, supportive, and the most bloody-minded determined group of people I know. I am certain that if Gareth had survived -- and we miss him terribly -- he would have been so proud of what TB has become. He'd never actually have told you that, of course, but I know he'd have felt it.

I recently read an old Mexican proverb that information sums up the campaigners nicely:

"They tried to bury us. They didn't know that we were seeds."

My final message is to the people that caused this in the first place. It's to the politicians who have lied, including on several occasions misleading the House; to the doctors who didn't see children, babies and mild haemophiliacs but simply guinea pigs ripe for experiment; to the pharmaceutical companies and the scientists whose greed and tunnel vision rode rough shod over one of society's most vulnerable groups, to all of you

I say this: you have taken away so much from so many people. Your actions have taken people's health, their financial independence, their dignity, often their homes, their families, marriages and their friendships and, in thousands of cases, life itself leaving behind bereaved families, orphaned children and a grief that for many is still as raw as the day their loved one died. You have reduced many of us to rock bottom. But you know what: you can't take the most important things, the things that you yourself have lacked, humanity and the love that binds us together.

I am extraordinarily proud of what I see every day on the TB Facebook group. If someone is down, there is a flurry of messages to support them. If someone has a problem and needs advice, that advice comes in shed-loads. If someone is dying or sick, I see a gentleness and a reaching out to do what we can to help. When someone dies virtual arms are wrapped around the family and someone is always there for them. This amazing support and compassion goes on pretty well 24 hours a day. I know a lot of nocturnal people.

We know that we are just very little fish in a very big pond and that because of your money and

your power you have always had the upper hand. But we have one overwriting quality that gives me some hope and that is the truth. We have only ever told it as it is and it is the truth that has been heard so far by this Inquiry. I, and I imagine hundreds of others, are sick and tired of your platitudes and your tree-hugging simpering. We don't want to hear that you deeply regret or that you are sorry. Nor do we want to hear that it should never have happened. Of course it should never have happened. That much was understood by us decades ago and surely to goodness isn't rocket science.

No, we only want to hear one thing from you and that's the truth. We want to know why a human life was downgraded ahead of scientific research and making money, and why the victims you created have since been treated as second-class citizens. If you have to be dragged kicking and screaming to this Inquiry, then so be it. Please don't think that sudden memory loss, old age or ill health will be an acceptable excuse not to turn up or to give inadequate evidence. You won't fool us and I'm pretty sure you won't fool the Inquiry team either.

My hope then is that this Inquiry will give us closure but if it all goes pear-shaped, then all

I can say is that history will be your judge and for that I'm very glad.

Final thanks must go to Andy Evans for sitting with me today and also the many other campaigners for their amazing support. A special mention must be given to my incredible and talented friend, Richard Warwick, without whom the next bit would not be possible.

I want to finish with a very short list of names. I must stress that they are no more or less important than anyone else who has died because we have all known huge losses. However, as people who have been associated closely with Tainted Blood, and who in some cases campaigned for decades, literally up until they died, they represent other campaigners, UK-wide, who have quietly and privately suffered the same fate due to the wicked intransigence and abject cruelty of Government. Their efforts have been no less value.

Having said that of course the first name is that of someone who never campaigned in his short lifetime but who has become the one who gets us through the night and whose image makes us pull ourselves together when we feel like giving up. So, on behalf of everyone in Tainted Blood, please join

me to remember the following with thanks and gratitude for what they did and what we have tried to continue doing in their memory.

MS RICHARDS: Paul, can you play the slide show, please.

A. "You can have my toys when I'm gone." Colin Smith, died 1990 aged 7.

"You don't know what's in it." Bob Threakall, died 1991 aged 47.

"We've been given a life sentence without parole, while those who are responsible continue their high-flying careers." Gary Kelly, died 2008.

"What they are hoping for is that we'll all get picked off one by one and eventually there will be no-one left to answer to." Charles Loader, died 2009 aged 43.

"It is not an Act of Parliament that is needed but an act of political will." Haydn Lewis, died 2010 aged 53.

"Life's a bitch and then you die." Gareth Lewis, died 2010 aged 52.

"You can't get worse off than dead." Mike Dicott, died 2015 aged 47.

"I've seen things you people wouldn't believe. All those moments will be lost in time like tears in rain. Time to die" from the bedroom wall of Darren

Flack, died 2016 aged 47.

"They really have treated so many with so little concern or respect. It seems to me they make up the rules as they go along." Paul Hooper, died 2017 aged 53.

"I'd like them to never enjoy a night's sleep ever again for what they did." Steve Diamond, died 2018 aged 62.

Thank you.

Q. We're going to end with Bob himself. Could you play the video, please, Paul.

(Video played)

SIR BRIAN LANGSTAFF: Sue, thank you very much. As perhaps befits a former teacher, you have used your words to paint very vivid pictures, first, the first part of what you were saying, a picture of the human being that Bob was, and in the second part how you described your struggles that came in the aftermath of what we have just seen was his death in 1991. Thank you very much indeed.

We'll take a break until 2.40.

(1.26 pm)

(Luncheon Adjournment)

(2.43 pm)

SIR BRIAN LANGSTAFF: Ms Fraser Butlin, our next two

witnesses together or Barry and Ronan, are they?

MS FRASER BUTLIN: That's correct, sir.

SIR BRIAN LANGSTAFF: Barry and Ronan, please.

BARRY FITZGERALD, affirmed

RONAN FITZGERALD, affirmed

Questioned by MS FRASER BUTLIN

MS FRASER BUTLIN: Barry and Ronan, you are here to tell us about Jane, your late wife, Barry, and your Mum, Ronan.

BARRY: Yes.

MS FRASER BUTLIN: You have provided a photograph of her that we're going to put up on the screen now and leave it there throughout your evidence.

Barry, can you start off by telling us a little of what Jane was like.

BARRY: Where does one start? Vivacious, lovely, full of life, liked travelling, loved children singing, liked animals, loved gardening. I would promote her to sainthood if I could. She was perfect.

MS FRASER BUTLIN: In August 1978 Jane was 17. It was before you met but she had an ectopic pregnancy.

BARRY: That's right, yes.

MS FRASER BUTLIN: And was given a blood transfusion.

BARRY: Yes.

MS FRASER BUTLIN: As far as you know, was the transfusion given in emergency circumstances?

BARRY: No.

MS FRASER BUTLIN: As far as you understand, was she warned of any risks involved in receiving that transfusion?

BARRY: No, she wasn't.

MS FRASER BUTLIN: You met her a year later.

BARRY: Yes.

MS FRASER BUTLIN: And married on Valentine's Day 1984.

BARRY: Yes.

MS FRASER BUTLIN: From then until 2004 was there any indication that Jane was unwell?

BARRY: None at all.

MS FRASER BUTLIN: During that time --

BARRY: Sorry, not in a serious sense.

MS FRASER BUTLIN: Do you want to say anything more about that?

BARRY: No. Nothing that would account for what happened afterwards. Just the various regular things that everybody has.

MS FRASER BUTLIN: During that time, from the date of the transfusion through to 2004, was Jane ever contacted by way of a look-back exercise to say that she should be tested for hepatitis C.

BARRY: No, not at all.

MS FRASER BUTLIN: If we look at W2819015 please, Paul, we have a reply from Jane's GP to a complaint letter that Jane wrote at the time in about 2011 about the lack of information. In paragraph 3 of the letter the GP says this:

"As far as we are aware we have not received any letter or notification from the Chief Medical Officer in 1995 ..."

That was in relation to a question from Jane about whether they'd received the letter from 1995 where the Chief Medical Officer asked GPs for their help to identify patients who may have been infected, so the GP here is confirming they didn't receive that letter:

"... nor were we informed by the Regional Transfusion Centre that you had received contaminated blood as a possible cause of hepatitis C. You will appreciate that in view of our lack of notification we were unable to trace, test or counsel you at that time."

BARRY: That's correct.

MS FRASER BUTLIN: In October 2004 Jane went to see her GP. Do you remember what the problem was?

BARRY: Not specifically, not specifically. She had trouble in swallowing large lumps of food that she

couldn't chew enough to be able to swallow and I think she thought that maybe she had a growth or something in her throat and she just needed to be tested, checked out.

MS FRASER BUTLIN: She underwent a serious of blood tests at that stage.

BARRY: Yes.

MS FRASER BUTLIN: And then received a letter telling her she had hepatitis C.

BARRY: That's correct.

MS FRASER BUTLIN: What was her reaction and what was your reaction to that letter?

BARRY: Shock, absolute shock. It came out of the blue and what we knew, what little we knew of hepatitis C that only a certain segment of society contracted hepatitis C and suffered from it. So there was no way that we thought that we would be part of that section so it baffled us and bamboozled us and puzzled us. We didn't know what to do. We were shocked. So obviously we had to contact our doctor to find out the veracity of the information and possibly how Jane would have contracted hepatitis C.

MS FRASER BUTLIN: Jane was then referred to the hospital and underwent further testing and you had an appointment at Bournemouth hospital where more was

told to you about hepatitis C. Can you tell us what you were told.

BARRY: That hepatitis C was contractable through various different ways, none of which applied to Jane, things like sexual contraction with multiple sexual partners or drugs and obviously she wasn't a drug taker either, so we were puzzled as to how she had contracted hepatitis C.

MS FRASER BUTLIN: You were also told something about what would happen when Jane died.

A. That's correct. Yes. As a result of finally recognising that she had hepatitis C, we were then informed by the attending doctor that as a consequence of both our lives, I would have to wear condoms to protect myself and in the event of Jane's ensuing death -- just like that "ensuing death" -- that she would have to be buried in a sealed coffin.

MS FRASER BUTLIN: That was at your first appointment at the hospital having been just told that Jane had hepatitis C?

BARRY: That's correct, yes.

MS FRASER BUTLIN: Can you tell us a little bit about the manner in which that news was delivered to you.

BARRY: Very cold-bloodedly, to be honest, with you -- very cold-bloodedly. There didn't seem to be much sympathy involved in the way it was delivered and it hammered home like a bullet blow really. Just so cold, just so cold. You're married to somebody. You have been married to somebody for almost -- well, when you've been with somebody for almost 20 years and then to be told you would have to wear condoms, you know, like she was like a prostitute if you like and that she would have to be buried in a sealed coffin. It just seemed cold. All of a sudden you felt like a leper, just felt like a leper. It was just awful, just awful.

MS FRASER BUTLIN: At that appointment, was the possibility that Jane had been infected through a blood transfusion raised with you?

BARRY: Well, that was the only assumption we could come to and we did actually find out afterwards that that was the case because obviously we'd met when she was 16 so we met on the streets and fell in love like Julia Roberts, and she'd never taken drugs in her life either, so it was obvious there had to be some other source and through finding an old medical card of hers that was stamped with the fact that she had had a unit of blood in 1978 as a result of an ectopic pregnancy, that that was the cause. That was the reason why she was infected, through the blood.

MS FRASER BUTLIN: But were you ever told by a doctor at that stage? Did anyone actually communicate with you that that was the cause? At that first appointment?

BARRY: Not at the first appointment, no, not at all.

MS FRASER BUTLIN: If we can have document 2819005, please, this is a letter from the consultant in November 2004. At the end of the first paragraph we see that he's written to Jane's GP:

"Clearly the news that she has hepatitis C has come as something of a shock to her. Discussing risk factors with her the only one I can find is that she had a blood transfusion at the age of 16. This is the likely cause."

So it is in the letter to the GP but hadn't been told to you.

BARRY: That's correct.

MS FRASER BUTLIN: If we look at the very bottom of the letter we have a handwritten note which says:

"PS, well done for diagnosing the hepatitis C!"

What's your feeling about that handwritten note?

BARRY: Totally and wholly inappropriate. I mean, you don't deliver a verdict like that in that manner. No bedside manner there at all, just hard and harsh.

I mean "well done"? What was well done about it?

MS FRASER BUTLIN: Jane was -- sorry, go on.

BARRY: I was going to say certainly not for us.

MS FRASER BUTLIN: Jane was offered a liver biopsy but declined to have one, why was that?

BARRY: She was extremely needle phobic -- extremely needle phobic -- so she couldn't go through with that. So we did ask for other alternatives to which we were told that there weren't any, not in this country at all. So upon research we found out that there was such a machine called a fibroscan machine that examined the liver at close hand but there were no fibroscan machines available in the country on the National Health and there were three in Europe, one in Milan, one in Madrid and one in Paris.

So we discussed it and I elected to phone Paris, a hospital called Bondy, which is in the east suburbs of Paris, to see about arranging a fibroscan for Jane at their hospital and -- funny really, tragic, but through pidgin English and pidgin French we managed to arrange an appointment and we did end up in Paris.

MS FRASER BUTLIN: What did that test show?

BARRY: That, yes, the hepatitis C was present in her liver and that -- I can't think of the exact --

there's a particular -- sorry, you are going to have to bear with me, with this. I forgot what it's called now. No, I'm sorry, I can't remember. There is a medical terminology to it and I can't --

MS FRASER BUTLIN: Do you mean cirrhosis or scarring?

BARRY: Yes. No, not cirrhosis, there was something else, there was something else describing there were stages of the cirrhosis and that she was at -- approaching stage 3. But, yes, she had mild cirrhosis.

MS FRASER BUTLIN: You then decided to continue having her monitored in the UK rather than going backwards and forwards to Paris.

BARRY: Yes.

MS FRASER BUTLIN: But Jane couldn't get an appointment with a consultant. What happened in that regard?

BARRY: I remember the consultant, I'm not too clear on it now for some reason but I do remember that there was a huge pressure for Jane to have a biopsy but she couldn't go through with the biopsy and, as a result, we did feel that there wasn't a lot of sympathy for her in that direction.

MS FRASER BUTLIN: In the end you involved your MP.

BARRY: Yes, Tobias Ellwood.

MS FRASER BUTLIN: What happened then?

BARRY: He took up the cudgels for us on our behalf to see what he could do and in the end really he could do nothing because there was no fibroscan machines and the biopsy was the only option.

MS FRASER BUTLIN: If we can have document 2819004, please, we've got the letter from Dr Winwood back to Mr Ellwood here and towards the end of the first paragraph it says:

"The plan was to have a further investigation which I can't go into detail of for reasons of confidentiality but matters were complicated as Mrs Fitzgerald did not wish to have this done according to normal procedures. I had written to a colleague to arrange this investigation and it would appear this was never organised. In this respect, we are at fault and can only apologise for Mrs Fitzgerald."

Then he goes on at the end of the letter to raise own concerns:

"Whilst writing" -- it's the next page, Paul:

"Whilst writing you will be aware that there are significant commissioning issues between the local PCT and this Trust. This affects my department significantly. Specifically, last year, the availability of funding for the treatment of hepatitis C was inadequate with the result that

there were nearly 60 patients left at the end of the financial year who needed treatment but could not be treated within that budget. We have already committed the funds for this year and still have 60 patients waiting for treatment until the next financial year unless there is an agreement to increase funding for hepatitis C this year. Negotiations are ongoing with the PCT but I would value your support in ensuring that resources are available for all patients who need treatment for hepatitis C according to NICE criteria. We should be able to provide this within a reasonable time-frame which I would suggest is no more than three months."

So on the back of the letter that Mr Ellwood had written to Dr Winwood he also raises his own concerns about the ability to treat patients with hepatitis C.

In terms of Jane's treatment, was she able to have a fibroscan at Bournemouth?

BARRY: No.

MS FRASER BUTLIN: So where did she then -- where was she then transferred.

BARRY: Well, upon investigation we then discovered that Frenchay Hospital in Bristol had acquired a fibroscan

machine, so I contacted Frenchay Hospital with the support of our doctor to go to Frenchay to have the fibroscan treatment there.

MS FRASER BUTLIN: When Jane was diagnosed she was in her 40s. Can you tell us what her health was like initially.

BARRY: Perfect. It was good. Like I said, apart from the odd little thing that people get, flu and stuff like that, she was a very robust healthy girl but then we both liked walking and just took in lots of fresh air as and when.

MS FRASER BUTLIN: You said in your statement she was fairly sprightly at first but she did then start having some general aches and pains.

BARRY: Yes, as the years went by from 2004 to 2015 she did deteriorate but not rapidly but there were signs of her becoming more and more tired more and more quickly, but over a period of time, like I said, they did worsen.

MS FRASER BUTLIN: Emotionally, how did Jane cope with her diagnosis?

BARRY: Well, emotionally that's harder because the impact on our lives was very overpowering and dramatic because we had to change our way of life. We had to change our way of thinking. Obviously Jane felt

guilty because the advice that Dr Winwood had given about wearing condoms didn't sit prettily with her or with me. We had been married a long time. You know, she said -- I mean, I'd already told her, you know, "Forget that, you know. You're my wife. Your wedding vows say in sickness and in health. We sink or swim, sail together". That was the way it was. But I know she never felt too good about it because she thought she would be putting my life at risk but we did find out it was minimal to catch hepatitis C through sexual contact.

So for that matter it kind of like made her feel a little bit better but she still had it in the back of her mind. Also, socially, she wasn't allowed to drink alcohol anymore. She didn't drink a lot but we did have friends, close friends, that we used to go out and socialise with a lot and, of course, that kind of inhibited that because once she found that she wasn't able to drink, and she stopped drinking straight away, she was very good at that, she stopped straight away, we found out that we couldn't socialise too much so we didn't go to parties and functions and she felt very much isolated within our friends' company, so that suffered as well.

But the relationship between her and I was rock solid. It was excellent. She stood by me and I stood by her, sink or swim together. That's what the marriage vows are all about. But our social life suffered completely. But, you know, small potatoes. We were still together and she was still fighting the fight.

MS FRASER BUTLIN: You said in your statement that Jane, it weighed on Jane's mind knowing that she had a terminal illness.

BARRY: Yes.

MS FRASER BUTLIN: She was scared of what would happen to her.

BARRY: She was scared of the final consequence which is an early and an imminent death, yes. Yes, she was prone to long bouts of depression once we found that out and that impacted upon some family incidents which followed. Again, it wasn't her fault but people around didn't understand.

MS FRASER BUTLIN: Was Jane or were you offered any counselling at this point specifically to address the hepatitis C diagnosis?

BARRY: There's a Bournemouth hospital at the Bournemouth New Hospital in Castle Lane. On a Thursday evening, there was a group practice where people who had

acquired hepatitis C came together to discuss their situation. So we attended because we thought it might help but in actual fact it didn't help. It hindered, really, because the huge amount, a good 90-odd per cent because, I believe, Jane was the only one, unless somebody hadn't admitted to it, they were all hepatitis C acquirers through drugs and they were drug users and that's how they acquired hepatitis C, totally different to the way Jane had acquired it. So there were two sides to the hepatitis C story there but they were brought together as one, so counselling didn't help, counselling didn't help at all.

MS FRASER BUTLIN: Ronan, what do you remember of how your Mum was after her diagnosis?

RONAN: So Mum, there was a constant fear of the unknown, how she would deteriorate over time and, you know, the fear of needles, as Dad mentioned, she knew that was coming, didn't know to what end. But yes, it was just that constant worry. You know, Mum wasn't -- she was a strong lady in a lot of ways but at the same time, very similar, yeah, she, you know, she felt like she was on her own, even though she definitely wasn't, and it was her way of, sort of, she'd push people away. It was as if I'm not going to be here and she found it a lot harder to open up to people. She thought, "I'm

not going to be here, so why make these friends?"

But at the same time she, you know, never gave up. She always kept on fighting. You know, she went out but it was very much she stuck close to those that were close to her and, as I say, the drinking, Mum had one drink when she became a grandmother in all the years, a small one as well, because she wanted to prolong her life as long as she could.

So, yes, you know, it was just that real fear of the unknown but at the same time she kept a lot from me as well and my brother. You know, that's what mums do. They protect their children and, you know, you could see that it changed Mum forever. She wasn't as warm and as happy as she was before she was told that she had hepatitis C.

MS FRASER BUTLIN: Jane was seen in Bristol Hospital for a period but was then lost to follow up again and eventually in 2009 she went to Southampton for treatment and she was seen there for about five or six years. What was your experience of her treatment there?

BARRY: At Southampton?

MS FRASER BUTLIN: Southampton.

BARRY: It was like a breath of fresh air to be honest

with you within the medical profession because they seemed to be more *au fait* with the hepatitis C disease and, therefore, they knew how to empathise with the patients. Bedside manner I think you call it. It was excellent. It was excellent from the clinical nurses up to the consultants themselves, so we felt a lot more comfortable about it.

Obviously we had to travel but it was worth it. It was worth it. Bournemouth was just across the road but Southampton was up the road a lot further, but it was preferable, much preferable.

MS FRASER BUTLIN: Jane was offered treatment during this time for the hepatitis C but declined it. Why was that? During this time she was offered interferon treatment on several occasions between 2004 until 2015. Do you recall what her reasoning was of declining interferon treatment?

BARRY: I'm unclear about that. I'm not too sure whether that was going to be administered through an injection. That I'm not sure. If that is the case and it wasn't just tablet form then she would have kept that from me.

MS FRASER BUTLIN: You have said in your statement it's because of her needle phobia.

BARRY: It was, yes.

MS FRASER BUTLIN: Because of the low success rates and because she knew that the side effects were terrible.

BARRY: That's right, yes. Like I just said, her needle phobia was huge but she did keep a few things from me because she knew that I would worry. So if I did not know certain aspects of her treatment that she was terrified of and if I didn't know them, I wouldn't bully her gently into going ahead with them. So some things, like I say, and like Ronan has said, she did keep from us.

MS FRASER BUTLIN: She ultimately started treatment in August 2014 with ribavirin, sofosbuvir and ledipasvir which were non-needle. They didn't need to be injected.

BARRY: Yes.

MS FRASER BUTLIN: Do you recall how Jane coped with that treatment?

BARRY: Well, admirably better than having an injection. Mentally she improved because she thought now that she could have treatment that didn't involve needles that maybe, just maybe, she had a chance but unfortunately that wasn't to be.

MS FRASER BUTLIN: By the time she was having the treatment, her liver had deteriorated quite considerably.

BARRY: Yes, it had, yes.

MS FRASER BUTLIN: And she had developed ascites which had to be drained regularly.

BARRY: Yes.

MS FRASER BUTLIN: Ronan, you have quite a strong recollection of your Mum having to have those procedures. Can you tell us about that.

RONAN: So Mum had to be drained seven to ten days, every seven to ten days and, you know, she got very, very large from the fluid and, yes, there was quite a few occasions where she would get there early to Southampton really early, I think it was 7.30/8 in the morning, thinking she'd be -- sort of start -- receive the treatment, you know, within an hour but she'd be left in the waiting room for five hours, up to seven or eight hours before they even get going with the drain. So then she would be there all night and then obviously the commute to Southampton there and back, absolutely exhausting days.

You know, this is all obviously taking a toll on myself and it happened too often. I did phone up Southampton Hospital to lodge a complaint. After that, it improved significantly but I felt like it had to be done because I wasn't happy the way my Mum was being treated and being left in a waiting room

that was uncomfortable at her size and especially after at one time she had been left too long and her abdomen ruptured, which was horrific. So, you know, knowing that I didn't want that to happen again. So, yes, on the whole, you know, the treatment from Southampton was a lot better than at Bournemouth but, yes, just the waiting that she was made to go through was just unreasonable and I had to get involved as a protective son.

MS FRASER BUTLIN: You went on a family holiday to Florida in October 2014.

BARRY: Yes. Sorry, it was September into the October.

MS FRASER BUTLIN: September/October.

BARRY: Sorry.

MS FRASER BUTLIN: No, that's fine.

You said in your statement that you think Jane had the sense that would be the last family holiday. What makes you say that? What was it that gave you that sense?

BARRY: Well, our grandson that Ronan mentioned, his birthday was on *[redacted]*, so the plan was for him to see Disneyland for the first time, Disney World, and she was looking forward to seeing that, but she had this overriding feeling that if it was the last time she'd rather she went alone with me, because we went

to America a lot, twice a year sometimes, and we loved it. It was our favourite place and I think she'd like to have had a last holiday in America with me, I mean notwithstanding the fact that we were with the family, of course, but it was then I began to feel that she thought she was never going to go again and, of course, she was right. But it was a nice holiday and our grandson had his -- I think it was his *[redacted]* birthday then and it was a joy to watch him enjoying Disney World seeing it through new young eyes again. It's a great experience.

But yes, she was right. It was the last time she ever went.

MS FRASER BUTLIN: In June 2015 Jane was referred to Addenbrooke's to be considered for a liver transplant.

BARRY: Yes.

MS FRASER BUTLIN: What happened at that review?

BARRY: Right, well, we were there for four days and I stayed on site in a cottage which they provided, which was damn good actually, really good. She went through all the appropriate tests and at the end of the tests we came back to Bournemouth and we then received the news that it wasn't necessary for her to have a transplant at all, that she was in some form of remission. We thought, wow, that's incredible, that the treatment she had had had reversed what she was going through in her liver and that she was now no longer considered a transplant patient.

MS FRASER BUTLIN: Can we have document 2819010 and it is the fourth page, please. This is the clinic letter from September 2015 so a further review in September when they said this:

"We were all struck by the improvement in [Jane's] condition. She has put some weight on which is muscle mass and her ascites is completely resolved. She is going to see if she can wean off her spironolactone by using her weight as a guide as hopefully she will no longer need that. Her liver function tests are excellent and at the current time she does not need a liver transplant. She is aware that this situation could change but she is aware that I will monitor her in my regular clinic and refer her back to the transplant team if this situation deteriorates."

So as far as you were concerned at that point you had turned a corner?

BARRY: Yes, yes, we were very happy. Fantastic news.

MS FRASER BUTLIN: But sadly that wasn't the case with Jane. She deteriorated further.

BARRY: She did, it was like an Indian summer before the

winter, if you know what I mean, and that was our Indian summer.

MS FRASER BUTLIN: Jane developed cancer in her lungs.

BARRY: The linings of the lungs, yes.

MS FRASER BUTLIN: And in her brain stem.

BARRY: Yes.

MS FRASER BUTLIN: And at that point you have written that she was unable to fight on any further.

BARRY: No, everything was breaking down completely because the liver had stopped functioning. She had had a stent as well which I don't know if that's been mentioned, but everything was going wrong at the same time. She had her back to the wall and there was no way out for her.

MS FRASER BUTLIN: In October she was admitted to have the ascites drained and the stent fitted.

BARRY: Yes, the ascites came back with a vengeance.

MS FRASER BUTLIN: Then she returned home briefly. You have described that she fell into a zombie-like stupor on 10 November.

BARRY: Yes, she was in hospital for my birthday, which is October 27, which -- it was incredible really because she was more upset about that, missing my birthday so we couldn't go out and celebrate it, than what she was actually going through. But, you know, we'd already

been told the news that she had a year to live and I said never mind there's always next year, but we weren't given that luxury of time unfortunately. But, yes, she came out and on November 10 I went to get our grandson from school, I came back and she had slipped into a semiconscious stupor where she could function but it was strange, it was like a zombie-ish stance, yes. She walked around the house, walked out into the garden, held my hand and said, "I want to see it. I just want to see it". She looked round the garden, smiled and said, "I've seen what I wanted to see", came in and ... called an ambulance. Took her to hospital, Bournemouth Hospital, and that was that. Four days later she totally give in, totally gave in.

MS FRASER BUTLIN: Jane died on 13 November 2015.

BARRY: Yes. 11.33 in the evening.

MS FRASER BUTLIN: Just before we talk about how you've coped since then, you mention in your statement that during a period of lucidity when she was at home you and Jane talked about going out in the car. Can you face telling us what you talked about at that point?

BARRY: Well, we had had -- excuse me.

We had a long conversation about what was going to happen, what we both wanted, what she particularly wanted and I felt then that I couldn't

do it alone. I wouldn't be able to. I mean, we'd been together a long time, you know, best part of 40 years really and I said, "Why don't we just go to our favourite place, just sit in the car and go together", and she didn't want that. She did but she didn't because she said, "You've got such a lot to do when I'm gone and if you're not there to do it there's nobody to do it". I mean, Ronan, bless him, he's good he would have known what to do but there are other things that only me as a husband would have been able to do.

So I left it at that. We left it at that. Whether it would have come up again I don't know but fate intervened pretty quickly after that. But, yes, that was the intention. That's what I wanted to do. But it didn't happen. I'm still here. But at least I can talk about her and fight her case for her and all the other victims of this terrible disease that's affected so many.

MS FRASER BUTLIN: After Jane died, you then had a battle about her death certificate.

BARRY: That was thanks to Ronan to start with, yes.

MS FRASER BUTLIN: Would one of you like to tell us about that.

RONAN: So obviously Mum had passed and we were presented with a death certificate which had no mention of contaminated blood. It said Mum had died of pneumonia due to liver failure and obviously Dad was -- we were both in a bad way of course but I think because Dad was in denial for quite a long time and, you know, looking back it was in a good way because it kept Mum positive whereas I was very realistic. I didn't live with Mum every day and I saw her deteriorate when I saw her, whereas Dad didn't see that. So when the death certificate was presented, I wasn't happy and I did advise Dad that we need to get contaminated blood put on the death certificate as the reasoning for Mum's death, and we spoke to the consultants who they hadn't heard anything to do with contaminated blood and they were reluctant to put that on there for whatever reason.

Yes, Dad did that. We contested and got that through a few days later and it was added to Mum's death certificate but it was as a result of, some way down, you know, but as a result of contaminated blood, liver failure and such like but, yes, we had to fight tooth and nail for that, didn't we?

BARRY: Yes, we did.

RONAN: Just to add insult to injury really.

BARRY: To be honest with you, I was stunned and shocked

so, you know, I didn't care really at all. It was thanks to Ronan saying to me, "You know, Dad, we have to fight that". It was down to me to fight it. Again, not just for Jane but again for all the victims of contaminated blood because if the victims of contaminated blood all had pneumonia or whatever on the certificate then they and their families would have been cheated of a decent reputable verdict and Jane did not die from pneumonia.

They said the final cause of her death at the last minute was pneumonia. I knew it wasn't. It's impossible. It couldn't have been. When I said, no, I'm not going to sanction the release of her body without some notification of contaminated blood on the death certificate and they then came back to me and said to me that, you know, that that was an offence if you don't accept to receive the body after 12 days I believe it was and I said, well, I can't not without a decent verdict on the death certificate.

Finally, though it was good. We finally got it. Death was due to the administration of a contaminated blood product.

MS FRASER BUTLIN: We can see the death certificate. It is 2819011. We can see in part 9 cause of death

pneumonia -- 1A pneumonia, 1B adenocarcinoma of the lung pleura and 2 liver cirrhosis due to hepatitis C acquired by transfusion of contaminated blood products.

BARRY: I would just like to say, pneumonia, I know it can be deadly to certain people who are weak, physically, but when you've got the adenocarcinoma of the lung plus the pleura and metastatic and then liver cirrhosis due to hepatitis C, contaminated blood product, it does make the addition of pneumonia totally irrelevant as far as I'm concerned.

So, yes, thanks to Ronan I did fight it and there was no way I was going to give in. I would rather have been indicted for not performing my duties and accepting the original, I would rather have gone to prison than done that, to be honest. So I'm glad we did fight it and win in the end but that would have given me a pulpit by which I could have talked about hepatitis C anyway and I think they knew that because I told them, so we got it.

MS FRASER BUTLIN: Ronan, you had suffered from ill health while your Mum was ill and after she passed away. Can you tell us about that.

RONAN: So, I remember vaguely, you know, Mum and Dad sitting me and my brother down, you know, with the

news that Mum had contracted hepatitis C and that we should get tested regularly. You know it was every six months I'd get tested. I was 22 years old and I was in the army. I think I was very naive not just to hepatitis to a lot of illnesses. I've been fortunate having had good health and not being around people -- I didn't know a lot about haemophilia, so I was young, I was -- I'd been to war and, as I say, I was very naive and I wasn't aware of the facts. It wasn't until Mum showed me the Tainted Blood group and I went on there and read a lot of information and watched a lot of videos and it was scary, and I can't remember timescales of when it really sort of hit home of the severity of the situation but I looked at my Mum and thought, you know, she looks well, you know. I thought, you know, shorten her life by a year or two or something.

But it was only when I, you know, liver failure and everything else, I just got -- I worried, you know. It was, for me, it was -- I know my Mum, I know she's got a fear of needles and a fear of the unknown and I was just constantly worried of what the future would hold, how long did she have left.

I had -- full of anger, I mean real anger, without anyone to take it out on which, you know, it affected my health which I was always feeling guilty about when you meet such lovely people here in the room and elsewhere with real medical conditions and I was you know a young man with headaches and severe tiredness and I was thinking, "My Mum's dying here. I shouldn't complain", and I didn't want to tell my Mum about that because of what she was going through, I didn't want to add to her worry but I did feel worse and worse and worse and worse. I became a father in 2010 and I became a step-parent as well, so I had all that going on and I became too unwell to really support my wife.

I was misdiagnosed for about two/two and a half years. I was treated for depression. I knew I was sort of down and I didn't know what was wrong with me. I knew I wasn't well but I didn't feel depressed but, you know, I wasn't in a good place and you listen to the medical professionals so I gave it a go and took some tablets and, you know, took it seriously and I didn't feel any better really, you know, not enough to be back to how I should be feeling.

It got to the point I remember being at work, I was an engineer and I remember the day I remember

having a job to fix someone's broadband a block of flights on the third floor I couldn't climb a flight of stairs. I was 29 years old. I remember turning round back to my van and that was it. I cried my eyes out. Enough's enough.

I went back to my doctor desperate and I think he thought I was really aggressive, maybe I was but I was just desperate, and he said, you know, "I don't know what else we can do for you. You've had a brain scan", and I was like I don't remember having a brain scan. How can I not remember that? Crazy. He said, "Right, we'll do another lot of blood tests". I had the blood test and within an hour the doctor phoned me back up and said, "I'm really sorry but yes you've got a hyperthyroid problem. Your levels are three times higher than they should be and it's pretty dangerous if untreated".

I thought great, at least I know I'm not crazy or depressed or whatever. So, yes, he was great and I told him he didn't need to apologise. We got on a course of treatment and I did start feeling better. But it wasn't until Mum finally passed away that actually my symptoms improved significantly because I didn't have to worry about her anymore,

which you feel guilty again, you know.

So, yes, you know, I suffered with depression on and off and, as I say, it's got better as time has gone on. It's been almost four years now since Mum passed and I feel the strength from Mum. I've been very lucky having that contact and she's been gone and I've pushed on in my career and that's all because of Mum behind me.

MS FRASER BUTLIN: But your doctor when you were diagnosed with the hyperthyroid problem indicated that it was probably caused by the prolonged stress and worry that you had been under.

RONAN: Absolutely and, as I say, I was told that it could be that it's a permanent condition. There was a genetic thing in the family with hypothyroid, so the other way, and we wouldn't know without going through a bit of time whether this would be a permanent condition or not or whether I'd end up hyperthyroid or not but it turned out it was thyroiditis and it was temporary and it was purely prolonged stress and worry, and that was only because of my Mum, no other reason. Life was good, I'm healthy, I got a good family and healthy children.

So I put it all down to my Mum because I went from strength to strength, you know, every week

after Mum passed.

MS FRASER BUTLIN: Barry, when Ronan was speaking earlier he said that he was the realist and that you had been in some denial while Jane was ill.

BARRY: Yes.

MS FRASER BUTLIN: Can you tell us a little bit of the impact on you since Jane has passed.

BARRY: Blimey.

MS FRASER BUTLIN: If you would rather I can read a section of your statement.

BARRY: No, thank you. I don't know if anybody agrees with me but, yes, I was in denial and I think a lot of people adopt that stance to help them get through things. That was my way of fighting and I've always been a fighter. I love fighting -- principles that is.

But the year after it's just numbness. The real pain -- I don't know if anybody agrees but the real pain when something like this happens to you on a personal level comes the year after when the numbness wears off and it's when numbness wears off that you feel pain. You bang your thumb with a hammer you don't feel it at first because you're numb and then when that numbness goes God does it hurt. It's the same with this. It's the same with me.

As Ronan says it's been almost four years, in fact, it's four years next month and the pain's increasing. It's never going to decrease. Like I say you can't spend almost 40 years with somebody for it to just go away overnight and the nights seem to be so long and it's just getting darker. I'm lucky I have got support, Ronan, Rory my other boy, one or two other friends who can sympathise and empathise.

But, I don't know, another very good friend of mine who was a friend of Jane's, she said to me your life will carry on she said but it will never be the same again, ever. Don't ever look for it, don't ever expect it. Just be pleased that you have had it, but your life will never be the same again and she is right. She's right.

Life does go on but in a totally different way, a totally different vein. Can't hear a record without reminding yourself, can't go back to America without thinking about certain memories, Christmas. My other son, he became a father last year. Jane didn't get to see him. He got married. She wasn't there. It goes on and on. It's just a never-ending spiral. It's like a perpetual torture really, like

perpetual torture.

I can involve myself doing some things that momentarily will distract me. Hey, Bournemouth might beat Arsenal 4-0 fantastic, but after the thrill of that has gone it's back to normal again. Life is just a series of distractions and that's all they will be unfortunately.

MS FRASER BUTLIN: After Jane passed away, you decided to get her medical records.

BARRY: Yes.

MS FRASER BUTLIN: Can you tell us about how you went about that.

BARRY: I contacted the practice manager of our surgery and always had a really good relationship with the doctor anyway and so I didn't think it would be a problem, but it did seem to be quite problematic. Nothing appeared for a long, long while and after a year or so I recontacted them and asked them where they were and they said, "We still can't contact them yet, we can't find them at all".

I said, oh, I had heard, obviously through the Tainted Blood website, that medical records had been burnt, but I'd heard that a few years before anyway, before Jane had gone and so I was wondering if I was going to be in that same position. But then after

I kept phoning and pushing and pushing miraculously they turned up, everything from when Jane was about three years old. All I really wanted was back to 2004 but I got it from when she was 3 years old and my God was it thick.

MS FRASER BUTLIN: In those records there was a letter dated 12 September 2013. It is document 2819007. It is as letter from Public Health England to her GP informing her GP that she had, in the first sentence:

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

That was almost ten years after her diagnosis. You have no idea why that letter was sent at that time.

BARRY: No, not at all.

MS FRASER BUTLIN: If we look at the next page, it contains an information sheet that sets out the Dorset viral hepatitis referral pathway and you've both said that you find it very upsetting because there's no reference in the pathway to infection through infected blood or blood products.

BARRY: That's right.

MS FRASER BUTLIN: The discussion is focussed on sexual activity and drug misuse.

BARRY: Mm-hm.

MS FRASER BUTLIN: Barry, you retired early in order to care for Jane.

BARRY: Yes.

MS FRASER BUTLIN: You have said in your statement that you are glad you did so, so you could spend as much time as possible with her.

BARRY: Yes.

MS FRASER BUTLIN: But financially that made things difficult for you. Can you tell us what it's meant for you.

BARRY: What, from the minute I retired or now?

MS FRASER BUTLIN: No, just now, what financially the impact has been.

BARRY: Well, obviously retiring from a fairly well-paid job that was a blow and then, obviously, Jane wasn't able to work so we lost her salary as well. However, we did have some form of compensatory payment from the Skipton Fund and the Caxton Fund. It wasn't as much but it was still good but after Jane passed away, they paid it for another year and then after that it was just stopped dead. So then all I was left with was my occupational pension from my previous job and now since *[redacted]* of last year I get the national pension. So it has relieved it somewhat but it has been quite difficult, yes, it has been very difficult.

MS FRASER BUTLIN: When Jane was still alive you had already downsized to release some money.

BARRY: Yes.

MS FRASER BUTLIN: From a three-bed house to a two-bed bungalow.

BARRY: That's correct, yes.

MS FRASER BUTLIN: But now you describe that you live fairly frugally:

"I feel I have everything I need now, even if not everything I want. I live fairly frugally and if I were to receive any more money I would likely give it to the children to help them or to visit America once more to see the places that were meaningful to Jane and I."

BARRY: That's correct. If you want to pardon a very, very poignant reminder, when the money is received it's -- I just term it blood money and I don't want any part of it and that was one of the things that I discussed with Jane during her last few lucid moments that I would make sure our two children were well looked after and that they had everything they wanted. That's the way it's going to be. That is the way it's going to be.

I have no need for it because obviously her

passing away has provided the passageway for the freedom of the money to come my way, so how can I prosper from that? I just don't want that. So we both -- well, I told her and she was pleased about it that I'd look after Ronan and Rory.

MS FRASER BUTLIN: Ronan, after your Mum passed away you found boxes of letters that your Mum had written.

RONAN: Yes. I had some things in Mum and Dad's attic and, yes, I was just shocked, boxes and boxes and boxes of files of letters that, you know, Mum had sent and I had no idea that she'd sent. I knew she had written. Mum would always write letters but to prime ministers and -- I don't remember recall who but it was all the medical staff for answers, and for advice and for help and support. So she was always really keen to understand what it was she was dealing with and give her the best fighting chance but, yes, I was just shocked at the amount of letters there were contained in the attic. I couldn't believe it.

MS FRASER BUTLIN: Shortly after your Mum passed away, you attended a debate at the Houses of Parliament. What happened then?

RONAN: I can't remember quite how long after it was. It was the first few months I think, six months. So yes me and Dad went up to London for that campaign. It

was the first one I'd been involved with actually and it was subsequently delayed by the Steel debate at the final hour. There was a lot of really poorly people there and some had to leave early and actually miss our debate as a result and it was just, yes, deeply upsetting that it just got pushed to the back of the queue, you know.

This was my first experience of it and I just thought this had been going on for so long, how many times has this happened, you know. But I did -- it was great to be involved and to meet so many people that had supported me over the years and be part of that. I just wish I could have done more campaigning but I think, you know, the more -- if I could have done more, I could always think there was more I could have done but, you know, when you're working full time, you know, I've done what I can.

But yes, that day was just deeply upsetting that we were pushed to the back of the queue again.

MS FRASER BUTLIN: You both have something you want to say to end your evidence but before I invite you to do that I am just going to turn to Ms Gibbs and see if she has anything she would like me to raise.

BARRY: Of course.

MS FRASER BUTLIN: Ronan, I think you had something you wanted to finish with.

RONAN: So when Mum passed I wasn't in the best place, I wasn't well enough, I wasn't strong enough to speak at her funeral so I wanted to say a few words and a poem and I'll finish off at the end.

At 11.33pm on 13 November 2015, your pain and suffering came to an end. But losing you has left an irreversible and immeasurable ache in our hearts. We think about you every single day, every family meal, every birthday, every time the sun shines down on us, every time a robin lands close by, every day. My father has lost his wife. My brother and I have lost our Mum. My 9-year old son will grow up without his nanny. What memory will he have of her? Mum is not here to see my brother get married or get to hold her second grandson. One day we will all be together again at the back left-hand corner of heaven. Until then, we will continue to meet in our dreams.

I just want to say a poem called Remembering My Mother by Belinda Stotler.

"My Mother seems so far away from me,
On that beautiful white shore across the sea,

Yet I remember love's soft glow upon her face,
And the feel of her touch and tender embrace.

When I am weary from the burdens I've borne,
And the path is unclear and I feel so forlorn,
I remember her loving support was always near,
And her advice made the path ahead seem clear,

When I feel there is no-one who seems to care,
Or when the heartache seems to hard to bear,
I remember how she always stood by my side,
And would tenderly wipe away the tears I cried.
When there are moments of great joy and pride,
And I wish my Mother was standing at my side,
I remember she saw more than I thought I could be,
And know I owe my triumphs to her belief in me.

When I reminisce about the things she used to say,
And I miss her and I think she is so far away,
I remember what she gave lives on through me,
And one day I'll see her on the shore across

the sea."

Mum was cruelly taken away from us through no fault of her own and so we must continue to fight on in her honour. For my mother, Jane Yvonne, Fitzgerald for all the victims and their families, whole bloods and haemophiliacs, we want answers, we want the truth, and we want justice. Those responsible must be held accountable and those who have suffered must be compensated appropriately.

Thank you.

MS FRASER BUTLIN: Barry, I think you had something you also wanted to say.

BARRY: Wow. How can I follow that? I would just like to say this picture that people are looking at, that was at Ronan's wedding and it's just heart-breaking that the two of us couldn't have been together at Rory's wedding. But she was there. We know that. I just couldn't hold her.

Right, all I want to say is I just want to recite Jane and I's favourite poem that sums up life for me and hopefully other people like me. It's by Housman, AE Housman. I don't know if anyone has ever heard of him. He wrote a Shropshire Lad and there is a part of it called The Blue Remembered Hills and it's very, very pertinent for me.

"Into my heart an air that kills
From yon far country blows:
What are those blue remembered hills.
What farms, what spires are those?
That is the land of lost content,
I see it shining plain,
The happy highways where I went
And cannot go again."

That's how I feel about my life without Jane.

SIR BRIAN LANGSTAFF: Your testimonies show how valuable oral evidence can be in understanding the full depth of what you have to say in a witness statement. There's something about the way that both of you put matters in a matter of fact way, but when you listen carefully you begin to realise how deeply Jane's suffering and death has affected you both and how difficult it must have been to be able to show that as you have done in public.

Thank you very much.

Tomorrow we start at ten o'clock?

MS FRASER BUTLIN: We do, sir.

SIR BRIAN LANGSTAFF: And we have?

MS FRASER BUTLIN: We will be hearing from Trevor and Louise Marsden, Mark Stewart, Annette Hill-Stewart and

Baroness Jane Campbell.

SIR BRIAN LANGSTAFF: So tomorrow, ten o'clock.

(3.47 pm)

(Adjourned until 10.00 am the following day)

INDEX

F:

F:

F:

F:

F: