Wednesday, 3 July 2019

(10.06 am)

SIR BRIAN LANGSTAFF: Good morning, Ms Fraser Butlin.

MS FRASER BUTLIN: Good morning, sir.

SIR BRIAN LANGSTAFF: Our first witness this morning wishes to be known as Eileen, does she?

MS FRASER BUTLIN: That's correct.

SIR BRIAN LANGSTAFF: Eileen, please.

EILEEN DYSON, sworn

Questioned by MS FRASER BUTLIN

Q. Eileen, you are here to tell us about your infection with hepatitis C. Before we discuss that, can you tell us a little bit about your professional background before you became ill?

A. Yes. Before I became infected and seriously ill, I worked as an international tax manager dealing with ex-patriots in the oil industry and throughout the world. It was really looking at how the financial affairs of the movement of employees, their contracts, et cetera, and I worked for a major accountancy firm during that time.

I really was also not only dealing with UK tax but I was also trained and qualified as a US tax adviser and I met the IRS regulations for the production of US tax returns as well.

Q. At that time, what were your expectations of your future career?

A. Because there was only two people in Scotland with the qualifications that I had, and I'd obviously travelled to London, worked with teams in London and abroad in fact most of my colleagues were based in other countries, I fully intended to become an expatriate tax partner and that would have obviously meant that my financial situation and my family's financial situation would be of a very, very secure standard.

Q. In 1998, you gave birth to your first child. What can you tell us about that.

A. Yes. In April 1998 my son Keith, he was -- my labour was 36 hours at Bellshill Maternity and for much of the time my husband and I were left on our own and it obviously with our first baby it was very, very traumatic. It was only when the baby got into distress that doctors were called and I was actually taken for an emergency section, a caesarean section, and once that was done, because I'd had an epidural they allowed me to see Keith, but then they took the baby away and they put me in a high dependency unit and there I was given three units of blood at that time.

Q. When you were given those units of blood were you

given any advice about the potential risks of receiving it?

A. None at all. None at all.

Q. Then after the transfusion you became unwell?

A. Yes, that's correct. Within a couple of days I became violently sick and I was on, obviously, a normal maternity ward and during the night I was wakened and told that I was being removed from the hospital because I was a risk to mothers and babies. They didn't tell me what was wrong, why, and, as I say, it was all done for me in secrecy. It was done at night. I was taken in an ambulance. They took Keith as well. A nurse was taking care of him and the ambulance -- they didn't tell me where I was going but they transported me to the infection diseases ward in Monklands Hospital which I didn't even know was there.

To explain it, the kind of circumstances, I didn't know if I was actually going underground because there was no windows, no lights, no clear daylight and what they actually did was they put me in an isolation unit which had sealed doors. The staff all had protective clothing and I didn't see Keith again.

All they gave me were anti-sickness drugs and I was left in that ward.

Q. As you say, you didn't see Keith. During that first week of your son's life, did you have any contact with him at all?

A. No, the most callous and traumatic aspect of that was that the nurses that worked in the infectious diseases kept telling me what fun they were having having a baby to look after when that wasn't their normal job and how much fun they were having feeding the baby, changing the baby, playing with him and cuddling him. I just found it incredulous that they knew they were talking to a mother who'd just given birth who was missing her baby to talk in that manner -- and that was heart-breaking.

Q. After about a week you were discharged from the hospital?

A. Mm-hm.

Q. What were you told at that point about what had been wrong with you?

A. Well, obviously while I was there I kept asking them and they said, well, we've taken bloods, we're doing tests and as the week went on they just come in and said get dressed and the other thing that made it difficult was that when I'd been moved they hadn't told my husband that I had been moved.

He phoned the maternity hospital and was told she's not here, so I'd only seen my husband through the window using the protective gloves screen and they basically kept both us very much in the dark. So at the end of the week they just told me get dressed you must be excited going to see your baby and I said well can you -- what is wrong with me? Why have I been sick? And they said you shouldn't be thinking about that now. What you should actually be doing is being happy just go home and enjoy your baby and they ushered me out the hospital.

There was no doctors that I could go to and because of the actual environment that I was in, there weren't any other patients there. This was just an isolation unit on its own and Kenneth my husband came for me and we went home with our baby.

Q. About a month later you were admitted to hospital as an emergency?

A. Yes.

Q. What happened?

A. What actually happened was I was at home on my own with Keith and I started to haemorrhage very, very badly and an ambulance was called and I was taken and what they discovered was that the post partum was actually left in after the caesarean and it had become infected then the lining of the womb had haemorrhaged.

So they removed the post partum without a general anaesthetic which was very painful and they gave me more blood. They gave me two more units of blood.

Q. You had two more units at that point?

A. Yes, yes.

Q. How were you physically during that time?

A. It was very difficult because I'd had a caesarean section I was very unwell but I didn't know whether that was simply because I'd just had surgery and I was very, very weak and because I'd obviously never had a baby before and I knew I'd had a very long labour, I put most things down to being part and parcel of what I'd been through but I knew I wasn't well at all.

Q. February 1989, you went back into Monklands Hospital --

A. Yes.

Q. -- to have a barium meal test?

A. Yes, that's right.

Q. Can you tell us what happened then.

A. Yes. They'd sent me for tests because, basically, I didn't -- my health didn't improve and when I went they said that they saw how they termed it a shadow and that they wanted to do a biopsy. So I had to come back in the afternoon and I went back and they took

a biopsy, sent me home and said, you know, "We'll get back to you. We'll let you know the results", and that was it.

Within 24 hours of that biopsy, I started vomiting blood and haemorrhaged very, very badly. An ambulance was called and I was taken to Monklands Hospital and I was put in a ward and when I was in the ward, they gave me milk and they said, "Just drink milk and you'll be fine".

A few hours later another elderly patient found me on the floor basically vomiting excessive amounts of blood and so I was put back on to the bed and then they cut away my clothes and quickly got me prepared for surgery and took me to surgery.

Q. You had major surgery on your liver?

A. Yes, I did.

Q. And received 16 units of blood?

A. I've since found out it's actually 30 units of blood that I had. The reason that I thought it was 16 was and I think this will come out later on is that I found that the doctors would just quote fake figures to me without really checking my records or anything like that. But, yes, I was given large -- a large amount of blood.

What had happened was they'd punctured my portal

vein and during surgery they weren't able to control -- first of all, they couldn't find where the bleeding was coming from and I was losing blood so fast it was only afterwards when I was in intensive care that I could see that basically every artery they could put blood into had maybe about five in my head, my ankles, my hips, my arms. Basically, they were trying to transfuse blood as much as they could while the surgery was going on.

Q. Again, were you given any advice about the potential risks of receiving those transfusions?

A. None at all.

Q. The hospital trusts have been invited to respond to your statement and they will be responding in due course. They've indicated that responses are being prepared and they will be published at the appropriate time.

While you were in hospital, you were told that you were pregnant. What monitoring were you under during that pregnancy?

A. They told me that in intensive care, they told me I was pregnant because the contraceptive I'd been using wouldn't work because I was so sick. So after I got home from -- I think I was in hospital about three weeks they then said that I had to attend

Monklands Hospital for bloods. I had to go -- which Monklands Hospital is in Copebridge, I had to go to Hairmyres in East Kilbride and I also had to return to Bellshill Maternity which is obviously in Bellshill because I was pregnant as well, but all three places I had to go there every three months and give blood.

I asked can I not attend one hospital and you can you know you are taking the same blood and you'll give them that information but they weren't willing. They basically they were trying to put over the idea of, "Well, you do want your baby to be healthy and born like you should accept the care that you know that we're giving. So basically don't challenge what we're saying".

Q. You had your daughter in 1989 but you were still unwell?

A. Yes.

Q. Can you tell us what was wrong?

A. I think that to say that I was tired is like one of the biggest understatements. I remember trying to explain to my GP and they said we all get tired and I said no this is fatigue. I found even trying to wash my hair I could hardly lift my arms. I could hardly walk any distance. Lifting the babies even just to put them in their cots I was like this is not

normal.

I had very, very bad pain. I couldn't -- lots of foods it became obvious there was lots of food I couldn't tolerate. I had a lot of abdominal pain because my liver was compromised, I couldn't take paracetamol or the normal pain relief and my episodes of pain would be so severe that my GP would have to come and give me morphine and pethidine and obviously I've learned in later years that to give you that combination is actually quite dangerous. But that was the extent of the pain that I was experiencing.

Q. When you say that you knew your liver was compromised, what are you referring to at that stage?

A. At that stage, all I thought it was was to do with having -- they told me that I had had jaundice at one point but I thought, again, not knowing why I'd been sick at the time Keith was born, I thought maybe, you know, I've wakened it or, you know, that was about as much as I thought but I thought maybe that's what's wrong that I've still got to recover.

Q. Given how unwell you were with two babies, how did that impact on your care of the children?

A. It had a profound effect. When they were little I would be sick quite often and my husband would prepare bottles for Julie and put them beside the bed

and if I wasn't well enough to be literally on my feet or I was dizzy I would take the children into bed and make a tent and let them play around me.

But what was distressing to me was, first of all, I didn't want them to see me being sick and being in pain and also it upset me that I wasn't really being a good mother because I would see a sunny day like today and not be able to take them out in the pram or take them to the park, so it had a profound effect on my own self-worth and what I saw as being a mother.

But from a practical point of view, everything that a mother does in looking after babies and taking care of them was really difficult. It was made more difficult because I just wanted to basically get back to normal. I was like I need to get myself well, I want to go back to work, this has been a very hard time for me but at that time I thought just give it time, you will get better, you will. So that was where I was at.

Q. Your GP had made a request for you to receive some help from Social Services.

A. Yes.

Q. Did you receive any?

A. What they did was they came to the house and

I explained to them the difficulties I was having and how hard it was to look after two small children and all that -- after the assessment all they could offer me was to make someone to come in and make me a meal and to me that was no help at all because at that time I could hardly eat. I asked like could I get help with the children and they said no and it would actually take another three years before I finally got a place for them at a nursery in the afternoon, so that while they were in nursery I could rest in bed.

Q. In February 1992, you were referred to the hospital again.

A. Mm-hm.

Q. What happened when you then went there?

A. I was taken in for a week. They told me, "We can't get to the bottom of what's wrong with you", my GP said, "so I'm going to refer you to Glasgow Royal Infirmary" and I was there for a week. Every single day they carried out a number of tests. They didn't tell me what they were testing for and each morning what I found really unusual, because I was used to the procedures within the hospital and the doctors' and consultants' rounds in the mornings was a group of about eight doctors, eight consultants would come to my bed, not talk to me but talk among themselves and they would, basically, by the third day I became impatient and said I know that you're carrying out tests but there must be something you've been able to establish at this point and they said -- they wouldn't reply and walked away.

One of the consultants came back and said, "It's just that you're an interesting lady. You're a fascinating case", and on one other occasion one of the doctors who was visiting was an African doctor said have you ever been in Africa and I had said no I hadn't. But the actual communication of telling me what they were doing or even explaining was non-existent.

Q. That in-patients date was December 1993?

A. Yes, it is.

Q. Then a few weeks later you went round out patient appointment in January 1994?

A. Yes.

Q. What were you told?

A. When I was called in, actually my husband was with me but where you have to park in Glasgow you need to keep going out to check the meter. So he had literally just gone out to put more money in the meter and I got called in and there was a group of doctors which I found unusual because it's a busy clinic. I sat

down and the consultant said, "I'm very pleased to tell you that we've done all the tests and so many things that we were looking for you don't have. I'm pleased to say you have hepatitis C".

Q. What was your reaction to that?

A. First of all, I didn't know what it was so I said what is hepatitis C? What is it? And they said it's a virus and it's usually caused -- it's usually found in drug users or those with many sexual partners and at that point my husband came in and I spoke to him and said, "They've told me I have hepatitis C", and my husband, like myself, were like what's this about? I said this doesn't make sense that I would have hepatitis C. I said neither my husband nor I take drugs. We were married very young. We don't have any other or had any other sexual partners. So I don't understand.

Q. How did the doctor respond?

A. The doctors were very, very evasive to the point that their body language just was one of discomfort. They were uncomfortable that I wouldn't just accept what they were telling me. Their attitude was very evasive. I was waiting for them to explain. All they wanted to do was to talk about going forward and I was like concerned that they weren't -- I said the only

other way that I could have had infected blood I said you do know I've had lots of blood transfusions has it anything to do with that? But you can imagine I didn't know how serious hepatitis C was and I didn't really -- I'd never heard of it so I was almost like grasping for an understanding myself and they were, like -- wouldn't respond to that. They wouldn't actually answer my question. They said no, what we've got to do is think of how we're going to manage this and they said -- I said, "Well, what does hepatitis C do? What will it do?" And they said, "Well, what we will be doing is we will monitor you every three months for the rest of your life at this clinic for cancer and cirrhosis because that's what hepatitis C gives you", and I said, "Well, is there any treatment for it?" And they said, "There is a treatment called interferon but it is highly -- it's very difficult and harsh to be given and we would think that it wouldn't be effective in your case, so there is no treatment. All we're going to do is monitor it".

Q. Were you told anything about the risks of transmitting the virus?

A. No. No, I wasn't. I was told that about using like separate toothbrushes but that was it. That was all. But that was almost like a kind of off-the-cuff

remark. It wasn't saying to me these are the lifestyle changes you need to make or that my husband needs to make or -- they made no reference to the children, nothing, nothing.

Q. When you received that diagnosis, how did you feel?

A. I was absolutely devastated. Maybe some people here know Glasgow Royal Infirmary but when you leave the building, there is a kind of archway that's like a kind of concrete and when I was walking out, I was in tears but actually I know I was in shock because when I got to the entrance where you're about to go out, I actually froze because I knew that once I left, I actually had to go into the world where hepatitis C was very much in the 1980s associated with AIDS and I had to deal with the stigma, I had to go forward knowing that I might not live very long for my children, which was very significant for me because my own father had died when I was eight years of age and so I knew what it was like as a child to lose a parent.

So I was completely in shock and knowing that the doctors that had so flippantly told me that I had hepatitis C but then sent me away without any support or even any offer of counselling, just anything, just, "Now, you go home. We'll see you in three months".

Q. Again, I should say the doctor's been invited to respond to this statement and any statement will be published in due course.

After your diagnosis what did you do to find out more information?

A. I think it's important to remember this was before Google and I just went to the library, just by the nature of my own professional training I decided to do my own research. I found two books that, first of all, told me about hepatitis C but also I found something that said you can find out the batch numbers of any blood transfusion that you'd had. So I thought, "Right, I need to find out if the hospital isn't going to help me I need to help myself".

So I did that and a couple of days later I found that blood transfusion the Scottish Blood Transfusion Service and I had the books and things from the library in front of me and I asked them if they could help and what shocked me was just how rude and how abrupt they were with me.

They wouldn't help me, this wouldn't give me any information. They basically said why was I phoning them and as I was trying to speak to them they put the phone down on me. To be honest, at the time I thought naively, "I've just got someone on a bad day. I've

got an employee who's, you know, cheesed off and I've been on the receiving end", so I waited a couple of days and I phoned back and got someone completely different asking if they could give me some advice and they said that they couldn't.

I told them where I'd been given the bloods and they said that I had never received any blood transfusions. They asked for my date of birth and things like that and at that point I just knew I was being lied to. They weren't helpful at all.

Q. Just this morning a few most before the Inquiry started this morning, a statement from the Scottish National Blood Transfusion Service was received responding to your statement and they have apologised for your experience when you contacted them.

They have said that they wouldn't be able to trace the original donation without the blood component numbers and they say they don't hold those in relation to your transfusions. You would need to have them from your records.

However, they've also said that they would be willing to carry out a reverse look-back if the blood component numbers were available. In the absence of these, SNBTS believes that "the blood transfusion Mrs Dyson received between April 1988 and

February 1989 are the most likely source of her infection and offer our sincere apologies."

SIR BRIAN LANGSTAFF: Thank you very much. That was the reason for the slight delay I think this morning.

MS FRASER BUTLIN: It was, sir, yes. That statement will go up on the website once the team have dealt with it as they need to.

SIR BRIAN LANGSTAFF: Thank you.

MS FRASER BUTLIN: That was your experience with the SNBTS. You also spoke to a lawyer.

A. Yes, I did.

Q. What happened when you spoke to them?

A. Well, when I realised I couldn't get anywhere with the Blood Transfusion Service, I got in touch with my lawyer and explained to them the situation. They made their own enquiries and they came back to me and said that as it stood at the moment, there was no Legal Aid available for anyone with hepatitis C to take a case to court.

They told me that a company called Thompsons was dealing with the case but that it would probably take 20/25 years for anything to happen and, sadly, there was nothing that I could instruct my lawyer to do and that basically my husband and I would have to just -- we were on our own and we would have to just live with

what had happened.

Q. How did you feel after that?

A. I felt completely abandoned. I felt abandoned and I also felt very much of no value in society, completely rejected by society at all its levels. So it was the state was basically completely dismissing me as an individual, my dignity and my human rights.

Q. You've described a moment ago that fear as you left the hospital knowing your diagnosis but at that early stage you were able to tell some friends that you had been diagnosed with hepatitis C?

A. Yes.

Q. What was their reaction?

A. I think I was naive. I thought -- obviously, my friends knew that I'd been in hospital and the circumstances and I thought it was better to be truthful, to tell them, and so I did. I told them that this was the diagnosis and that was it, but sadly, and to my shock, very, very quickly friends just disappeared. It was social events I wasn't invited to, children's birthday parties, different things at play groups and nurseries. It was like I realised that they -- I wasn't welcome or I wasn't even invited.

Q. You attended the hospital every three months?

A. Yes.

Q. Can you tell us what that was like.

A. What I had to do was to go with the children and the setup at Glasgow Royal Infirmary was basically waiting maybe two hours and more in the waiting area but most of the people for the clinic to be tested for hepatitis C were drug users and often they would offer me drugs. I was completely traumatised just because I wasn't part of that culture. I didn't have any experience. I was afraid for my children because I knew that drug users had needles, they had things. So I would literally hold on to the children and keep them close to me for the time that I would sit and that went on for the whole time that I was there.

Q. What was your experience of the staff at the clinic?

A. What was really hard was that when I was going in to get bloods taken, they would treat me as a drug user and that went on for a long time until one day that I went I broke down, I just started to cry and I said, "You're treating me like a drug addict and you're not recognising that I got infected from a blood transfusion", and the nurse that was attending me said, "Yes, we are because we don't" -- I said, "How can you," and she said, "We have no facilities for someone like you".

It was cold and callous. It was heartless.

Q. You carried on attending there for seven years and then asked to move somewhere closer to home. Why was that?

A. Because I was so unwell, it was a struggle for me to take the children, to try and find parking, the usual things that everyone who's an out-patient understands. I would be worried that I would be unwell in the hospital because if I'd just had an appointment and gone in and back out, I probably could have managed but the fact that they were making me wait two and three hours made it very, very difficult, so I kept asking, "Could I please be moved closer to home. You're not treating me. You're only taking bloods. You're not doing anything", but that was ignored until I was finally moved.

Q. Because during that whole period all that was happening were blood tests?

A. Correct, correct.

Q. You've said you were unwell. Can you describe that for us.

A. Yes. I think when, as I say, it's complicated to try and deconstruct what fatigue really means. It means insomnia. It means pain, the onset of pain without any warning. It always meant that I was in pain

basically all the time and because I couldn't rely on -- first of all, I couldn't rely on strong pain relief because I couldn't be drowsy, I had to be responsible for very young children and it would have been reckless to be like heavily sedated or anything like that.

So I was in pain most of the time but those episodes of pain, abdominal pain, joint pain, difficulty walking, one thing was even a sensitivity to light. I had to wear like sunglasses all the time at that time.

Q. So in about 2001 you did transfer over to Strathclyde?

A. Yes. Strathclyde Hospital is basically an annex of Wishaw General Hospital, it's in Motherwell, and they were very old buildings but a small group of buildings and I was transferred there for them to start taking bloods every three months. So that's again all that was done and I was there going back and forward but obviously that was easier for me. By that stage, after seven years my children were in school so most times I could go to an appointment and be back home.

Q. In 2007 you became very unwell. What happened to you?

A. What happened was that things developed very quickly. I started to get blockages in my bile ducts which caused me jaundice, very, very serious infection which

had to be treated with very powerful antibiotics to stop me getting sepsis.

I was basically going through periods of jaundice, not being able to eat maybe for three or four weeks, losing about a stone in weight and waiting until the blockage cleared. That obviously threw up a flag to the hospital because obviously I was being admitted as an emergency patient and, after being admitted on five occasions during January and February, it was decided to put in stents into my bile duct to try and keep it open because it was closing.

That was attempted three times and three times it failed. But that was the stage it was at at that time.

Q. During that period of really very serious ill health, you were on holiday in France.

A. Yes.

Q. And had to be admitted to hospital there on one occasion.

A. Yes.

Q. What was your experience in a French hospital?

A. Yes, from the moment I arrived at the hospital in Auxerre, the thing that was most striking was that every single member of staff that I met, once when they asked for my medical history and I told them I'd been infected with hepatitis C from a blood transfusion, the compassion and the care was incredible.

I had never experienced anything like it and it was every -- even with the language barrier, every single surgeon, radiologist showed nothing but compassion and real genuine sadness that I had been infected in that way and it was a real eye-opener for me because I was quite flabbergasted because it made me realise how badly I had been treated by the NHS in Scotland and so many different hospitals because obviously, as you can see, I was sent to many different hospitals in different areas and so it wasn't my experience of one place, it was endemic.

Q. You returned from France to have the stents put in on three occasions, as you have said?

A. Well, the stents were done prior to France. They were put in -- it was after France that they put in a permanent stent. These were temporary ones.

Q. Thank you. By September 2008 you were becoming much more unwell and you were becoming worried?

A. Yes. My main concern that there was no treatment plan. There was no management. Everything was dealt with on an emergency basis. Too often I was being sent home unable to eat with a very serious infection

and no-one monitoring it, no-one actually looking for the danger signs, and I knew that there was only so many times I could get to this point, that I knew I would die.

So I decided to phone the British Liver Trust and I said to them I wanted just general advice, "If I could tell you my situation and what treatment I'm getting and if you think that is correct, if that is normal".

After they'd listened to me, they said absolutely not. You're not getting the care that you need and they strongly advised me to get in touch with a liver specialist because it was actually then apparent to me that no liver specialist was looking after me and they gave me -- they told me to go to my GP and get a referral letter and see if I could be seen by, at that time, the liver unit in Edinburgh Royal Infirmary.

Q. In October 2008 you did attend the liver unit at the Edinburgh Royal?

A. That's correct.

Q. What were you told?

A. When I went to the liver unit in Edinburgh, I met Dr Blair and she epitomises what a great consultant is. She has shown me that there are genuinely good

people within the NHS, which I hadn't had up until that time.

First of all, she said, you know, she wanted my history and she said, "What I'll do is I will get in touch with Glasgow Royal Infirmary. I'll get in touch with Wishaw. I'll get all your records and we will meet in six months' time and we will decide what we feel is necessary because obviously the liver unit, the liver transplant unit are a team that work there".

So that's what she did and when I came back six months later she said that she'd been told by Glasgow Royal Infirmary that all my records had been destroyed, even though I had been going there for all those years. She said that Wishaw General Hospital couldn't give her any documentation, they could only provide some information through a telephone conversation.

So from that point, she basically tried to construct from what I was able to tell her my medical history because she had absolutely no medical records at all.

Q. Despite the fact that you had been in Glasgow between 1993 and 2001 and Strathclyde 2001 to 2008?

A. Correct.

Q. Since then have you been able to obtain any records?

A. The only records I've received I actually just received a couple of weeks ago literally, in fact less than two weeks ago, and they cover a very short period in the early '90s and obviously I have the medical records from Edinburgh Royal Infirmary which are intact since Dr Blair took charge.

Q. Before we talk about the treatment you have had under Dr Blair, can you tell us what impact the lack of records has had on your ongoing care?

A. Yes, I think that's a very important point. Recently, about a year or so ago, again I was admitted on an emergency basis to Wishaw General and the consultant surgeons that saw me obviously don't have any records and they asked me to tell them my medical history, which I did.

What I just found astounding was that they said that what I'd told them was highly unlikely to the point that they basically ridiculed it, they smirked, they said basically there's absolutely no way and when I tried to explain the scars I had, they said -- they just dismissed it and left.

It really, really came home to me then, which something I'd never thought, was that the impact of not having your medical records is not something from the past, it's going to affect me for the remainder of my life.

Q. You described earlier to me that there were both practical implications but also issues of trust.

A. Yes. I think that what it has done has made me very, very distrustful of the medical staff in general. I now feel that they have to earn my trust. I see the NHS as a service and that they have to prove to me that they are professional. It's not enough that -- their badge or their title is not enough.

But in that occasion, I think what makes it very, very complexed is the fact that what do you do when you are weak and vulnerable and need medical care but you can't trust the people who are appointed for that care? Like, I felt I couldn't trust those doctors if I did need surgery, how was I going to consent when they didn't believe what I was telling them?

Q. You saw Dr Blair again in early 2009. What did she say to you about treatment and what happened next for you?

A. Okay. She first of all gave me some medication that she thought would help with the blockages I was having but she wanted to talk about the bigger picture which was obviously the hepatitis C.

What was complicated was that she said, first of

all, she was absolutely astounded that I'd never been offered any treatment. She was very concerned that I -- that the hepatitis C could be cleared from my body because in her judgment she thought I would need a liver transplant and obviously that would be compromised, if I had a new liver that would then be infected.

So she was very keen to address the issue of hepatitis C.

What made it more complex was the fact that I was actually very, very ill at the time and we talked together for the first time as a partnership for how we go forward and she said that -- and I explained to her my concerns about how I would manage on Harvoni and the harshness of it when my body was actually very weak.

Q. I think you mean interferon rather than Harvoni?

A. No, she mentioned interferon and how it would be difficult for me. She then said what I do want to tell you about is that we're actually trialling a new drug, it's not ready yet but we're seeing very, very positive results and she put me in touch with the liver nurse, specialist nurse, and allowed me to talk through the options and weigh up.

So after those discussions I decided to wait and

see when the Scottish Government would give funding for Harvoni.

Q. While you were waiting, what were you trying to do?

A. The main thing I was trying to do was to get strong. I was trying to get myself as strong as I could be so that whatever treatment I had to get, I would -- whatever side effects I would be able to deal with them and be able to complete whatever course of treatment it was.

Q. You had to wait until 2015 and then you were able to start Harvoni treatment?

A. Yes.

Q. How did you come to receive that treatment in terms of the funding of that?

A. Obviously, I was an outpatient at Edinburgh Royal Infirmary but I was living within Lanarkshire's Health Board and so Dr Blair explained to me she couldn't give the go-ahead or the authority and that, in fact, she would have to refer me to Monklands Hospital, so that the team that were there they would have to make the final decision as to whether I would get treatment. So the first administrative step, if you can call it that, was actually to refer me to a hospital that had the authority for that funding.

Q. That went through and then before you had the

treatment you had to undergo a psychological assessment?

A. Yes.

Q. What were you told about why that was?

A. The reason I was told that I had to get this assessment was because, because Harvoni was such an expensive drug they weren't prepared to gamble with anyone that they thought wouldn't complete the drug treatment period because of their lifestyle or their mental health, if they had mental health issues.

Q. And the assessment process took about eight months for you?

A. Yes, it did.

Q. Once you started the treatment, what were the side effects of it for you?

A. For the first two weeks I felt absolutely amazing. I could do anything and I was, like, this is -- I've never felt like this since I was in my 20s. But after the first two weeks, the headaches, the weakness became very, very bad and actually when I had to go back to Monklands because they routinely took bloods, I couldn't walk and the nursing staff were actually shocked when they saw how bad I was.

Q. In June 2016 you were told you had cleared the virus but what's your physical health like now?

A. I think that I've -- obviously I was delighted to be told that and I found that I didn't -- I was actually, the side effects and the effects of the treatment left me very, very weak and ill, and I remember going back to Dr Blair and saying, "I'm surprised I can't really walk very far or I can't do much and I've still got quite a lot of pain and those symptoms", and I would say that that weakness actually continued until probably seven months ago and it's only more recently that those symptoms have lessened.

But I still have a very restricted diet. In fact, I have to take medication five times a day to be able to eat. I'm in pain at any time I eat but with no pain relief. I get blockages, still get blockages that give me, you know, a lot of complications.

Q. What's the situation now in terms of your liver and health going forward?

A. Going forward, Dr Blair's explained to me that the medication I'm on, she knows that it will not -- it's not a solution, it's not a solution. She said it will stop working and when it stops, then -- or they can see it failing, they will then have to assess me for a liver transplant.

Q. How has all of this affected your mental health and well-being? If you would rather I can read something

from your statement.

A. Yes, please.

Q. In your statement you said this:

"The impact of these experiences of the last 30 years on my mental health is in reality beyond any narrative I can provide. Words are inadequate. They fail to convey the whole truth and by this omission the enormity of my pain and suffering remains hidden and indescribable."

A. Yes.

Q. You have talked in your statement about your Catholic faith?

A. Yes.

Q. Can you tell us how that has helped or been important to you?

A. It has been absolutely crucial to my resilience and my strength. In fact, last week my husband and I travelled to Lourdes and most people think that you go there for a miracle, you go -- that's why people would go to Lourdes but as a Catholic I actually my family we have gone to Lourdes many times with the children not for a miracle, not for a cure but actually to counter the cynicism of living in a state where the sick are so badly treated.

When I was in Lourdes, the sick are visible.

They are supported, they are cared for and they are valued and when I would come home it would help me see that humanity and my faith were right, that there were good people in the world who cared about the sick and not what I saw when I came home where the sick are hidden, abused by the NHS, discarded by society, and that this fight for justice and for us to be listened to, to be heard, was I could carry on through my faith.

Q. Can you tell us a little of the impact of the hepatitis C on your husband and your children.

A. Yes. I think I would actually like this moment to publicly acknowledge not only my thanks but to acknowledge the courage of my family, for their care and support. Like all families, they look after their Mum, you know.

Everybody loves their Mum and they look after her, do their best. But what it asked of them from my husband it absolutely compromised his career and what choices he could have because he had to be a carer and the limitations that put on him for a healthy man who had no need to go near a hospital to spend most of his adult life in hospitals is absolutely tragic. For a long time, I blamed myself for ruining his life.

For my children, they have looked after me since

they were little children and that is not right, that anyone who's a child carer knows or has seen what children do to care for an adult, that's not right. They should have had a care-free childhood, not worrying that mummy's sick again.

But it wasn't just in childhood, it was when they were in high school, when they were in university. But I think the most profound thing and why I say that the courage they have is that when they found out -- when they were old enough to understand why I was sick, they then had to carry the burden of the injustice of it, and that has ramifications for them in their own lives going forward, now that they are actually both of them are older than I was when I was infected.

Q. You told us at the very start of your evidence about your career. What happened to your working life following your diagnosis?

A. After I was diagnosed, at that time for a couple of years I tried to get stronger and I actually did. I had a spell where my health did improve and I was able to take up a post with an accountancy firm to be an expatriate tax manager and my children were in school and I was delighted. I felt it was good for my self-esteem but also because I knew I was very good at my job and it was such a specialist area I knew I could return to work.

So I thought maybe I can manage this illness. But sadly about a year and a half afterwards I took very sick again and I was off work for six months, and because I was in a managerial role it's normal practice that you go for a medical before you can come back to work. I wasn't worried about that because I'd had colleagues and partners, it was a partner actually at the time who had a brain tumour and he was very well supported in the office and allowed to do a staged return or stay off if he needed, so it never concerned me. I thought, yep, I know this accountancy firm. They understand the procedures.

So I went for the medical and obviously gave the doctor the full history and when I went to my GP and said, "I think I want to try and go back", I got in touch with the HR and said, "I want to try and come back", and they said, "No, we'd like you to come in at some point and have a meeting with the partners".

I came in to see them and, basically, to cut a long story short once the partners knew that I had hepatitis C -- and if I can just clarify I'd put hepatitis C on my application form when I'd applied for the job, and I was thinking about this recently

and I wondered if either they didn't read it or they didn't know what hepatitis was either at that time. But my application form said that I had hepatitis C. But once HR explained, and explained what the doctor's report had said, they basically said they were making me redundant because there was no work which I -- I literally couldn't believe.

My medical wasn't kept private. Everyone in the organisation knew. When I went to clear my desk, everyone knew and I knew that it wasn't through lack of work and, in fact, a couple of months after I was made redundant they transferred staff from Edinburgh to take over the work case load that I had.

Q. Just before you started treatment, you by then had started a PhD?

A. Yes, that's right.

Q. Can you tell us what happened with that.

A. Yes. Because -- obviously once I knew I couldn't return to the profession that I wanted, I decided to use my experience for the help of the sick and the dying and so I went to university and took qualifications in that. I started a PhD on spiritual care of the sick and dying but because of my treatment and because of the sickness that I had, I obviously had to stop my studies.

Sadly, the university said that I had exceeded the amount of time that I could have off and obviously the progress that I was able to make and so, because of sickness, my PhD was stopped.

Q. Have you been able to return to anything in terms of work or study since then?

A. Not yet, not yet.

Q. What impact has all of that had on your financial situation?

A. I think one of the greatest difficulties is that now that I face old age I have no pension, I have no savings, I can't -- my husband and I can't clear our mortgage and considering the potential and the salary I have had, to be dependent on the benefit system but more importantly all my financial decisions have had to be through the earnings of my husband and so I have had no independence of my own and that's exactly where it stands.

Q. You receive some payments from the Skipton Fund and from the Scottish Infected Blood Support Scheme?

A. Mm-hm.

Q. You also applied for some funding from the Caxton Fund?

A. Yes.

Q. Can you tell us about that and your experience of applying to Caxton.

A. Yes. Because I had already dealt with The Skipton Fund and I knew the procedures, I thought that Caxton would be similar but it turned out to be -- I think it was actually one of my breaking points of my mental health, I would say.

I had gone to them. I'd read the information and I had contacted them asking if they would give me financial support for education and what I got back was a means tested document which in its detail I found insulting for the number of things that I had to explain: how I was spending money, you know, the household money.

But because of my own financial background, it wasn't I was intimidated by form-filling or financial matters -- I was quite competent -- but it was the nature and the approach. I sent the forms back, months passed, I contacted them and all that I was told was, you know, it's in the system, the teams that -- the group that review them only meet once every few months and then they will come back to you.

So obviously I waited. When they came back they sent a letter saying, "No, we're not giving you any funding but because we've had a look at your household spending, we really don't think you know how to manage money", which I just couldn't believe, and they referred me to an online service which was actually run by a woman from her home called Pennywise.

When I spoke to this woman, she basically -- her advice was you would manage better if you cancel your husband's life insurance policies or if you -- basic, absolutely basic things. She said too many people think they need them and they don't. As the conversation -- I honestly was, I was literally is this the level that the state has brought me to, that here I am being told that, "Not only we're not giving you money but we want to tell you how badly you are managing your poverty".

It was -- I do -- I remember coming off the phone and putting my head in my hands because I was like really -- are we that badly supported, which is no support at all.

Q. You described it as being offensive and degrading.

A. Totally. Totally degrading.

Q. Eileen, those are the questions I have for you. Is there anything else you would like to say?

A. Yes, I do. If it's okay with you if I can read.

There's actually three points that I want. First, I want to speak about the infected and affected, then with reference to the NHS staff, and

finally to the Inquiry team yourselves.

The first thing I would like to say is that the infected and affected are experts in understanding the impact of NHS policies. They know the NHS truth and how they truthfully operate. Our knowledge is vast and it should be valued. The Scottish Government in 2020 in their vision for health and care strategy stated that by 2020 every person in Scotland is given the best standard of care with the patient at the centre of all decisions.

When is our community going to see this person-centred care?

With regard to the NHS staff, I would like to see teaching in medical schools and the ongoing training in hospitals for consultants. It must change. I want change. Doctors have no God-given right to hold all the power. These last 30 years since I was infected were made much worse by the abuse of power by doctors and nursing staff when I was at my most vulnerable and my weakest state.

If I can turn to the Inquiry team, I wish to raise two points with you, Sir Brian, and your team. Firstly, I would like you to consider how you intend to record silence in testimonies. When the depth of suffering is so great that all language fails and what

we recognise is that the pause is as valuable in conveying the trauma as the spoken word. This is very important for future researchers who will study the final report in generations to come.

My second point is how will the Inquiry team quantify the loss of potential. How can you, Sir Brian, and your team really establish the scale of loss for the infected and affected that you are so keen to put first.

To demonstrate what I mean, I was infected when I was 29 years of age and most people here know what stage they were at in their careers at 29. I want to give you two examples. At 29 years of age John Major with no university education and working for Standard Chartered would take another eight years to become a Government minister. Nicola Sturgeon at 29 was a young solicitor. What compensation would they be seeking today if they had been infected at 29 years of age and their political ambitions had been destroyed. I hope these examples focus the Inquiry team's and the public's minds on what it truly means to lose your career, your health and your financial security. Thank you very much.

Q. I am just going to turn and ask Mr O'Neill and Mr Dawson who are representing you if they have

anything they wish to raise. *(Pause)*

There are just two points that Mr O'Neill has asked me to raise.

Firstly, in your witness statement you've commented and noted that you felt that the Penrose Inquiry was unscientific?

A. Yes, I do.

Q. Do you want to add anything to your statement?

A. I think that with regard to the Penrose Inquiry, I see it as a flawed document because as a researcher and the training I've got is that any document of that nature has to have a balance between both sides of the argument and I see it as a totally unbalanced and it doesn't have the professional rigour that it should have. Certainly any document I would produce wouldn't be accepted if it was as biased as the Penrose was.

Q. The second point is you mentioned that while you were pregnant with your second child you had regular blood tests from multiple different hospitals. In your statement, you have described your concern that that may have been for research.

A. Yes.

Q. Would you like to explain that to us.

A. During those years doctors would refer to me as an interesting lady and fascinating, "You're a fascinating case". Any scans, any times I had to be an out-patient they would keep me for hours examining -- if I was, for example, having an ultrasound they would also want to check my heart, they would check other organs in my body they would actually keep me for long periods of time.

But I actually grew tired of -- it was language that was used across hospitals, it wasn't a specific doctor or a certain context or environment. I knew that they were definitely -- what I felt was that what they were doing was to further their careers, that they were actually gatekeepers who were preventing me from getting treatment but actually studying me as a case study.

MS FRASER BUTLIN: There are no further points to raise, sir. Do you have any questions?

SIR BRIAN LANGSTAFF: No. I want to thank you for that powerful account if I can call it that of social exclusion and the difficulties of being a mother which you amongst all witnesses have highlighted whilst being ill.

A. Yes.

SIR BRIAN LANGSTAFF: Can I thank you also for the thoughtful points you made at the end particularly the two directed at the Inquiry. You will understand why

I don't say anything about the second.

As to the first, I shall give it thought but it does seem to me that silence speaks in two ways. One, silence in the sense of what is not said but might be said and the other because silence in itself can be a form of communication when at least it book-ended by words or expressions and I hope that we have that well in mind.

Certainly those who have watched the testimony will understand it when I say that a lot of the impact of evidence such as yours has come not simply from the words that are used but the pace, the way they have been delivered, the emotion which goes into it and the sheer courage of their expression.

A. Yes.

SIR BRIAN LANGSTAFF: But thank you very much for that.

A. Could I just say one last thing?

SIR BRIAN LANGSTAFF: Of course.

A. Although I'm sitting here as a woman infected, I see that I represent the family. This is about when you poison a mother with infected blood when she's giving birth you attack the family and I don't -- I am not here just for myself, I'm here for every family that has gone through this terrible ordeal. So thank you very much indeed.

SIR BRIAN LANGSTAFF: Well we will take a break now until 12.00.

MS FRASER BUTLIN: Thank you, sir.

SIR BRIAN LANGSTAFF: 12.00.

(11.24 am)

(A short break)

(12.03 pm)

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

MS RICHARDS: Yes, sir.

SIR BRIAN LANGSTAFF: John. I think Kate is coming to sit with him.

JOHN MCDOUGALL, affirmed

Questioned by MS RICHARDS

Q. John, you're here to talk about your son Euan. You are also going to tell us a little about your brother-in-law Terry?

A. Yes.

Q. And Euan's mother Kate, Terry's sister, sits beside you and she has also provided a statement to the Inquiry?

A. Yes, indeed.

Q. Euan was born in 1977?

A. That's correct.

Q. And diagnosed from an early age with severe

haemophilia A?

A. Yes, indeed.

Q. You knew, you and Kate knew about haemophilia because Terry had severe haemophilia himself, Kate's brother?

A. That's correct, yes.

Q. Terry had been treated as a child for his haemophilia how?

A. Terry, who was a couple of years younger than Kate, had been treated initially with snake venom which must have been in the 1950s and then with whole blood transfusions, apparently, by the time he was four years of age Terry had had over 100 pints of blood, whole blood, and then he was treated with plasma and then cryo (cryoprecipitate) and then latterly with Factor VIII.

Q. You've said in your statement that from Terry's perspective at the time the Factor VIII products seemed a godsend because they were more convenient and easier to use.

A. Yes, indeed, yes.

Q. Now, Euan was under the care of Yorkhill?

A. Yes.

Q. And what was the treatment he received in the first couple of years of his life?

A. As you said, Euan was born in 1977 so his first couple of years he was treated with cryoprecipitate and probably 1980 -- '79/80, '80 let's say, he was treated with Factor VIII.

Q. Was that on a prophylactic basis?

A. It was not initially on a prophylactic basis. Initially it was a reactive basis, if there was a bleed, and in the very early days if there was a bleed then we would take, Kate and I would take Euan to York Hill Hospital and he would be treated at hospital.

Q. There came a point at which Kate was trained to give Euan the Factor VIII injections at home and he moved on to a home treatment programme; is that right?

A. Yes, that's correct.

Q. How often would Euan receive Factor VIII products?

A. Again, in the early days when it was on a reactive basis then Euan would require Factor VIII for a bleed, maybe fortnightly, two or three times a month, that sort of frequency, initially, and then once we moved on to the prophylaxis, then it was twice per week and that was a great benefit at that time. The home treatment was a great benefit and the prophylactic treatment was a great benefit, the combination of these two things meant that from about 1981 or so Euan was -- he was normal boy. He was a four year old,

five year old boy playing football, running about, just normal.

We felt we'd sort of conquered haemophilia.

Q. What can you recall about which factor products at this time Euan received, where they were from?

A. The earliest days that I recall -- because they resided in our fridge so I would see them alongside orange juice and things like that -- at the early stage, I remember they were from the Scottish National Blood Transfusion Service and I remember that there was an address in Ellen's Glen in Edinburgh and then at some point in '81, '82, '83, then American blood started appearing and it was from a company called Armour.

Q. Did there come a point at which Euan was receiving almost exclusively the Armour products or the US products rather than the Scottish products or did it continue to be a mix?

A. It continued to be a mix and the balance switched, the balance switched to Armour, to the US product. I wouldn't say exclusively because by the time we got to about '83/84 then we were requesting Scottish -- Factor VIII from Scottish donations, but sometimes all that was -- most times all that was available was the American product but we would still be requesting the

Scottish product so there must have been occasions when it was there.

Q. We will come on in a moment to the specific reasons why you were making that request but just the earliest stage when Euan started to be given the American products or the commercial products for the first time, was anything said to you at that stage or indeed at any of the early stages about any risks of infection associated with that?

A. No. Indeed, it was the benefits that were stressed, the benefits being benefits of administration. The kit was all together. For the Scottish one you had to go and get distilled water and do things and it dissolved more quickly. The American product dissolved in 20 minutes or 25 minutes and the Scottish product for some reason took 40 minutes or 50 minutes, so it was more convenient in those terms.

Q. In terms of the balance of convenience versus safety, if anything had been said to you and Kate about any risks of infection associated with the use of the products, balanced against the convenience and the advantages, what would your decision-making have been?

A. Oh, I mean a complete no-brainer and I think for any parent if you're comparing convenience with eliminating risk for your child, then you're always

going to select the elimination of risk for your child over convenience, of course.

Q. So when Euan first started using the Factor VIII concentrates, the products, no advice or information about infection. When he moved on to home agreement or prophylactic was any advice or information or warnings given at that stage?

A. Regarding risk?

Q. Regarding risk.

A. No.

Q. Were you given any product leaflets to read and consider in relation to any of those products?

A. Again, specifically just the American product? No.

Q. Any of the Factor VIII products that Euan received?

A. We had leaflets on how to administer it, how to dissolve it, how to put it together and we had training starting I remember with injecting oranges, because apparently oranges have got the same degree of resistance as human flesh so, yes, we had a training package.

Q. But nothing that related to risk?

A. Nothing that related to risk.

Q. You had a recollection whilst you were on a business trip to Holland in about 1982 of reading something that gave cause for concern. What was that?

A. Yes, it was against the background, as I say, by '81 we sort of felt we had conquered haemophilia and at that time I was working in the Netherlands quite a lot and I think it was during -- I was working in the Netherlands '81/82 and I think this was in '82, and I was on a KLM flight from Glasgow to Amsterdam, and as you go on to the flight they've got newspapers that you pick up, and I was reading the Times and there was an investigatory piece in the times, quite a long article, and it was about HTLV-III, HIV, and it was talking about the prevalence of HTLV-III in the States and of which I'd read about before, but what made this article different was it then moved on to say that haemophiliacs were particularly at risk and it could mean the elimination of haemophiliacs. They could all die.

It was saying that the reason for that was because it took so many pints of blood, I've forgotten the number but it was hundreds of pints of blood, perhaps even thousands of pints of blood, to make a phial of Factor VIII and so the risk -- you weren't just being exposed to one person, you were exposed to hundreds of people and it was talking about, because of that, that magnified the risk for haemophiliacs.

So where someone getting a whole blood

transfusion it might be a one to one but for a haemophiliac it might be a thousand people to one and, therefore, the risks were greater and, therefore, statistic -- and there was no cure and, therefore, statistically it could mean all haemophiliacs dying.

I remember reading that on the plane going to Amsterdam and I just froze.

Q. Was anything of that kind, any of those concerns conveyed to you in 1982 by any of the doctors or staff caring for Euan and prescribing his treatment?

A. No, they were not conveyed to us but obviously we were then aware and it was popping up in the press but, no, we were not -- it was the other way round. We would approach the staff at Yorkhill Children's Hospital in Glasgow rather than them approaching us.

Also at that time there was a number of haemophiliac boys, all boys, obviously, at Yorkhill at that time, I think the number was about 20, and we formed a haemophiliacs' parents' support group. So typically there might be a dozen parents or 14 parents, a social thing. It was a support thing rather than anything else and Kate was the secretary. So there was minutes taken of what we were discussing and I loosely chaired these meetings. So it's cups of tea and biscuits and a chat about American blood and

things like this, so we discussed it in the parents' group and we discussed things like heat treatment in the parents' group as well. I'm talking about the end of '82, '83, '84.

As a consequence of these discussions in the parents' group, we would then approach the staff with questions that had arisen.

Q. When you, either on Euan's behalf or as part of the parents' group, when you and other parents approached the staff to ask questions, to express your concerns, can you recall what, if anything, was the response?

A. The staff knew as well, you know, they would -- I mean, clearly they weren't living in some bubble where they were denied access to this information, so they knew that type of thing as well but they would -- they would try to reassure us but also if we were going in for Factor VIII and we were asking for Scottish factor they would be pleased to give us Scottish Factor VIII.

I say Scottish. I understand it was Scottish and Northern Irish funnelled together. We were told that at the time. They were sort of pleased to give us Scottish product rather than American product but if there were no Scottish product, and increasingly that was the case, increasingly it was just the Armour

product that was there, then they would sort of apologetically give us the American Factor VIII.

Q. Now, in 1983, Terry, Kate's brother, your brother-in-law, started to become ill and was diagnosed with what we would now refer to as HIV, HTLV-III.

A. That's correct. Terry was a severe haemophiliac as well, a different generation to Euan, so by '83 Terry would be 33 years of age so he was a man and as a haemophiliac round about '82, so he would be 32, Terry chose to move from Wishaw in Lanarkshire, he chose to move from there to Newcastle, and his reason for moving to Newcastle was to be treated at Newcastle Royal Infirmary, the infirmary in Newcastle, but particularly the magnet for Terry to go there was a Dr Jones who terry believed to be the foremost expert on haemophilia in the UK and so that's why, as a man, Terry chose to, as an adult, Terry chose to go to Newcastle in '82.

He'd been there a year or so, so as you say, perhaps the middle of '83, September '83, something like that, autumn '83, Terry started to become ill and he later died of AIDS.

Q. Terry started warning you and Kate about American products specifically. He would telephone you and you would have conversations. What can you tell us about those?

A. So you know, again, as I say, Terry was an adult and he was in Newcastle because he believed that's where the best treatment was and I don't know if that was the case or not but I knew Terry and it was probably very, very good treatment.

So he was at -- he had access to information that was telling him and obviously he had a very strong vested interest in this, so it wasn't just tittle-tattle, but from the back end of '83 he was contacting us every couple of months -- this was before email so he would be telephoning or he'd be sending letters -- and he was saying don't use American Factor VIII, and then he was also saying heat treatment is the answer. So that was the two messages coming from Terry.

Q. You and Kate from then onwards renewed your efforts, as it were, to try and avoid the use of US products for Euan and you asked for non-American products as much as you could but they weren't always available.

A. They weren't always available and sometimes, you know, if Euan had a particularly bad bleed and if we went into Yorkhill, Euan was still treated at Yorkhill at that stage, and if we went to Yorkhill and they only

had American Factor VIII then, as I mentioned before, it was a sort of Hobson's choice. You either let the bleed continue, which is a guaranteed very negative scenario, or you take the risk of the American Factor VIII with the medical staff, the nurses and the doctors, assuring you that it's okay. So there's a choice and given that choice you are going to choose the American product.

Q. Your impression as described in your statement is that the decisions at Yorkhill on what products would be used and maintained in stock were the decisions of Dr Willoughby, then one of the consultants.

A. I think that. I mean, that's what I believe to be the case. My reason for saying that is Dr Willoughby was -- he was one of the pioneers and one of the drivers of home treatment and of prophylactic treatment and that, as I said earlier, that made a big difference. That was a boon. That was a big positive for us and for any haemophiliac or parents in that situation.

So Dr Willoughby was at the cutting edge, at the leading edge of prophylactic treatment and home treatment for -- remember these boys are 7, 8, 9, 10 years of age, so it was quite leading edge, you know, for home treatment for relatively young --

you're not talking about 25-year old adults. So he was driving that and we much appreciated that.

My belief then is that -- and prophylactic treatment, as I said, we injected Euan at home twice per week, so you needed more Factor VIII as opposed to on a reactive basis where you are maybe using it once a fortnight, so you probably needed four times as much Factor VIII as would otherwise have been the case and you've got the same level of blood donations, so actual raw blood coming into the system would be roughly the same amount.

But in order to use it for home treatment on a prophylactic basis you would need more Factor VIII, so my belief then is that with Factor VIII, with American Factor VIII being cheaper, because it needed more then it probably made sense to source the cheaper product because you could get more of it and that could allow you to have more home treatment, more prophylactic treatment, which were good things.

So I can well understand that it would make sense in someone's minds to do that, to get the cheaper product, because you can get more of it and it allows you to do this good thing with the greater amount of product.

But that was at the same time as the risks were

known regarding American Factor VIII the risks were beginning to be known. I mentioned the article in the times and we spoke about Terry and so on, so it was against the background of it not being risk-free or thought to not be risk-free, and if Dr Willoughby was comparing convenience of home treatment and prophylactic treatment, which was great, with a risk then, again, as I said earlier, any parents would want the elimination of the risk rather than the -- I mean, you're talking about a 20-minute drive to Glasgow so the convenience, you've got to put it into perspective. It was convenient but it was, you know ... that's -- it was convenient in that sense.

What he certainly didn't do was to discuss it with the parents or to discuss it with us or to discuss it with other parents and to come to a consensus. In that sense then I think it was his decision. My take on Dr Willoughby also at that time, he was about 20-odd years older than me but he seemed to be at that time, bear in mind we are talking early '80s, he seemed quite old school, and within the haematology department then I would imagine that Dr Willoughby would make the decision rather than ... I don't think the haematology department was a democracy. I don't think they had a vote on it.

I think that Dr Willoughby would make the decision.

Q. It's also your understanding, as set out in your witness statement, that Yorkhill used more American products and for longer than other hospitals in Scotland?

A. The thing as a parents' group and as individuals one of the things that really surprised us was not surprised but perplexed us for a long period of time was, as I say, with this drip feed of information from Terry telling us not to use American Factor VIII, we heard in the press there was indications that American Factor VIII was risky and given the reasons why, and then increasingly you saw other Scottish hospitals stopping using American Factor VIII. You put all these things together, then you know it's a bit of an outlier to continue to use American Factor VIII.

So Yorkhill was a bit of an exception, and the only reason I can think of why it would be an exception like that was the reason I gave earlier, which is with Dr Willoughby being a pioneer and home treatment, prophylactic treatment, and perhaps he thought, you know, it was necessary for that. But that was -- he was coming to a conclusion that was different from the conclusion, as far as I know, different from the conclusion in other hospitals in

Scotland.

Q. Terry's health continued to deteriorate throughout 1984.

A. Yes.

Q. He died of AIDS on 3 November 1984?

A. Terry was in Newcastle, as I said. He became very ill in Newcastle. I can remember that in April or May 1984 -- I remember it was April/May because, completely unrelated, I was in hospital April/May 1984 so I know where I was at that time and I remember Kate's family at that time went down to Newcastle to bring Terry back, so Terry clearly couldn't come back himself. He was clearly incapable of getting on a train. I don't think he drove but getting on a train and coming back, so the family went down to bring Terry back April/May 1984 and Terry died on 3 November. He stayed at home in Wishaw. I remember a bed was made up for him downstairs in the living room beside the television, beside the family, so the family all sat together.

Q. There was a lot of press attention after Terry's death. What can you recall about that?

A. When Terry died 3 November 1984, it was a different background then. That was 35 years ago, and AIDS was seen very much as being the gay plague. It was seen

in very negative terms. There was an incredibly negative stigma that was associated with it. I'm saying things that you know. All references to it in the press were very, very negative at that time, very sensational.

When Terry died beginning of November, then my memory of if we went out to Kate's parents' home in Wishaw and the curtains were drawn because the body was in the house, I think the body was in the house but the curtains were certainly drawn, and if you opened the curtains then the press were outside on the pavement and the photographers, the camera's would start flashing and you'd close the curtains quickly.

It was front page news. Terry was the first haemophiliac to die of AIDS in Scotland; so it was front page news but it was also a milestone for haemophiliacs in Scotland. He was the first one to die.

The tone of the article -- not all of them but the tone of the articles, most of them were placing it against this, in the context of the gay plague and homosexuality and so on. By that I mean when Terry died he would be 34, so there would be sentences like "34-year old unmarried man from Wishaw dies of gay plague, AIDS", you know, so the insinuation would be

that Terry was gay, so it was against that sort of background.

But, as I say, that's 35 years ago so it's -- that and lots of other things about it, the stigma and so on, it's difficult to understand it now.

Q. We've got an example of a newspaper article.

Paul, could we have 2850002.

It's perhaps one of the less unkind articles and I know you've seen it, so it's 20 November 1984 in the Daily Mail:

"Seven-month hell of man dying from AIDS.

"AIDS victim Terry McStay went through seven months of hell before he died, it was revealed yesterday. The haemophilia sufferer contracted the virus after being treated with the blood plasma product Factor VIII at Newcastle's Royal Infirmary. AIDS most prevalent amongst homosexuals destroys the body's defence mechanism against disease."

Then it quotes Terry's GP saying that:

"'Terry showed tremendous courage. It was a nightmare for him. None of the treatments we tried had any effect. He just got weaker and weaker and all we could do was help relieve his pain. Terry had suffered enough in his life battling against haemophilia without catching AIDS. He had gone through hell all his life but was actually managing to keep the haemophilia at bay when AIDS struck.' It was stressed that Mr McStay, a 34-year old lab technician, was not homosexual."

Then if we just have the whole page, please, Paul. Can you go down towards the bottom of the page, please.

We can see there some other examples and reference in the bottom one, not specifically there about Terry but about the gay plague.

That was November 1984. In December 1984 you have a recollection of Euan receiving heat treated Factor VIII products for the first time; is that right?

A. Yes, correct, and we've a record of it as well, so not just a recollection. As I said earlier, about a year before that, so in the back end of '83, in June '83 actually, from early '83 probably, Terry had been telling us from Newcastle that heat treatment was the answer.

He was telling us not to use American Factor VIII, use Scottish, but clearly there would still be an imagined risk or a potential risk with Scottish Factor VIII but heat treatment was the answer, so regardless of the source of the product if

you heat treated it then that was Terry's message, because the heat treatment kills the virus.

So we knew that from about '83. We discussed it in the parents' group, as I said before. We had information from Terry. Two months later Terry would contact us again saying, "What have you done? Have you done anything about it? Have you got them to change it yet?" Then Terry died on 3 November '84.

Prior to that clearly we had been pushing for heat treatment and as a parents' group we had been pushing for heat treatment for the reasons I just said, because we believed it was the answer, and we were told repeatedly, six times, ten times, you know, lots and lots of times, we were told that heat treatment was not -- it was not possible to introduce heat treatment on the Factor VIII product, so it's the Scottish product I'm specifically talking about here, for two reasons. One was it reduced the efficacy of the Factor VIII, of the product itself, and it would increase the cost, so efficacy would go down and cost would go up.

We had received that answer many times during '83 and '84, then Terry died on 3 November '84 and those articles that you showed there were from 20 November. So these articles were from 17 days

after Terry died and those articles mention the introduction in Scotland, going to introduce heat treatment, which was impossible three weeks before, and our Euan was then treated with heat-treated product.

Q. That was on a date in December?

A. On 15 December '84. So five weeks after -- five and a half weeks after Terry died Euan was given the heat-treated product, and ...

Q. That's okay.

A. My understanding ... my understanding is ...

Q. John, shall I paraphrase and you can tell me if I'm correct.

A. That's okay. My understanding is that no haemophiliac that was treated solely with heat treated Factor VIII after that date that no haemophiliac then died. So I think the heat treatment, indeed, was the answer. I think that's proven. I think it took Terry's death to -- death and the attendant publicity, which was, as I say, was quite sensational and quite negative, and I think it took that death to spur the appropriate health authorities in Scotland and in the UK more widely, certainly in Scotland, into action. It took a death.

Q. Just dealing with the record that you mentioned you

have, your solicitors have asked the relevant health authority for copies of Euan's records and, as I understand it, they have been told that there are no trace of any records for Euan that are now held, none at all?

A. None at all.

Q. You've got this one record which shows the details of the heat treatment that Euan received in December 1984 that you yourselves have kept.

A. Yes, at the request of the hospital, at the request of Yorkhill, so when we started heat treatment in 1981 let's say then every -- on this home treatment -- sorry, home treatment, on this home treatment scheme then there was probably a dozen or 15 haemophiliacs at Yorkhill participated in this, and we were all given the format in which to -- we were all given the training that I referred to earlier, the oranges and so on, but we were also given a format in which to record what we were doing. So any time you administered Factor VIII you had to record the date, you had to record the reason -- so it was a bleed in the left knee or the right elbow or whatever -- you had to record the batch number of the Factor VIII that you used, you had to record the impact that that then had, like 12 hours later how did it look, 24 hours later how did it look, plus any other details. So there was that. If it was today it would be a spreadsheet but then it was just a piece of paper with columns and rows on it.

We were all given that format to record each administration at home of Factor VIII, so we started doing that and Kate recorded it from '81 onwards and -- so we've got a record of all the administration of Factor VIII with all the batch numbers and all the other parents must have had that as well, and then on 15 December 1984 in Kate's writing is "heat treatment" with asterisks along -- heat treated batch with asterisks alongside it. That was the introduction of the heat-treated product at that point, 15 December '84.

Q. So you've got your own records that you maintained at home but there are no hospital records in respect of Euan's treatment at all.

A. No hospital records. The hospital records disappeared and are gone, destroyed. York Hill Hospital at some point after that then requested that we send the home record back to them and we did not do that. We retained it.

Q. In April of 1985 Kate took Euan to a regular appointment at Yorkhill and saw one of the doctors

there, Dr Pettigrew I think, and was given some information about Euan. What was Kate told?

A. It was April 1985, as you say, so that was like five months after Terry died, four months after Euan had started receiving heat-treated Factor VIII. So at that point then clearly what's in our mind is we're absolutely delighted that Euan's getting heat-treated Factor VIII but we're wondering about this legacy of Factor VIII that they had received up until December 1984.

And then there was a regular clinic every two months or something like that and Kate took Euan along to that on April '85. I was not there but my father was with Kate and he stayed in the car, so he remained in the car park in Yorkhill and Kate went into the clinic, and while she was in, then she was informed that Euan was HIV positive.

At that same clinic, then there were at least two other parents who were also -- of other haemophiliacs who were also informed that their son was HIV positive because one of these other parents said to Kate, and Kate recorded it, one of these other parents then said to Kate, "I've just been told my son's got AIDS", so there was at least three who were told on the same day in April '85.

Q. Had you and Kate known that Euan was being tested for HIV or HTLV-III?

A. We didn't know. We sort of suspected it would be the obvious thing to do but we weren't informed of it, we weren't -- if we asked about it we weren't told that he was, but it would have been very strange if they had not been.

Q. And then a few days after that first visit where Kate had gone, you both went to see Dr Pettigrew?

A. Yes, and --

Q. What did he tell you?

A. What I recall, again against the background of the way it was at that time so, you know, you think this is a death sentence, and I remember asking her that question, how long we -- Euan was not in the room -- how long we had ahead of us and I remember she said it's a virus with a very long incubation period, it could be up to five years' incubation period before it actually activates and then once it's activated it could be another two years before he actually dies. So that was in 1985, so that was suggesting 1992, and he died in January '94, so as an estimate it was quite accurate.

Q. How old was Euan when you learnt he had been infected with HIV?

A. That was April '85, so Euan was -- he would have been eight in June '85, so he was just short of eight years of age.

Q. The two of you knew because of what had happened in particular to Terry what being infected with HIV could mean.

A. Yes.

Q. You decided at that point not to tell Euan who, as you say, was very young what his diagnosis or prognosis was.

A. Yes. You know, again I say it was 35 years ago and you've got to remember the climate, the social climate at that time, the way it was viewed, which was very different from now, I hope. But it seemed to make sense -- it totally made sense. It wasn't even for debate. It totally made sense to keep it secret. We decided we had to tell Euan's teacher so that she could organise things properly at school and make sure that, you know, just in case Euan got a cut or ... so we told her.

If we were away someplace -- I remember once we were in Oban and something entirely unrelated happened to Euan and for some reason we had to go to -- we had to see a GP in Tobermory, and we told the GP and he said that's fine, no problem, and he just -- it was as though we said he's got a heavy cold. He was not phased in the slightest.

But we told so few people you can actually remember the instances, generally we told no-one and we didn't discuss it with Euan and Euan didn't discuss it with us, which he would not necessarily do in the early stages because apart from knowing he was HIV positive he continued to grow and he continued to be normal and he continued to play football and so on.

So he wouldn't necessarily discuss it with us at that stage but even later on then we did not discuss it and it seems really odd but it seemed natural at the time.

Q. For the first four or so years, 1985 to 1989, after you were told Euan's diagnosis, life carried on in terms of Euan's life pretty much as before, as I understand it. He wasn't particularly unwell during that period?

A. '85 to '89?

Q. '89.

A. No, he was at school. He was captain of the school quiz team. He was intelligent. He played football, not very good but there was no injection of lack for talent so ... but no, he was -- he led a normal life.

Q. Then in September of 1989 you got a call from

Yorkhill. What were you told?

A. It was ... it was a Saturday morning. I remember where I was and I remember I was driving to a particular supermarket and just before I left I'd got phone call from Yorkhill saying could we pop in and see them later that day, and then I was driving over to the supermarket and I was thinking why would they phone? It's a Saturday morning and why would they want to see us on Saturday? Why not Monday? You know, and what's the only explanation for that? I worked it out on a five-minute drive. I knew why it was.

I come back and Kate and I went up to Yorkhill. This would be September '89 and they took us into a little annex actually, it wasn't the place we normally went to, it was a little annex, and they told us that the HIV virus had activated, was the word that they used.

Obviously, they told us Euan was infected in April '85 so we had been sort of expecting this as you were getting close to April 1990, so this was like six months, seven months, eight months short of that so they told us that it had activated.

Q. You were told that they were going to put Euan on a drug called AZT?

A. Yes.

Q. What did that comprise, that treatment?

A. That was Euan went on to AZT so they said that it wasn't a cure but it could hold the progression of the virus and Euan was put on to a daily dose of AZT, seven tablets per day I remember, which at the time seven tablets per day so, you know, you don't think quite why is it not four or three or 17, you just think it's seven.

So seven times each day -- seven tablets a day you had to force these down with water, which was always a bit of an episode getting him to do that.

Then later, a couple of years later, three or four years later, ten years later, it became clear with experience and with medical experience and so on, that seven a day was a very, very high dosage of AZT. I don't know what the dosage is now. I know there's a triple treatment along with two other drugs and AZT as well. With Euan it was only AZT and seven which, as I say, was quite a high dosage.

I don't blame anybody for it being seven. If ten years later ... if ten years later, people ...

Q. If people subsequently discovered that that was a high dosage you are not blaming, as I understand it, the doctors at the time.

Euan seemed okay for about another year until the autumn of 1990 when his health began to deteriorate.

You've given --

A. Yes.

Q. -- a couple of examples, John, in your statement of how it used to become evident that he was very tired.

A. Yes. As you probably gathered, he was quite keen on football and we were at a football match in Glasgow. This would be September/October 1990 and there's quite a large crowd and Euan would be -- 1990, so he would be 13 years of age, so he was smaller than most people in the crowd but when we arrived and people were standing -- in those days people stood at football matches and Euan was sitting on the terracing and, of course, there's a big crowd so there's people standing immediately in front of him so he couldn't see anything and I was saying, "Stand up, you know, you won't see anything", and he said, "I'm too tired. I'm too tired. I can't stand", and we left -- we actually left at half-time because he couldn't see anything. He was just sitting on the terracing, and we went home.

By the time we got home it was probably 4 o'clock in the afternoon and one of Euan's friends arrived and so we were looking for something else to do and we decided to go to Dumbarton Rock for some reason, as you do, and Dumbarton Rock is about 200, 300, 200 feet high and it's got steps all the way up and Euan was saying he felt fine by this time, despite the episode a few hours ago at the football, he now said he felt fine, and we started going up the steps and he'd gone up about five or six steps and he said, "I can't go any further. I'm too tired", and he sat there.

I and Euan's friend went up to the top and we come back down again and Euan was still sitting on the step. Both of these things happened on the same day and that was the first physical impact that I could see in Euan was that totally debilitating tiredness that struck him on that day.

Q. In the course of 1991 the physical impact became more apparent and Euan started losing weight. He'd previously you described been one of the tallest in his class but his peers were now outgrowing him and he was the smallest and the thinnest.

A. From that age, from about September 1990, you know, the day that I was talking about there, he didn't grow from that point. He shrunk. He shrunk in all directions. You know, you've seen it. You've seen

photographs of it. You've seen it on television but he just shrunk in all ways, just gradually over time.

So there are photographs of him, school photographs, you know, where they all line up and the big ones are at the back and the smaller ones at the front and so on, and so from photographs where Euan would be one of the -- he'd be in the middle at the back because he was tall, then a couple of years later by the time you got '91, end of '91, '92, then he was the smallest in the class, the smallest and thinnest and the weakest.

So from being a very outgoing -- enjoying cycling, footballing, that type of boy, very bright, as I say, you know, captain of the quiz team at school, and went on the Scottish quiz championship, within 18 months/two years then he completely changed physically and obviously affected his social abilities as well, so he became much shyer and less willing to mix with his friends and that type of thing. So it had a huge impact on him, yes. It gradually happened during '91.

Q. Christmas '91 you went on a holiday to Tenerife but Euan was unwell and you had to come home.

A. Six months before that in the summer of '91 we'd gone on holiday to Spain, Majorca, and that had been a big

success. So that was, you know, that was a good thing to do. We sort of knew to do it again. If it works try it again, so when it came to Christmas then we decided to spend Christmas in Tenerife. When we arrived I remember it was 75 degrees Fahrenheit, so I was thinking it's really good, Christmas in 75 degrees Fahrenheit.

Then within an hour or two Euan became very ill and he was very ill overnight and his chest and his breathing was incredibly alarming. So the next morning we knew that we had to get back to Glasgow, back to Yorkhill, so we went to the airport and -- obviously we were booked on our return flights a week later or something like that, so we explained why we needed to return so quickly within 24 hours or whatever of having arrived, and they wouldn't let us on the plane and we tried again on another plane, we tried various airlines. We couldn't get insurance to get Euan back and then eventually we did find an airline that was willing to bring Euan back, so we come back to Glasgow, straight up to Yorkhill and that probably would be Boxing Day then, and I recall we also spent New Year's Eve, Hogmanay, in Yorkhill that year.

So we must have been in Yorkhill from Boxing Day

to 3 January or something like that, so the Tenerife adventure didn't quite work out.

Q. For the next few months Euan continued to try to go to school but he was increasingly unable to go to school full time, it dropped down until the following year he wasn't able to go to school at all.

A. That's correct.

Q. Euan had episodes of paralysis or seizures. What could you tell us about that?

A. That was incredibly alarming. It happened a handful of times, I can't remember exactly how many but four, five, six times. The first time in particular was incredibly alarming because you don't know what it is, you don't know what's happening. But gradually, over a period of an hour or so, he would be unable to move his limbs. He would be totally paralysed, just comatose, like a seizure, and it would end up that his entire body was -- he couldn't move his body whatsoever apart from his eyes. All he could move was his eyes and he'd be obviously lying flat. He could hear and he could understand but he couldn't respond. And then it would last three hours, four hours and then gradually, you know, his right leg would start moving and then his left arm and gradually he would come out of it, five or six hours later it would pass.

So the first time was, you know, enormously alarming. Third or fourth time you sort of get to know the pattern and it always started with his lips would -- there was some feeling he would get in his lips, so he would say, "It's starting. You know, get me to Yorkhill. It's starting now. I can feel it. I can feel this tingle in my lips", and we could get him into Yorkhill in time.

I remember one occasion arriving at Yorkhill, getting him into the lift, and other people come into the lift -- oh, when it was happening his legs used to involuntarily flip up, like a seizure, and I remember in the lift in Yorkhill, we're going up to the seventh floor, and we were in the lift and there was two or three other people in the lift and I remember him saying, "If you stand in front of me. I can't stop my legs moving about here, flipping about".

By that time, there was a normalise to that. As I said before, you go through -- it's like a staircase. You go down, and each step you go down you reach this new level and it becomes normal. So, you know, he's got haemophilia and that's normal; then he's HIV positive and that's normal; and then it activates and that's normal; and then you've got these seizures and that's normal; and he losing weight and

that's -- these things last six months, eight months and life normalises at this new level and then something else happens and takes you further down.

It's only later you look back over the decade or something and you realise it was a serious of steps that were taking you down.

In just exactly the same way, the seizures, the paralysis is probably a better description of it, that became normal. We adapted to that, in the sense that one of the main -- the paralysis, as I say, it would last maybe four or 5 hours, six hours, that sort of thing, which is bad and is inconvenient and so on, but I used to say to him, "It's not all that bad. You can still listen, put on the radio and listen", you know.

He didn't know when it was going to happen, so it affected his life all the time. If he was going out he didn't know if it was going to happen when he was out. If he went to school, he didn't know if it was going to happen at school. If he went to Glasgow with his friend, he didn't know if it was going to happen -- you know, you didn't know and that was not knowing and worrying ...

Q. You knew of other boys at Yorkhill who'd been infected with HIV and you've said in your statement that between 1992 and 1994 a number of them died. Euan

didn't attend funerals but he was aware that he had friends, acquaintances who were dying.

A. *(The witness nodded)*

Q. You have said in your statement Euan didn't know what his diagnosis was from you --

A. No.

Q. -- but you wonder whether he may have known it from other circumstances or what others might have said?

A. Yes. Euan was friendly with other boys that were in the same situation, obviously. Not only was he friendly with them, he'd known them since he was a baby so he was friendly with them, very comfortable in their company. They shared all the issues that they'd had through their entire lives, and by the time you get to '93 -- '92/93, Euan by that time is 15/16 years of age so he's -- so he wasn't discussing the situation with us and we were not discussing it with him, not in terms of AIDS and so on. We were discussing it in terms of the symptoms and the paralysis and the other things that happened as well but not the underlying cause of it, so he did not have these discussions with us.

We also recognised at that point that given that Euan was 15/16 that he was also not having that discussion with us. He was not initiating that

discussion either, so perhaps he didn't feel comfortable talking about it either to us. It was a reciprocal thing, perhaps.

But given that he was friendly with other boys in the same situation and given that there had been deaths already at that point within the group, then we were pretty certain and remained certain that Euan did discuss it with other boys who were in the same situation as he was in and roughly the same age.

There's one that's in my mind just now that's maybe two years older than Euan, so when Euan was 15/16 he was probably discussing it with a young man who was about 17/18.

Q. In early '93 Euan began to experience problems with his left eye. What happened? What treatment did he have to have for it?

A. He had -- he started -- he developed, in his left eye he developed tunnel vision. So he could see through his left eye but he could only see like looking down a tunnel. So he would move his head round to -- if there was a noise in this left-hand side he would turn his head to see what it was. He couldn't just look out the corner of his eye. That happened quite quickly and the treatment he was put on to was a drip which lasted three hours, so he was fixed up to a drip into his arm and, as I say, it lasted three hours, which is a long time, but more seriously it also had quite an impact on him in terms of nausea. It would make him very sick feeling.

So for this daily drip we then -- because we did it at home. We had all the gear, all the stuff which we did at home as well. In fact, we had a mobile. We would take it and we'd got a mobile home, a motorhome, and we'd take all the drips with us.

But we would time it to be starting maybe 7.30 in the evening so it was finished by 10 o'clock/10.30 and straight to bed, so when the nausea kicked in then he was in bed and sleeping and that was seven days a week with that drip.

Q. But he lost the sight in that left eye in about the spring of 1994?

A. He absolutely hated the drip. It was absolutely ruining his life and he was very keen but it arrested the progression of the deterioration in his eyesight and he was very -- so things weren't getting worse, so he was very keen to reduce the frequency of the drip and so they decided he just needed to get the drip Monday to Friday and not at the weekend, so he'd get the weekends off, which he was really pleased about for a couple of weekends and then within a month he

lost his sight in his left eye.

Q. You and Euan went on a trip to London at a point in time at which he wasn't able to see out of his left eye.

A. Yes.

Q. You had some mobility problems and Euan made a joke as you walked through London.

A. Yeah, it was actually when we were on the train and the train was shaking back and forwards and I've got some mobility problems, as you say, and Euan couldn't see through his left eye, he'd just lost sight, and so we were going down the corridor on the train and I remember him saying, "You know, you couldn't make a single human being between us -- you couldn't make a whole human being between us".

Q. By the autumn of 1983 Euan's right eye was affected and he lost the sight in his right eye too. Euan said losing his sight was the worst thing that happened to him.

Euan's HIV care had transferred to a different hospital from Yorkhill. What was the experience for him like there?

A. He lost his sight in his right eye about October '93, October '93, so May for the left and October for the right. As I said before, you know, by that time Euan

was 15 years of age/16 years of age, and Yorkhill, obviously, is a children's hospital, so round about the end of -- round about the end of '92 beginning of '93 Euan's treatment which increasingly was not haemophilia they were treating, it was the AIDS they were treating, so his treatment was transferred to Rock Hill which was the serious infectious disease hospital in Glasgow, and that was obviously very, very different from -- so that's adults who are there. Everyone there had a serious infectious disease. I remember the first day that we were -- Euan was 15, like he would be 15 when we were first there.

I remember the first time we went into his room, he had a bedroom, and I remember two uniformed people sitting outside the rooms on either side, because I didn't understand why there were uniformed persons sitting outside the rooms, and these were prison guards that were sitting outside the room because the patients were prisoners and so the guards were sitting outside, so it was a very different environment from Yorkhill.

Things like sometimes if we went into Rock Hill there'd be no room available so Euan would just be out in the corridor, on a trolley in the corridor, he'd spend a day, maybe two days, just on a trolley in the

corridor.

There was a social room, you know, there was a television in it and we would -- remember Euan, after October '93, when Euan could not see at all, when he was blind, if we went in there and half a dozen men in there who'd all be smoking and Euan would go in and he hated smoke and he couldn't see where he was and he just totally hated that.

Q. Euan had got a payment of £20,000 in 1993 which initially the plan was to spend it on a caravan but then he changed his mind and you bought a boat?

A. Yes, that's right. It was -- that was -- that would be about April '93 that we got £20,000 and it was in full and final settlement and we had to sign as such that it was full and final settlement, and we made the decision that any money that we got we should ...

Any money that we got we should spend on Euan while he was alive, so we said ...

Q. Shall I?

A. It's okay.

Q. Shall I set out my understanding?

A. So we said, "What do you want, anything up to £20,000, not a penny more", and he said, "I want a motorhome", because we'd been renting motorhomes with the drips and all that sort of thing, so he obviously fancied motorhomes. He liked travelling, so we went up to Glasgow to buy a motorhome and, you know, there's a dozen motorhomes to choose from but there was a boat, and this boat caught his eye and he said, "I want that boat". I said, "But you want a motorhome". He said, "No, I want a boat", so we bought a boat which was 29 feet long, which is quite a big boat for complete amateurs.

So the next day, everything had to happened very quickly, so the next day it's in the water, so we got it into Loch Lomond, 26 miles long, and we got this 29-foot boat that we'd never seen before. It was a power boat and it had planed and it come up out the water. It went very quickly, and I was demonstrating to Euan how to drive this boat and he nudged me out the way and he said, "Let's see what this baby can do", and he took over the wheel and for 26 miles he drove it up to the top of Loch Lomond and turned it round and drove it back down again. We were overtaking the traffic on the road, I remember.

Yes, so that was -- that would be May/June '93.

Q. You spent and celebrated Euan's birthday?

A. That was the last time we were on it, 28 June 1993. It was his birthday.

Q. Euan died on 12 January 1994. Yours and Kate's life

in the years before Euan died had been completely devoted to caring for Euan and looking after him. He was yours and Kate's entire focus.

A. Yes.

Q. Kate had given up work to look after him.

A. Yes. Kate was a teacher. She was a senior teacher. She was a headteacher. She gave up work for eight years, something like that, yes. She went back to work after Euan had died.

Q. In the years since Euan died, how has the loss of Euan impacted on your lives?

A. We're now divorced.

Q. You developed serious health problems which you think may well have been contributed to?

A. I got a tumour, a benign tumour in the pituitary gland just below the brain, which was not diagnosed for quite a number of years but all the symptoms of that were attributed to -- the symptoms were attributed to the stress of Euan's situation and then when it was diagnosed as a tumour by that time it was the size of my thumb and then it's considered that the stress caused the tumour and the tumour then caused the symptoms.

Q. Kate's statement describes the huge void in your lives after he died and how you feel that you've never had

a normal life as a result.

John, those are the questions I have for you. Before I ask those representing you if there's anything further, what else would you like to say?

A. There are two things I'd like to talk about. One is the American blood and the other is heat treatment.

With the American blood product from Armour then we had information from Terry during 1983 and during 1984 that there was a high risk with that American product and that was known in the Newcastle Hospital and it was also in the press and generally discussed in society as well, so there was known to be a risk with American Factor VIII, and we had these prompts from Newcastle frequently.

Our parents' group meeting in York Hill Hospital frequently -- this is the irony of the situation, yes, it was discussed in Yorkhill by the parents -- so during '83 and '84 we were discussing the dangers of the American blood within the confines of York Hill Hospital as parents. '83/84 you also had other hospitals in Scotland, I believe all other hospitals in Scotland, stopping using American product. There has to be a very, very good reason why, given that sort of background, there has to be a very, very good reason why Yorkhill Children's Hospital continued to

use the American product during '83 and '84.

The only reason I can think of, as I said earlier, with Dr Willoughby being a pioneer of home treatment and prophylactic treatment then he would need more Factor VIII and therefore buying it more cheaply would perhaps allow him to buy more. That's just my speculation on that. I would love to know the real reason if that's correct or not correct.

Clearly there's a reason. It didn't just happen by accident. All the things that I said that we knew about then, Dr Willoughby and the hospital staff in the haematology department would know these things as well and they would know 100 times more. I would love to know why they made a decision that was different from the decision that other professionals were making in other hospitals at the same time.

I would also, on that one, I would also like to know why having come to the decision which there may be a valid reason for it that I'm not aware of why it was not discussed with the parents, why the risk was not balanced against the convenience of home treatment and prophylactic treatment, so I'd like to know these things and I've wanted to know these things for 35 years.

The heat treatment, again we had this stream of information coming from Terry telling us that heat treatment was the answer so Terry first told us that in 1983. So what's that? 36 years ago, so we've known the answer to this for 36 years and, as you saw earlier, I mean, it was introduced in Scotland in December 1984. So as parents we knew the answer 18 months earlier than that because Terry was telling us.

Again, at a parents' group we're discussing it and the parents' group would be nominating people to go and discuss it with the staff, you know, why we're not heat treating and we were getting reasons of reduction of efficacy and an increase in cost, and we're getting these reasons right up until 3 November '84 when Terry died and then you saw the press articles from 20 November, less than three weeks after Terry died, and several of these articles then they say that they are going to introduce heat treatment. Then Euan got his first great treated product on 15 December 1984, which is either a remarkable coincidence that it was introduced so quickly after Terry's death or, as I believe, Terry's death was instrumental in heat treatment being introduced.

That first batch that Euan got on 15 December '84. We've got the batch number. I want to know when

was that batch produced. I want to know. Was it produced before 3 November? Was it sitting in stock unused, waiting? Was it produced after 3 November? Did they just simply turn on the heat treatment production after 3 November? I don't know. One way or the other I'd like to know when that was produced.

Terry died on 3 November so was that product simply made available out of stock after that date or did they actually start producing it? They must know that. They must know that. That's the two things, that's the two things that I need to know. I need to know Yorkhill's policy why they were using American blood and I need to know why -- when the first batch of -- when that particular batch of heat-treated Factor VIII was -- when it was produced.

Q. Sir, before I ask John's representatives whether there's anything further I should say that Dr Willoughby has not yet been asked to respond to the statements but that process is in hand and he will be asked to provide a statement.

John, I am just going to ask Mr O'Neill if there's anything further. *(Pause)*

There are no further questions for you, John. Sir?

SIR BRIAN LANGSTAFF: There's just one from me. You've

described your parents' group at Yorkhill, which must have brought you into contact with Dr Willoughby more than most I suspect.

A. Not really. The doctor that was most involved with the parents' group was a Dr Han, less so Dr Willoughby.

SIR BRIAN LANGSTAFF: But you did meet Dr Willoughby on a number of occasions, did you?

A. Yes, a few times.

SIR BRIAN LANGSTAFF: You may be of an age to remember the doctor movies, Doctor in the House and so on?

A. Yes.

SIR BRIAN LANGSTAFF: How closely did Dr Willoughby in approach match up to Dr Lancelot Spratt?

A. Yes, quite closely. I remember when Euan was tested for haemophilia when he was only a few months old I got a phone call at home and it was Dr Willoughby who was on the other end of the line, and his purpose in phoning was to tell us Euan had been diagnosed as a severe haemophiliac. So it was a very, very serious message that he was putting over. But his accent was so old school I couldn't understand what he was saying and I had to ask him to repeat it three times. His accent was impenetrable to me and eventually on the third occasion I realised he was telling me my son was

a severe haemophiliac, so it was most unusual circumstances in which to learn that.

But I would describe him as being old school, yes.

SIR BRIAN LANGSTAFF: So does old school mean autocratic, as you saw it?

A. As I saw it, yes. I would say he was autocratic. I don't know the workings of his department, the haematology department. I wasn't there in any --

SIR BRIAN LANGSTAFF: I can only ask you for your impression, but you've told us quite a lot about him so I just thought I would ask.

A. My impression is that within that department that he would decide what was going to happen. I know that there was a number of staff within the department who are unhappy. I know that there were nurses, I know that there were doctors within the department who were unhappy. I can only guess about what they were unhappy about. They were unhappy enough to work to rule on at least one occasion for several days.

That then led to situations -- because they were working to rule, they would leave at whatever their formal finishing time was 4.00 in the afternoon or 5.00 in the afternoon or whatever whether something was finished or not which meant that Dr Willoughby and the senior consultants then had to finish whatever that task was because I remember him complaining about that and I remember the senior consultants complaining about that because the staff were walking. So it was an unhappy ship.

SIR BRIAN LANGSTAFF: Thank you very much. Thank you for coming and telling us what was an affectionate tribute to Euan which cannot have been at all easy for you or for Kate. So thank you.

We will take a break now until 2.40.

(1.35 pm)

(Luncheon Adjournment)

(2.44 pm)

SIR BRIAN LANGSTAFF: Now we have the Fyffe family, Gill, Stan, Rory and Lucy.

MS RICHARDS: Yes, sir.

GILLIAN FYFFE, SWORN

STANLEY FYFFE, AFFIRMED

RORY FYFFE, sworn

LUCY PARHAM, sworn

Questioned by MS RICHARDS

MS RICHARDS: Gill, you are here with Stan, together with your children Rory and Lucy, to talk about the circumstances of your infection with hepatitis C, the treatment you received, the consequences of that

treatment and the effect it's had on all of you and on your family lives.

GILL: Yes.

MS RICHARDS: Gill and Stan you met at school and, Stan, you subsequently qualified as a chartered engineer. Gill, you studied English and psychology and then went on to do postgraduate studies. You worked as a librarian and as a teacher and you had aspirations for a career in academia.

GILL: Yes.

MS RICHARDS: You married in 1980 and what years were Rory and Lucy born?

GILL: Rory was born in 1985 and Lucy in 1988.

MS RICHARDS: Now, *[redacted]* 1988 when you were pregnant with Lucy in the very, very late stages of pregnancy you were admitted to Ninewells Hospital Dundee where Lucy was born with a forceps delivery.

GILL: Yes, that's right. I had been admitted previously because she was lying the wrong way and then I went home again and I was told that if I didn't go into labour I would be induced and in the 41st week of my pregnancy we went into hospital for that induction to take place.

MS RICHARDS: Following the birth, you had to undergo a procedure that you, Stan, have described as a brutal

one which was to have the placenta manually extracted.

GILL: Yes.

MS RICHARDS: You bled a lot as a result of that procedure.

GILL: Yes, I certainly bled. I always find it difficult to quantify how much. I did bleed but there were no emergency buttons being pressed or -- it was -- the nursing staff reacted in a routine manner but because the placenta was removed manually, that's obviously not something that can be achieved without some bleeding.

MS RICHARDS: That was the point at which one of the doctors broached with you the subject of a blood transfusion.

What can you recall about that first conversation?

GILL: I think Lucy was born I think around about 3.00 in the morning. I think it was later that afternoon or possibly the next day. I know that Stan had left the hospital so I think it may have been late afternoon that same day. It was a Friday. I remember the doctor who had been in attendance when she was born but there had been a rush. Three babies were born at once. The hospital appeared to us understaffed and so one doctor had delivered all three babies.

He came that afternoon and said that, "We are going to check your bloods but we think we will transfuse you", and then subsequently he came back and he said, "Yes, we're going to give you a blood transfusion".

Because it was 1988 and we had had the AIDS campaign and there were posters everywhere and because I was teaching and we had been given a lot of advice, teaching advice had been given a lot of advice about how to care for children if they bled, which normally we hadn't needed that advice, if a child injures themselves you just rush to help but now we were told to put gloves on first, which seemed very odd to us.

So because of that advice, the idea of being transfused with a stranger's blood I recoiled from that and said, well, can I talk to my husband first and two things happened. I tried to explain to the doctor that I'm not averse -- I know everything in life is a risk, I'm not averse to taking a risk, but I wanted to find out how much I needed the transfusion because at the beginning, the doctor was talking about I would need two months' bed rest. He said you will have to rest for up to two months and possibly get some help at home, and I thought, "Well, I can manage. We're in the fortunate position that we can cope with that".

So I said, "Well, I think I'd probably rather have the bed rest", and he said, "No, we really want to transfuse". We had a sort of discussion. We didn't agree, and then I said I'd like to phone my husband. The sister I remember, who's name I don't recall, but the sister was quite annoyed with me by this point because it was sort of her job to make the patients behave I think and she said, "You know, you really ought to do what the doctor tells you", and I said, "Well, I'd just like to talk to my husband first".

There were no mobile phones in those days and there was a payphone on the wall, but I knew there was one on a trolley as well and she said -- I said, "Can you get me the phone", and she said, "Well, if you can walk to that payphone you can call your husband". It was at the other side of the ward.

So I walked to the payphone but, I mean, I was annoyed, that was why I got to the payphone, and called my husband and said, "Please, get to the hospital because they want to transfuse me and I'm not happy about why", so Stan came to the hospital -- is this still answering your question?

MS RICHARDS: Absolutely.

GILL: Yes, so Stan came to the hospital and I told him what was happening. Because he is an engineer and because I did science at school we were of the opinion that nothing is 100 per cent safe so every time we asked how much do I need this transfusion, the doctor would say the blood is totally safe and we were even more alarmed because we thought, well, number 1, that's probably not true and, number 2, it's not the question we're asking you.

So this went on and on and on and he was saying, otherwise I would need bed rest, which didn't seem sufficient reason to us. Eventually, it became -- to shorten this story, it's a very uncomfortable thing to do to disagree with a doctor.

The nurses started talking about it. One of the nurses said to me, "The whole hospital is talking about you", and I went, "Oh God". I said, "Well what would you do? Would you take the blood transfusion", and she said, "I wouldn't touch it with a tarry barge pole", which didn't exactly shorten the conversation.

Although we had never -- I can't remember the point at which this happened but although we had never -- I was worried about AIDS because I'd heard of AIDS. I had never heard of hepatitis, but we do remember an older nurse saying, "It's not just HIV

you've got to worry about. There's hepatitis and God knows what", but that comment just went over my head because I was just worried about HIV.

Eventually, the doctor said that another consultant was coming to talk to me and it's my recollection that was a consultant from the Blood Transfusion Service, but certainly another man of consultant age arrived at my bed. I don't think Stan was there at that point because obviously we had Rory to care for and you had just taken over running an engineering office in town, and so he was -- he didn't know how much of an emergency it was at the hospital and he was responsible for this office.

So I think you weren't there at this point and another consultant arrived at the bed and told me the blood was totally safe and I said, "That's not my question. My question is how much do I need it?"

Stan came back to the hospital and by this time I was getting really tired but I think because I'd just had a baby and because I felt I was holding out against the whole hospital, there were some sympathetic nurses, and anyway when Stan came back to the hospital, the consultant -- sorry, the doctor who had delivered Lucy said to him, "You see, if we don't transfuse her tonight and she haemorrhages again, we

won't be able to get the blood in fast enough".

So Stan immediately came to me -- I mean, they were standing just about six feet from the bed and he came over and said, "Gill, you have to take it because you might die if you don't take it", so I said, "Okay, I'll take it".

We were very scared I remember because I can't remember really pressing the doctor why you suddenly changed your mind. I think we just had the feeling oh we've pushed it too far and now it is an emergency so we went, "Okay, we'll take it".

The doctor said, "Well, the nurse will come to prepare you and it will take several hours", and all the rest of it. I remember saying to Stan, "Well, just go home and see to Rory", because Rory was with my mother and I knew that, you know, he normally would -- I wanted him to see Stan before he went to bed because mummy wasn't there. So I was saying, "Go, go, go and see Rory. It's almost done now. We know what we're doing".

So Stan came back to the hospital the next morning --

MS RICHARDS: Just pausing there and before we get to the overnight position, Stan, is there anything you recollect different from or additional to what Gill's described in terms of this conversation that was taking place with the doctors?

STAN: Yes, additionally to that, one of the things that was a driving force that I came back into the hospital and saw Gill very white on the bed and, of course, knowing nothing about how white people look with anaemia, you know, that alarmed me.

But I'm very, very much of the opinion that the doctors were given a specific mandate and they were told, "You're only being allowed to transfuse Gill on the basis that this is an emergency and that specifically you're being told to give her the blood now such that it's safe overnight".

It's not just you're getting blood to make you safe. It's because you've told us it's an emergency and you've told us that you need to get the blood in right now and, oh, yes, that's what was going to happen.

GILL: Sorry, can I just say, you mean the mandate from you.

STAN: A mandate from us, yes. "We are telling you as a doctor this is what we will accept."

MS RICHARDS: That's the point at which, the way you've put it in your statement, Stan, is the doctors changed tack almost and it was now being described to you as

something that was needed as a matter of emergency.

STAN: Sorry, that's slightly out of order, because Gill was resisting it and we were then both saying we're not prepared to take blood unless it's an emergency, at that stage they changed tack and said, "Oh, yes, she'll" -- in fact, the phrase was, "If Gill haemorrhages overnight we won't be able to get the blood into her fast enough".

Now, that was when I persuaded Gill to take the blood. I now subsequently think we should have, in hindsight I think we should have pressed the doctors a lot harder than that. I still haven't gone into how fast you can get blood into people and all that sort of thing, but we took that for granted and that was the instructions that were given, "Yes, it's an emergency. You can put blood in tonight".

MS RICHARDS: You went off to see Rory.

STAN: Yes.

MS RICHARDS: Your shared expectation was, in light of what you had been told, that the transfusion would begin pretty much straight away.

STAN: Right away.

GILL: Yes.

MS RICHARDS: What in fact happened, Gill?

GILL: What happened was that I waited and the nurses --

I think I fed Lucy and then I fell asleep and I remember waking for the 2 o'clock feed and -- or being woken for it and saying, "Oh, what's happening", and a nurse saying, well, they are just going to wait until morning now. I think she said, "Because we're short staffed". So I fed Lucy and fell asleep again.

I was, because I had been up all the night before -- I feel I should say I think I've missed something out at this point which is that when, just before the manual extraction, I said the labour suite seemed to be understaffed and the doctor was running round and round and just after Lucy was born he arrived in our room and shouted at the midwife, who was a lovely young girl but young, and he shouted at her and she burst into tears, which rather shocked us. Then he came to the bed and said, "What's happened is an injection has to be given at the right time so that you will -- you're body will -- you'll have another contraction to release the placenta and it's been given at the wrong time and I can't repeat it so I'm going to have to do manual extraction".

So to go back to -- sorry about that -- to go back to where we were, what happened overnight was I fed Lucy and was told that the transfusion wouldn't take place until the next morning, and I didn't quite

know what that meant in a hospital because they seem to -- it's anything from 5 o'clock to 10 o'clock.

So the next morning they -- everything started in the ward as usual, they brought breakfast for everybody, including me. I fed Lucy again and then they said, "Right, let's get this transfusion started".

I'm shamed to say now that I was just -- by then I was just mortified that I'd -- the whole, you know, everybody was talking about the fact that she's held out for I can't remember how long it was now but 36 hours or more than that and now she's having it and I think I just didn't have any fight left in me.

So the transfusion started and Stan arrived half-an-hour later and was -- and said, "Oh, you nearly finished", and I said, "No, we've just started". I know that I had actually, because I remember watching the blood come down the tube and reach my arm and I remember saying, "Please, don't let me get HIV", but I didn't know to say, "Please, don't let me get hepatitis", and then Stan came in and I said, "We just started", and he said -- he was absolutely livid. He was furious.

By then I was just like flattened but Stan said, "This was not what they told us. How can it have been an emergency if they -- you were up half the night feeding your baby".

So we began to -- we thought and more and more have thought since then that the blood was given for some other reason and Stan will tell you what he thinks about that.

STAN: Yeah. I was very clear that the blood was to be administered that night and then if that didn't happen they had no mandate to administer it later.

So when I came in in the morning I think Gill said the blood's just, basically, just started going into my arm because I think saline solution goes in first. I said that's not what was meant to happen. I was furious, because we had asked to take blood only as an emergency and it wasn't being done as an emergency. So it made everything he said before a lie as far as I was concerned, added to the fact that the nurse -- in fact, I think the nurses changed the thing when I was -- the nurses were all covered in gloves and things and I thought, "Well, you've told us it's safe. You've told us it's an emergency. You put it in late and then you're all wearing gloves". We were just -- we were really upset by then.

GILL: I remember you asked, "Why are you wearing gloves", and the nurse said, "Well, that's our standard

practice".

But we just felt really frustrated that nobody had understood that we were not risk averse. You hear about people who refuse to take blood for other reasons and it seems a bit strange. We weren't -- if they had said, "Yeah, the blood's 90 per cent", or, "We've got this problem at the moment, so the blood -- there is a bit of a chance that the blood's not all right, however here are your chances without it", we would just have weighed that up and had a lot more faith in the doctors. But it was because they kept saying it's was 100 per cent safe that we kept thinking no it isn't and, however, at that point we decided, and I think I was instrumental in this, not to say -- I mean, Stan was raging but I was saying I've got it now --

STAN: There was no point in remonstrating. That was our decision.

GILL: Yes, and I couldn't -- you're in that position in hospital where you are totally dependent on the doctors you don't really understand, all the medical training, so you don't really understand what's going on and it's really quite a scary thing to annoy them and I felt we'd annoyed them enough.

MS RICHARDS: You had the transfusion, you left the

hospital to go home as soon as you could.

GILL: Mm-hm.

MS RICHARDS: We will just have look at one document. Gill, it will come up on our screens but you have it in hard copy there.

Paul, it's 0363002.

Gill, if you go just past your witness statement, your exhibits start and it's written in black ink. In the top right-hand corner there will be some page numbers and it should be page 1.

GILL: Yes, thank you.

MS RICHARDS: It's a letter, *[redacted]*, from the department of obstetrics and gynaecology and it refers to the circumstances of the labour and Lucy's birth and if we look at the second paragraph it says:

"Initially unwilling to accept blood transfusion but she was finally given one."

I understand you have an observation to make about that comment.

GILL: Yes. Well, I think it's the understatement of the year. I have sort of shortened the story so that we're not here all day but it went on and on and on and, you know, they were bringing consultants to my bed, the nurse said the whole staff canteen was engaged in a debate about it. It was utterly

humiliating. The sister was furious, so I think "initially unwilling" doesn't describe what happened.

I find six things in this letter which I think are varying degrees of inaccurate. One of them is that labour was spontaneous. It wasn't. It was induced.

I found six. I don't know if I will find them all now. Another one was that I was initially unwilling, which is an understatement. "Finally given one", I think my husband would argue with. He thinks I was coerced into taking one. There were another two but I'm probably too nervous to find them now.

STAN: You weren't just found to be anaemic, you were --

GILL: Yes, I wasn't just found to be anaemic. We had had a whole -- they knew why I was anaemic. They'd ripped out the placenta so -- but the way -- there's no mention here of a manual extraction. There's no mention it was induced. There was no mention the injection was given late, so I think it's a wholly inaccurate account of what happened.

MS RICHARDS: Stan, you have pulled no punches in your witness statement. You have described yourselves as feeling you were both tricked and conned and forced into having the transfusion.

STAN: Absolutely. That's what I think. I think we were -- I think the doctors wanted the transfusion because the transfusion was the best way of getting Gill right back to health, getting Gill out of the system, reduce their immediate risk of repercussions for what had gone clearly wrong and so basically to get them out of trouble and for their convenience they wanted Gill transfused.

There was no doubt when they first started speaking that when we asked them bed rest was all that was necessary but they then changed their minds and decided that they wanted to transfuse so basically they tricked, conned, duped, whatever, and in retrospect we should have pressed them harder.

Also seeing the other people this morning, I think everyone feels in retrospect they should have done something differently, so it's very difficult for the patient, so to speak, to be just as clear as they would like to be, so I think we were very much coerced.

GILL: I think we feel that we set the bar for transfusion and when they couldn't argue us into changing that bar they just met it and said, "Okay, it's emergency now", is what we feel happened.

STAN: Yes.

MS RICHARDS: Gill, I want to ask you next about the years

that followed the transfusion, 1988 through to 1995.

How were you physically over those years?

GILL: Well, this is -- I'm not quite sure where to start. We had -- we were ambitious in the small sense. We had a lot of plans and we'd worked hard at school and college and, you know, we had career plans, both of us, we wanted to build our own house. We did build our own house, but very quickly that building the own house became a way of Stan facilitating Stan's self-employment because it was obvious that I wasn't coping and -- well, it was obvious to us. It wasn't obvious to anyone else because I was utterly ashamed of it and would go to any lengths not to let people know how much I was not coping.

I was exhausted the way I've heard other witnesses describe today and it's really difficult to describe. I used to say, you know, sometimes if you are very tired just before you go to bed, I've heard people say, "Oh, I must get to bed I'm exhausted but I haven't got the energy to clean my teeth", so you sit for another half-an-hour trying to summon up the energy just to climb into bed. But I used to say I feel like that when I open my eyes in the morning and every single thing I do all day, it's just done just as an effort of will and, you know, my head is

just screaming "sit down, sit down" because I'm so tired.

I used to -- I used to -- I was also always cold, so I would pull my chair up against the radiator if Stan wasn't looking and just to get warm, and the reason it was if Stan wasn't looking was that immediately the heat of the radiator put me to sleep, and we have discovered that if you fall asleep on a radiator your own body weight presses you against and within about 20 minutes when your husband arrives to haul you off it a huge blister will appear. I'm happy to show you if you want me to but I've got scars all down my arms because I did it again and again and again.

I was absolutely ashamed about that as well. I think it's -- I want to talk about this later but the doctors had been -- we put the transfusion behind us and, obviously, this is seven years and the doctors had been adamant that we were wrong and they were right and the blood was totally safe and we felt we had -- did what we could in the situation and then we just got on with all our plans.

So when I wasn't coping and I would say to people, "I'm just really tired", of course everybody says, "Oh, I'm really tired too", so that conversation

goes nowhere and or else they say, "Well, you've got two young children, but I would look at my friends and they had two young children and they were going back to work and I just felt, you know, I sort of -- I'd been brought up to try hard and I couldn't understand why it wasn't working.

STAN: Just to add, this tiredness against the radiator was such that Gill was like very resistant, by the time she was so tired she was very resistant to be taken off the radiator.

GILL: Or being woken up.

STAN: Or being woken up, she was --

GILL: Get off, get off, just leave me alone.

STAN: Violently is the word for it. It got to the stage the only way that I could sort of deal with the situation was to cuddle round and put my arm on the radiated and I'd end up burning myself trying to keep Gill off the radiator, so she was really exhausted.

GILL: Utterly exhausted.

STAN: We resolved it in our own mind because other than that it was asymptomatic. She was just exhausted. We decided that Gill was getting old before her time. That was what we resolved in our minds. For years we thought that.

GILL: And, of course, I was ashamed about that as well.

Then on one occasion in that period -- so I did go back to work and we decided -- we built a house but we decided this has been too -- it's the house. It's been too much for us, too big an undertaking too soon, and I was going back to work and I had to give up again and then I must have tried that a few times and eventually we thought like let's just -- I had been happy as a student in St Andrews and we thought let's just go to St Andrews, a quiet little town, and we'll just rent and then we'll build another house but we just obviously need a couple of years to recoup.

So we sold the house, sold very quickly --

STAN: So we bought another one, a smaller one.

GILL: Sorry, we bought another one. We bought a little flat in St Andrews and I looked for teaching work again.

Just about the period just when we were moving to St Andrews it was Christmas and I'd ordered Rory's Christmas present in the toyshop at St Andrews and they phoned and said the present had arrived. So it was a drive of about 15 miles, so I said to Stan, "I'm just going to take the children and go and collect his present", and it was all sorts of laughter about how I was going to get it in the boot without Rory seeing, and off we went, and on the way -- so it was December,

it was dark about 4 o'clock and on the way to St Andrews I well asleep at the wheel and not for very long because when I woke up there was a line of cars and we were all travelling, obviously, at the same speed, and when I woke up I was on the other side of the road but still opposite the gap where I obviously slid across the road.

I remember thinking -- I knew instantly I'd fallen asleep at the wheel, although I'd never heard of that before but I knew that's what had happened. In the very far distance, I could see headlights coming towards me but they were literally -- I mean, they must have been half a mile away. It was the coast road to St Andrews and I just remember thinking if I hit that car I'll kill the driver. I knew there was a golf course and I stupidly thought I'm just going to drive onto the golf course and get myself out of this situation.

So I just turned the wheel and attempted stupidly to drive onto the golf course. I didn't know that there was a drop of about --

STAN: 15 feet.

GILL: 15 feet, there was a sort of culvert between the road and the golf course and Rory remembers being airborne.

RORY: Yes, I remember the car being airborne and obviously the impact and Mum was -- her thought after it had happened was that the car might catch fire or might explode.

MS RICHARDS: That was November 1991, I think.

GILL: I'll check dates with my family because one of the things about my treatment is that I'm rubbish at dates.

MS RICHARDS: It's the date you put in your statement.

GILL: It's the date I put in my statement. Yeah, we will have checked that all together, yes.

MS RICHARDS: In this period the seven years from 1988 to 1995 and we will come on to the significance of 1995 in a minute, you didn't go to the GP or to seek help.

GILL: No.

MS RICHARDS: What was the reason for that?

GILL: I was ashamed. I thought I wasn't coping. I was young. I was early thirties and I'd expected to do so well -- well, you know, I just wanted to -- I enjoyed teaching and I was teaching in that period latterly in schools in Fife, all sorts of different schools, and before Rory was born I taught full time and the financial plan was to start doing that again, so until a post became available I did cover and I did -- one of the jobs was a one-year contract but in the end

I had to leave that because what was happening was I would get home from school at 4 o'clock and say I'm just going to sit down for five minutes and I just slept. I would sometimes sleep right through supper and got upset because I missed the children, and just woke up in time to go back to school, so that wasn't working very well.

I also taught a little bit at St Andrews University. That was better and that was where I really wanted to end up but that was better because I took tutorials, you can go in -- you know, you just go and take the tutorial and go and work at home and I also taught in the evening programme for when the Government brought in the -- I can't remember what it's called, but it was adult education evening programmes based in university departments, so I taught on that.

That was easier for me to do but -- sorry, I've forgotten your question now but that's what I was doing latterly in that seven year period, but the last year of it we were getting concerned because I wanted to hold down these jobs and we needed to hold them down financially and when I got home I was asleep immediately.

MS RICHARDS: I wanted to ask Rory because you've got quite a distinct memory of this period from when you were about eight years old for the next two or three years before your Mum's formal diagnosis, about things being not quite right, not normal is the way you put it in your statement. What can you recall?

RORY: Yes. I remember my parents, the family making perfectly reasonable plans schedules throughout the day but then we never seemed to achieve them. Being late was a very common occurrence and, you know, that became -- it wasn't bullying, but teasing amongst my friends at school that the Fyffes are always late and we could never really understand why. Something seemed wrong. The more effort we put in the more tired we got and the less we seemed to achieve and something didn't add up.

MS RICHARDS: You remember your Mum falling asleep on the landing by the radiator and you and Lucy would sometimes curl up next to her and fall asleep too.

RORY: Absolutely.

MS RICHARDS: Lucy, you have a distinct memory of one particular occasion when that happened and your Mum had been holding a cup of very hot coffee and fell asleep with it in her hand. What happened?

LUCY: Yeah, it wasn't unusual for us all to curl up on the landing because if Mum didn't have energy to brush

her teeth she didn't have energy to put two young children to bed so we would -- we were too young to put ourselves to bed so we would sort of be tired and sleepily cuddle in and Dad got Mum a cup of coffee to try and give her the energy to get us to bed, and I'd fallen asleep. Then I woke to just a very strange feeling on my calf and I was whisked up and put into the bath and showered down, and Mum had fallen asleep and tilted the boiling water on to me.

I also remember I was given sweeties from the garage. So we showered it down and things, but it left a huge burn down the back of my calf, the whole of my calf, that took weeks to heal. I'm not sure if we went to the doctor but Mum would change the dressings every night it was just, well,I've put in my statement, at that age to me it looked like the lop of a lasagne. It was just an absolute mess, and I remember --

RORY: It's what we call a full thickness burn.

LUCY: Yeah, I remember Mum cleaning the wound, me lying on my front in the bath and hearing the scissors clink and thinking what were they for and, to put it nicely, they weren't just for the bandages, and then going into school and having this burn that soaked through my tights, through the bandages and into my tights so

we would have to soak my tights off, and all of these occasions leading to just a lot of confusion why has nobody else got this?

GILL: We used to say there's something going on that we don't understand. We actually used to say that.

MS RICHARDS: Then November 1995 you received a letter.

GILL: Yes.

MS RICHARDS: Paul, could we have up on screen please 063003.

It should be the third page, Gill, of the bundle you have got there. This is a letter from the East of Scotland Blood Transfusion Service to you, 17 November 1995:

"I am writing to you about the blood transfusion you had as part of your treatment in Ninewells Hospital in 1988. We have now discovered that the blood may have been carrying an infection known as hepatitis C. This is caused by a virus, the hepatitis C virus, which could have been passed on to you by the transfusion. I very much hope that this has not in fact happened in your case but I would like to recommend that you have a blood test. This will show whether or not there is evidence of hepatitis C infection."

Then there was a degree of further information

and an invitation for you to attend an appointment.

The first thing you did was to contact your GP. What can you tell us about what happen and, indeed, what was your reaction to seeing that letter?

GILL: Well, Stan was self-employed at that time so he collected all the mail. I'd come home from school, fallen asleep on the sofa, and he came up, as he always did when it was time to collect the children to say -- because they had after school activities to -- sometimes -- to say, "Who's collecting the children", by which he meant he was busy and was I up to it and he said, "Oh, and there's this letter for you". I think you'd opened it.

STAN: I'd opened it because of the sort of less than urgent language about it I'd kind of dismissed it as being one of these round robin type letters. Obviously, I hadn't read it very carefully.

GILL: I was so exhausted I didn't move from the sofa because I was angling for Stan to collect the children and me not get up. So I said, "What is it", he said, "I don't know. It's one of your well woman things". I don't know quite what he meant by that but ... so I mean, I might easily not have taken it. I might have easily just a minute.

So I took the letter and I remember as

I pulled -- it had a little one of those little windows in the envelope and as I pulled it out I saw "East of Scotland Blood Transfusion Service", and my heart just stopped and I -- then I read the first paragraph and I thought "I'm infected". I just knew immediately that because whenever I saw East of Scotland Blood Transfusion Service I thought of the transfusion and then I thought of the fact that I'd just woken up off the sofa and I just remember having this feeling that it was almost like there had been an enormous clang, my life will never be the same again. It was just an overwhelming feeling.

Then very quickly I said, "No, this is bad", and Stan was going, "It's nothing, it's nothing", and I said, "No, it's about the transfusion", and I said, "I'm infected", and he went, "No, you're not infected. What is this?" He took it and I watched his face change. I know -- I can recall the exact second that all of a sudden his face changed and he started to read it again and he -- and I said to him, "You might be infected", and he said -- he finished reading it very quickly and he said, "No, I'm not", and then he looked at me and what he meant was, "I'm not sleeping on the sofa", so he knew the vast difference between us.

As he said that, I said the children might be infected and then my world just fell apart. I can't tell you how -- it's a good point to pay tribute to the people who have spoken to you who have lost children because I don't know how anybody copes with that. I was so scared my children were infected. I started screaming and because it was seven years and I'd never seen my GP, though we had registered, and I was screaming at Stan, "Get the doctor. Get us to the doctor", and he said, "The practice is closed but I'll phone them", and I can remember screaming at him, "You make them stay until we get there", and -- which the GP did.

So we leapt in the car and raced to the practice. There was one car left in the car park and banged on the door and there was a receptionist with her coat on and she told us which room to go to.

As we were going up the stairs, I said to Stan she knows. I just -- she wasn't -- she had her coat on. She wasn't -- I just got the overwhelming feeling that this receptionist, who had kindly waited ten minutes, knew. So we went in and I met my GP and he said, "I was waiting for you to come because the Blood Transfusion Service have been in touch with me".

MS RICHARDS: If we look at just one entry from your medical records, Gill -- Paul, it's 363004 -- and Gill you should have it, I hope, on the next page.

GILL: Yes.

MS RICHARDS: Could we highlight please, Paul, towards the bottom of the page the entry for 28 September 1995, the first of those entries you've got there.

We've got:

"T, telephone, phone call from Dr Brookes, BTS Dundee, now found that the blood transfusion she received 1988 was from a donor now found to be positive for hep C", and then it says:

"Initially BTS will write to her and then I will contact her."

So the Blood Transfusion Service telephoned your GP on 28 September 1995. Your understanding is that your GP thought that it was information that should come to you from the Blood Transfusion Service rather than from him.

GILL: Hm mm.

MS RICHARDS: But, in fact, it wasn't until nearly two months later that you received the letter telling you.

GILL: Yes.

MS RICHARDS: Your primary concern is the seven years in which you could have infected Stan or Lucy or Rory but you do have an additional concern about that two month period when it was known to the Transfusion Service and your GP but not to you.

GILL: I was surprised at the time, although it wasn't the priority at the time. My priority was are my children safe. I have a feeling that it is not fair to pick out the GP in particular because I now know that the doctors who told me the blood was safe seven years earlier must have known that that statement was not true. Even if they thought it was pretty much safe, they knew that there was a problem and so Lucy was born in 1988, for example. It was on the front cover of newspapers in 1983 that there was a problem so I didn't know that in 1988 but I know it now.

So I feel I don't -- I feel very grateful that the look back survey found me. I wonder whether it might have been commissioned earlier. I think that is for you, Sir Brian, to discover. I mean, there may be good reason why it wasn't but it seems a long time to wait in order to try and find people.

I think I'm right in saying that it was commissioned or it actually got underway in 1995 is my understanding. I saw an Article in the British Medical Journal to that effect which gave the impression because of other dated articles that it was getting underway either late 1994 or 1995.

So I think that that is the bigger question, why were my children at risk for seven years. But in terms of those two months the GP in many ways was very helpful. He may have thought they'd get in touch with me immediately. I think it's just one of those -- I think any of us in that situation would wish that we'd got in touch straight away. That would be what I'd like to do.

MS RICHARDS: Your GP advised you to have the family tested and --

GILL: I asked, I asked, yes.

MS RICHARDS: Arrangements were made for those tests. The tests for Stan and Rory and Lucy came back negative.

GILL: Yes.

MS RICHARDS: Your test came back as requiring further testing.

GILL: Yes.

MS RICHARDS: You had a two-week wait before you got the final results.

GILL: I think it was about two weeks, yes. We had been told at the first test if you were negative you were clear but if you had a positive test result it may be a false positive so they would then do a more expensive test but, obviously, it was not a surprise and I -- I think in those two weeks or when we were waiting for the test result, I knew it was my last chance of a normal life that it came back negative. I didn't really think it would, whereas poor Stan was desperate that it came back negative and absolutely collapsed when it didn't.

STAN: Probably that's the case, yes, against all the evidence that it wasn't going to come back negative.

MS RICHARDS: What information or advice about hepatitis C or about treatment for hepatitis C was your GP able to give you?

GILL: My recollection is that, of course, you couldn't, as another witness said, you couldn't Google but because of teaching I had membership of the university library so we told him that and said can you give us some references. I remember him saying, "I don't know anything about this". Do you recall that?

STAN: Yeah, I remember that, and he also gave us -- he had more access to computers than we did. He gave us one of these old fashioned sheets of computer paper with a list, a huge list of references.

GILL: Yes, with all little lines on it.

STAN: Yes, there was no VDUs in these days. It all came out on paper. There was a whole list of references and we set about these in the university library in St Andrews looking for references and things.

GILL: And when we found them we couldn't make head nor tail of them.

STAN: We couldn't make much of them.

GILL: Very specific medical tests or specific lines of research that one would have --

STAN: They weren't, to use common parlance, user friendly.

GILL: No, they weren't for the layman, no, but he was trying to help.

MS RICHARDS: But you found subsequently in looking in your medical records an information sheet for GPs about interferon from May of 1995.

GILL: Yes.

MS RICHARDS: Paul, we will just have that up on screen, 363005.

It's page 4 of the bundle you have there, Gill. We don't need to see the detail of this but we can see the date, May 1995, Centre for Liver and Digestive Disorders, Royal Infirmary of Edinburgh.

You have, as I understand it, no recollection of ever receiving this document or the information contained in it?

GILL: No. I first -- have no recollection of seeing it. I was -- I first saw it when we requested my medical records for this Inquiry. I'd previously been advised not to request my medical records. When we first discovered I was infected I was advised by a St Andrews lawyer not to request my medical records because he said, "They will be filleted by the time you've got them", which I must admit stunned me at the time, but it was around the time we were deciding we couldn't afford to have a lawyer so we just left it.

We requested them from this Inquiry at no cost and found this information sheet and I have had two courses of interferon and have no recollection of seeing it before.

MS RICHARDS: Stan, what can you recall about the advice that was given, it may or may not have been by the GP. It may have been by others, I'm not sure, about how to deal with risks of infection and what kind of hygiene steps to take?

STAN: Obviously, hepatitis is a blood-borne disease and Gill's immediate concern was not to infect myself and the children and sort of, you know, people round about us.

Now, the advice was it's hard to infect people you meet because it's blood-borne but, of course, Gill being a woman with a menstrual cycle and all that she bleeds every month and the nurses were -- that's the background, but the nurses were saying, "Oh yeah, keep things clean, bleach things, don't get blood near anyone", and being so keen to -- not to infect the children, Gill just did this to the letter. She was --

GILL: We followed the advice to the letter.

STAN: To the extent, "Don't touch me, don't do this, don't" -- you know, I mean you sort of -- I can't remember the --

MS RICHARDS: You kept bleaching the bathroom in the middle of the night sometimes.

GILL: Exactly, because I said to the nurse -- well, when she said, "If you do bleed you must bleach the surface the blood is on", and I said, "Well, I bleed every month", and she said -- so I said, "What do I do then? What do I do about that", and she said, "Nobody's ever asked that question before", which -- and she said, "Well" -- I said, "We only have one bathroom now and she said, "Well, I suppose if you have your menstrual cycle and you use the lavatory you ought to bleach it before the children use it", so of course that was it. Every time I went to the lavatory I would bleach it and I would lie in bed at 2.00 in the morning thinking, "Have I got the energy", this was with hepatitis, "to get up, go to the lavatory and bleach it or will I just lie here and hope I get back to

sleep, because what I can't do is go to the lavatory and then I lie here awake trying to hear if the children are going before I get to it in the morning". So it became easier just to don't reinvent the wheel, just bleach everything, bleach everything, and then --

STAN: Sorry, just to interrupt, I think the thing was the advice wasn't balanced.

GILL: Yeah.

STAN: There was no sense of proportion. The nurses were sort of reading from a script, keep clean, bleach everything, and then when they delivered it to Gill who was taking it quite literally --

GILL: Because I was scared for my children.

STAN: There was no balance. It was a difficult thing for her to deal with.

GILL: Yes, if you'd said -- anything they told me to do to keep my children safe I would have done it.

MS RICHARDS: Lucy, you recall a strict regime of hand washing being used and if your Mum cut herself you would be sent to your rooms, you and Rory, to be out of the way while she could clean and bleach everything.

LUCY: Yes, exactly, and sort of a main note I would say of mine and Rory's childhood was often just waiting for Mum and Dad to -- if Mum had bled or cut herself

for them to clean it or, you know, for household chores to be done that could have -- that most people can achieve quickly to be sort of -- pull themselves through them and, yeah, we'll come to that, yeah.

MS RICHARDS: I want to ask you about the treatment that you then embarked upon, Gill, the first course of treatment. So this was interferon May 1996, a six-month course of interferon. You were warned of some side effects.

GILL: Yes.

MS RICHARDS: But what were the side effects that you experienced?

GILL: I was warned it would be like proper flu and I was told that the symptoms of flu are actually caused by your body's defences largely and that interferon boosts your body's defences so you would simply have flu symptoms to quite an extreme degree and that seemed quite accurate to me. I was even more exhausted. At that point I started walking with a stick. On one occasion or more than one occasion I think I had to sit down in the supermarket because I couldn't get round without ... anyway, I'd just take a little folding chair and I -- it was shivers, temperature, aching limbs and basically I just wanted to lie down. You just couldn't get my head down fast

enough.

I remember if I moved by eyeballs in my head it hurt like anything. If somebody spoke to me once I had taken an interferon injection, I would turn my whole head so that I'd try and keep my eyeballs still.

But at the same time, the bills keep coming in and so I had to keep -- we very quickly discovered that in that situation you have no flexibility. You've no resilience left to give, so generally when people offer to help you in a small way it's actually easier just to be left alone and we very quickly worked out if you rest you pay for it. So you just have to have a routine and do your best to stick to it, otherwise it all unravels and you haven't got the energy to put it back together again.

So that's exactly what Lucy was talking about, that once I started taking interferon we got later, it took even longer to do everything, Stan was still trying to run an office to pay the bills. It was chaotic.

MS RICHARDS: Rory, you described this period in your statement as the treatment and the effects of the treatment dominated your lives.

RORY: It absolutely did. The side effects that Mum's describing essentially left her asleep, bed ridden every second day, you had an injection every second day and so trying to meet all those challenges with half the available time, you know, and the drugs used to come in batches of a few months. I can't quite remember but the -- I remember us sort of planning our lives round it. If we start the next batch of drugs today, then Mum will be awake for her birthday and Christmas but if we start the batch tomorrow then she'll be awake for sports day and Hogmanay or ...

It completely dominated our lives down to the sort of minute day-to-day details because of the requirements for trying to prevent anyone else getting infected through to, you know, the bigger life decisions because, you know, the loss of time, the loss of the ability to work, the fact that Dad was not only trying to run a business himself but acting as a carer for Mum and, you know, without any recognition, really.

MS RICHARDS: You've said again of this period and, obviously, through no fault of your Mum's, that it didn't feel like you had a Mum because she was so exhausted from the condition and from the treatment.

RORY: Absolutely. There was -- she had no option. She was asleep every second day, so half our life for years at a time we didn't have a Mum.

MS RICHARDS: Gill, this first course of treatment wasn't successful.

GILL: No.

MS RICHARDS: How did you feel when you discovered that the course of treatment had not succeeded?

GILL: I trained myself that -- because it's agony waiting for test results every fortnight so I trained myself not to -- to make that not a priority, so I think when the -- and they kept coming back positive, and then they were negative for about a fortnight and then as soon as I stopped taking the treatment it was -- I relapsed.

So I just kept -- tried to hold on to this we've got other goals in life, this is not my primary goal. I used to say my primary goal is not to get well because I couldn't control that. I could try and achieve other things, like being a Mum.

So when I relapsed I think I was sort of mentally quite initially able to cope with that but then we were told that because I'd relapsed that precluded me from any other treatment and we were not able to cope with that.

That just destroyed us and because by then I knew that hepatitis C starts to seriously affect your health, can start to seriously affect your health

after ten years or maybe longer but it can start to -- and I had been told I was infected after seven years and this had all taken another at least another year more than that I think. So at that point I thought I'm not going to see the children grow up because I'm not going get any more treatment and that then -- well, we just began to plan for that.

MS RICHARDS: One part of the plans was Rory had been offered an assisted place at a boarding school.

GILL: Yes.

MS RICHARDS: You decided to take that up because you felt you couldn't look after him and you weren't confident you would be around to look after him.

GILL: It was mostly the second part. Friends of ours asked us -- friends of ours were taking this route for traditional family reasons, because in Fife everybody is friendly with everybody because there's hardly any people there and people were very kind and so we -- because we had a lot of friends and they -- some of them were taking this route and they said why don't you -- these schools have huge charitable foundations. Why don't you talk to them?

The reason that they said that was because they said, "You guys are really suffering. You would be eligible for something like this", not that we'd ever

considered it. When we heard that the treatment had failed and that particularly there wouldn't be any other treatment, I thought that -- well, there was -- I thought -- for me I wanted the children to stay with me, particularly if it's only for two years, and I thought I could, you know, I could look after them but as you've heard them say it was not normal, it was all to suit me.

So you know they couldn't have friends round because Mum's asleep every second day and we didn't go camping any more, and we didn't climb hills. So it started to feel like this was the life that I'd wanted for them, obviously it was Rory to start with, this was the life that we'd always envisaged for them and somebody else could give it to them, and that we were really lucky to have this chance.

So we did apply and I have to say at this point the school was Fettes College here in Edinburgh. It was the biggest -- it's such an act of charity on their part because they did offer Rory a bursary and when I -- and then they helped Lucy and eventually, as you will hear, they gave me a job and on the day I left that job when I became ill again, everybody who leaves the job has to make a speech. In my speech I said, "When nobody would help us, not the Government, not the lawyers, not the doctors, you gave my children a life", and that is true, they did. But what it meant was that -- I remember I was in the shower. We were waiting to hear whether Rory would get a place and I heard Stan shout, "He's in", and I heard Rory cheer and I remember just kneeling down in the shower and crying in the water because -- I mean, it was the result I wanted but -- and also I just worried ever since can he possibly understand.

But I think what that shows actually is, on behalf of everybody that this has happened to, just how scary it is. It's really, really scary and people are so brave. I think that doesn't always come across. I thought at that point I wouldn't recover, I was still frightened of infecting the children because I was still infected and I knew that I wasn't -- that I was -- their lives were now so constrained and I thought that would get worse. So Rory went off to boarding school, which ultimately has very many happy benefits. We're very grateful for them.

MS RICHARDS: You did embark on a second course of treatment, having been told initially that it wouldn't be funded and you did that through volunteering to participate in a research trial.

GILL: Yes, we got in touch with the hospital and said, you keep me right in this, but my recollection is you got in touch with this and said, "You can't just leave her like this. There must be something you can do" and they -- did we go together?

STAN: I'm not sure but we were very unhappy because the reason for not treating Gill again was purely financial.

GILL: Yes.

STAN: Gill was a good candidate. She wasn't one of the many chaotic people who get hepatitis who don't take their injections. Gill was taking injections faithfully, trying her best to recover and yet had relapsed, so for financial reasons, not because she wasn't a good candidate or anything, the doctors were saying, "No, we don't want to spent the money on the treatment", and we were very upset about that, obviously, because Gill had been given this infected blood product, then they didn't want to spend the money to deal with it.

So we were upset about that, but then they did sort of give in and say, "Well, it's not going to work anyway", but we were -- well, I can't remember they convinced or not, but then they came up with this possible drugs trial, of course.

GILL: Yes.

STAN: We would have signed our lives away to try and ...

MS RICHARDS: You did sign or you were asked to sign an agreement not to bring any legal proceedings arising out of the drug because it was a research project.

GILL: Yes. My understanding is that although both drugs, I think this is right, I think both drugs were licensed for other uses but this was a trial of their combination to treat hepatitis C.

MS RICHARDS: It was interferon and ribavirin.

GILL: It was interferon and ribavirin, so it was a second court of interferon, this time for 12 months while taking ribavirin at the same time.

MS RICHARDS: Again, you found in your medical records a patient information sheet about that dual therapy which you don't recall ever having seen before or being given.

GILL: I don't recall ever -- I don't recall being shown it, no. I have to say that I probably didn't press very hard for information because as soon as they said, "There is a drugs trial, would you" -- I just said "Yes", and they said, "You'll have to sign away -- you'll have to sign whatever it is to say that in terms of this drugs trial nobody is liable for anything", and I just said, "Yes". I mean we cheered. We were like yes, yes, we get a second chance.

STAN: Having said that, that document I've never found that document that we seem to remember signing.

GILL: No, we don't have a copy of it, no, no.

MS RICHARDS: What were the side effects like?

Stan, can you recall how the second course of treatment affected Gill? Was it in a similar way to the first course?

STAN: I think the side effects were very similar. Yes, I think they were. I think they were exactly the same. I think, perhaps even slightly worse because it went on longer. I certainly remember that once she had -- once the treatment had been deemed a success, Gill was, she couldn't walk straight. She had a terribly sore back for such a long time that we didn't think you were ever going to be able to straighten up.

GILL: Yes, I remember that.

STAN: She went to some kind of doctor who eventually fixed it. But she was so -- you know, she was curled up, she was small, she was -- she had a lot of hair but she had lost a lot of hair. I can particularly remember the fact that --

GILL: I was offered a wig at one point. I lost a lot of teeth.

STAN: The shower was always full of hair.

GILL: Yes, I've hardly got any teeth. It is a source of amusement how few teeth I have left.

MS RICHARDS: This treatment did ultimately succeed in clearing the hepatitis C virus.

GILL: Yes.

MS RICHARDS: Although it was ultimately 2000 before you were finally given an all clear message.

GILL: Yes. They keep testing in case you relapse again, yes.

MS RICHARDS: During the years of that treatment and the testing period that followed, you have explained in your statement that you would underplay to doctors how ill you were and how much you were feeling the side effects of the treatment because you were desperate that the treatment would be taken away from you. Is that right?

GILL: That's absolutely right, yes. To start with I tried to stay resilient just because that was my upbringing. So when they said, "You have got hepatitis C", I tried to be brave but very quickly I realised that everything was getting written down and when I -- and they spoke to me about -- I mean, I also was treated alongside convicts and -- in shackles on one occasion, and you were sitting in the

waiting room with people who'd brought their chaotic -- it was described as chaotic lifestyle and they brought it with them into the waiting room, so it was quite an eye opener sometimes and --

STAN: Sorry, just to add to that, one of the things that when they were testing Gill or giving the interferon and the ribavirin to Gill, they were always testing some kind of limits and I remember that Gill was always near the limits and if she went over these limits they'd have to stop it because it was too dangerous, so that was one of the reasons for Gill --

GILL: Yes.

STAN: "Oh, I'm feeling fine, I'm feeling great even though my platelets are low", or whatever it was, we were trying to give a positive impression to counteract the bad limits you were getting.

GILL: Absolutely.

STAN: The bad results.

GILL: They told us that because of these people with chaotic lifestyles, well, not because of them, they said sometimes we don't treat people because their lifestyles are too chaotic and they won't follow the treatment course properly and for the first course they said it's a success rate of about 25 per cent and I was shocked and said, "I can't believe that. That's

so awful", and the doctor I said that to was offended and said, "Well, actually, that's as good as some antibiotics". I still didn't think it was very good as a bolt from the blue.

So we resolved we were going to do everything absolutely perfectly and I comforted myself that maybe that would get it up to 50 per cent, so we actually bought a fridge -- well, we had a fridge where we put all our groceries, but we bought a fridge and put it in the bedroom so we could put the medicine in it and people weren't going in and out all the time affecting the temperature, so we just did -- we said if we just max everything then we will push that chance up as high as it can go.

So when the doctor -- so when I began to understand that there were ways to have the treatment taken away from you, and eventually we were told it had been, every time they said, "How are you coping", I answered, "No trouble at all".

"How are you feeling?"

"Very well", because then they had no reason to take the treatment away.

MS RICHARDS: Those references --

GILL: That was out of fear.

MS RICHARDS: -- in your medical records to feeling okay,

feeling well, et cetera, you have said in your statement that when you were subsequently involved in legal proceedings, litigation against the Scottish Health Service, Secretary of State for Scotland, those references were used against you to suggest that actually things weren't as bad as you were saying.

GILL: That's right, yes. They came back at us in a letter saying that your patient -- I'm not even paraphrasing, I don't have the letter in front of me but basically saying:

"We note that your patient was actually fine because ..." and quoting from doctor's writing down, "Patient reports that she feels very well", and at that time I had hepatitis and was being treated with interferon. I mean, I know that's my own fault, in a sense, because I should have said, "I feel absolutely terrible, I can't cope, and I can't function", but I was just -- it's just such a scary position to be in, especially -- and I'll talk about this later, but especially because not once did any doctor -- they were in the moment kind and helpful but there was an absolute blanket silence about how I'd become infected.

There was no comment from any doctor or any nurse about -- nobody ever said, you know -- let alone saying this should never have happened, nobody ever said what rotten luck or -- occasionally, I would say things and there was just no reply, ever.

So that's such a scary position to be in because you're now entirely dependent on the people who will not comment on what's happened to you.

MS RICHARDS: You have discovered again from obtaining your medical records that it appears you were enroled in the national HCV register.

If we have on screen please, Paul, 363025.

Gill, in the bundle you've got there it should be pages 28 onwards. We can see here there is a letter from the National HCV Register to a clinician, July 2006, and it refers to you, a patient who is involved in the HCV National Register, requests follow up.

Paul, if we just go on a couple of pages please to the National Register documentation.

So we've got there a National Register of HCV infections with a known date of acquisition follow-up form which is completed by a doctor.

Then, Paul, if you would just go on again just a few pages until we get to a patient information sheet, please. Next page. Next page. That's it.

We can see here a patient information sheet

which explains what the HCV National Register is. It says it collects information about patients, talks about patients being enrolled into the register. If you go down to the bottom of that page.

Sorry, Gill, do you have it?

GILL: Yes, I do. Yes, thank you.

MS RICHARDS: It says what information would be included, medical information, spare blood samples, spare liver biopsy sections and so on.

Do you recall ever being asked for your consent or agreement to be enrolled in the National HCV Register?

GILL: I've no recollection of that, absolutely none, and I -- obviously some things I do find difficult to remember now but I have absolutely no recollection of that. If they have a form that I have signed obviously then I have completely blanked it but to the best of my belief I have never seen that form and I don't think you can recall.

STAN: I've no recollection, no.

RORY: It's worth of pointing out as part of trying to maximise the chances of any cure working any documents were poured over at length and in great detail despite the memory problems would still be in your mind.

STAN: Probably, yes.

GILL: Yes. I usually have a glimmer of I know I've forgotten something.

MS RICHARDS: But I understand it's Stan who religiously keeps documentation and neither of you recall any documentation relating to that.

GILL: Yes. Stan has been totally vindicated by this inquiry because he keeps everything and now we're very glad of it.

MS RICHARDS: I wanted to ask you about two consequences of the treatment. The first one I wanted to ask you about is something Lucy talks about in her statement and that's the memory loss that you have observed worse previously than now, better to some strength now, but memory loss in your Mum.

What can you tell us about that?

LUCY: I remember starting to be really aware of Mum's memory loss when she was being treated, so I was about eight and that would be short-term memory loss.

The thing I most remember about that was being in the supermarket and Mum going to sign her name to pay and her pausing sort of looking away and vacant and it was such a long pause that I realised that what she was struggling for was her own name and so I offered her -- I said, "It's Gill", and she went, "Thank you", and wrote it down, which I can only

imagine what the cashier was thinking, so that was the short-term memory loss when she was being treated.

When I was an early teenager I would refer to things from that time from when I was about eight to ten, things that Dad would have remembered, Rory would have remembered, common things to remember that day at the beach or something and Mum would be blank on that, which I think was very hard for us both because it was hurtful. Neither of us was at fault but it was just a shame.

I think those memories have -- a lot of those memories have actually returned for Mum but now the biggest gap in her memories is from before her treatment, so you can talk about that more than I would be able to.

GILL: Yes. When I -- I can't even remember when this happened but I think it was when I went back to work when we thought I was cured -- well, when I was cured of hepatitis because the second course of interferon and ribavirin was successful, so I -- as soon as I was cured I wanted to get back to work because financially we were ruined and -- so I went back to teaching and, again, it was before kindle or anything like that, so everything was books on the shelf and we actually, and I can't remember the reason why we did this, but we were going through all my books and we were able to divide them into two piles, and there was this enormous pile of books which I knew I'd read and I had not the single idea what any of them about.

People -- friends were laughing because they were saying it's like free books and you can read them all again and I literally didn't know what was going to happen. It was all English classics but it was really weird going I wonder what's happens at the end of Wuthering Heights. So that was -- yeah, when I talk to my brothers and sisters half the time I don't know what they're talking about because I can't remember. They remember. They obviously have normal memories and a lot of it and I'm just -- I can't really -- I remember about a tenth of what they remember.

Also, my -- the way my memory -- I know this with trying to write, it's quite useful for writing -- is that I have suddenly very vivid memories where it's almost like being in the room and -- or particularly of different places and that's great for, you know, for describing a scene but they're not under my control. So if somebody says, you know, as Lucy was just saying, "Do you remember when we did this", I can't recall it when I want to but then sometimes

I'll suddenly have this really vivid memory and I'll say, "Oh, I just remembered that", and they'll go, "Yeah", so it seems to be the way my memory works has changed.

MS RICHARDS: The principal lasting consequence though of the treatment that you received for your hepatitis C has been an autoimmune disorder that you have developed which causes extreme photosensitivity, sensitivity to light.

GILL: Mmm.

MS RICHARDS: Can you tell us about what exposure to light does to you.

GILL: Well, I now know that if I face the sun or stand in direct sunlight or if I sit under normal -- what is regarded as normal interior lighting now, then my face will swell up, my face and neck will swell up, because they are the bits that aren't covered and, eventually, they'll -- and the skin will thicken and eventually little fissures will -- it will split and suppurate to the extent that it will glue my eyelids shut and my ears sort of half come off and it's all suppurating down my neck.

If I do that, if I expose myself to normal light levels, just live like anyone else would live day after day after day it's cumulative so it gets worse

and worse and worse. So that's eventually why I had to resign again because I -- I'll come back to that.

To answer your question, I now know that the skin is an organ so that is -- the visible organ, but I now know that because I'm autoimmune if I'm exposed to light it affects other organs as well. I was told at the Eye Pavilion yesterday that it's also affected my eye. There's a whole long story of that treatment that --

MS RICHARDS: The condition that you, finally, after a long time, as I understand it, been diagnosed with SLE, systemic lupus erythematosus -- we talked about the pronunciation of this.

GILL: You're best at it.

STAN: Erythematosus.

MS RICHARDS: Thank you, Stan. Put in very basic terms light causes your body to attack itself.

GILL: That's right, yes. Apparently, it's been explained to me that this happens, the figure I have been quoted is in about 1 in 100 people who are treated with interferon, so it's rare but it's known and it -- we discovered it for ourselves by researching medical papers when we began to suspect it was a consequence -- we thought, we were researching to see if it was a consequence of hepatitis and doctors

were assuring us it wasn't and then one day I said to Stan I mean -- when it happens I feel awful. I said to Stan, "I feel like I've got flu. It's like taking interferon again", and then he just looked at me and quickly Googled -- this is quite recently -- quickly Googled a link between interferon and photosensitivity and found it in, like, a minute.

So, sorry, can you remind me of your question, Jenni.

MS RICHARDS: I was asking you to describe the condition and that's exactly what you were doing.

GILL: Yes, sorry. So we then discovered that it affects 1 in 100 people, that's what I was going to say, and that you have more chance of developing autoimmune disease having taken interferon if you have what they call a pre-disposition, and that if you have an already slightly overactive immune system then obviously it's easier to -- because all interferon does is boost your immune system really high to clear the virus -- and if you have had eczema as a child or asthma as a child those are caused by a slightly overactive immune system.

MS RICHARDS: And you had childhood eczema.

GILL: I had childhood eczema, yes.

MS RICHARDS: In order to avoid these extreme consequences, the swelling, the lesions, the suppuration and so on, you have ultimately had to completely adapt your lifestyle. So for you to be sitting in the light you are sitting in here without wearing the hat you originally wore is very unusual.

GILL: Yes.

MS RICHARDS: The lights have in fact been adjusted to some extent.

GILL: Yes, that one has been turned off, yes. I came yesterday and your very kind technical team have reduced these lights by half, switched off the theatre lights that were here and switched that one off, so I can sit here.

MS RICHARDS: You essentially, you and Stan together, have reorganised your lifestyle so that you do much of what you would normally do in the daytime, in the daylight, at night or when it's dark.

GILL: Yes.

MS RICHARDS: When you do go out in sunlight you will be wearing the hat we saw earlier and you have a cream that you have to put on religiously several times a day.

GILL: Yes. The cream is -- I mean, I was -- it took a long time to get that diagnosed in hospital and then I tried various treatments that the hospital

suggested, but the treatments, the first one wasn't effective, the second one made me ill, and so I said, "Can I not just avoid light", and the hospital agreed for a trial period that they would monitor avoiding light. So with the same rigour, they did use that word, with which I used to clean everything for the children, I now avoid light, although not rigorous enough to suit my children, and the hospital monitored me and agreed that that was working.

Basically, when I have a reaction it will take me about three or four days to get over it, so there is a strong -- it starts quite quickly but it takes days to stop. There's a strong incentive not to let that happen and it used to be that if you have autoimmune disease the life expectancy is ten years from date of diagnosis.

That's not the case now because people can be treated and I'm hoping it's not the case for me because clearly if you just allow yourself to react all the time you just effectively wear your body out, so I think if I don't react I'm not living on borrowed time, I hope.

MS RICHARDS: You can't use a computer screen anymore because of the light from the computer, which is why the documents have been provided to you in paper form

rather than coming up on a screen. You cannot watch television for the same reason.

GILL: No, no.

MS RICHARDS: Rory, you --

RORY: Sorry, just to give a sense of scale to this, obviously we're very thankful to the Inquiry for the adjustments they have made to us today but today will be the trigger for three or four days of recovery that Mum has to do when pretty much the majority of the day will be spent caring for your skin and trying to minimise reaction.

GILL: Yes. I think, I mean they're not going to let me get ill so they have turned all the lights down, but it will probably mean that I have to pretty much stay in the dark for about three or four days just to let it all recover and that's basically what I do. Because it's cumulative I try and build up resilience by -- so if there's something I really want to go to that I can manage with a hat or people adjust the lighting or something, then I just avoid light as much as possible beforehand so that -- because if my skin is already a bit shaky then it will quickly degenerate.

That's how we live. So in order to stay healthy I drag Stan out for walks when it gets dark which at

this time of year is about 1 in the morning, and we literally walk about an hour a day for exercise when it's dark.

STAN: It's also a very strange thing because Gill's condition, apart from having slightly ropey-looking skin, isn't really manifest and the precautions that Gill has to take are quite extreme but if she takes them she looks fine, so she's also going about with the stigma that, you know, I'm behaving in a very strange way, nobody believes I'm ill, but -- I mean I believe it because I see sometimes if she sits at the table and she's too close to the light you see her just turning red or if she walks in the sunlight her hands are suddenly so sore with Raynaud's disease it takes her half-an-hour to thaw out and sometimes she gets a thing called pericarditis where the lining round her heart actually squeezes her heart.

So without -- so if she just tried to live a normal life all these things would be attacking her and she would probably die very soon, so she lives a very strange life but she's no way of showing it to everybody because she -- she's got this sort of double whammy.

GILL: Yes, you have the feeling like you look crazy and that is, I think, one of the great things about this

Inquiry because that I would like to talk about at one point, is that when there is no official explanation for what's happened to us all, you look crazy. You look crazy to your friends, you look crazy to the head when you go and say I have to resign now because of this thing that's not official and I think that's one of the worst aspects, asking people to cope with all this without any official backing, which thanks to you we now have.

MS RICHARDS: Rory, you have observed in your statement that avoiding light is an incredibly difficult thing to do in the 21st century and it's a very isolating experience for your parents, particularly your Mum.

RORY: Absolutely. The amount of light that Mum can endure without a large amount of information is incredibly small amount of light. The layman would call it pitch black and it makes life incredibly difficult to function and, you know, living in a room with blackout blinds or shutters, you know, contributes to a feeling of cabin fever, of isolation, of loneliness, coupled with the lack of acknowledgement and understanding from the public and friends and family is an incredibly lonely and isolating position to be in.

MS RICHARDS: Stan, one of your observations in your witness statement has been that it's the lack of recognition of the causal connection between Gill's condition and the treatment for hepatitis C has been at least until recently, a very frustrating thing for you to have to deal with. Doctor after doctor won't say there's a connection.

STAN: Yes. We were perhaps asking the wrong question for a long time, which was -- and the question was is this connected with hepatitis? And the doctors -- yes, the doctor was saying, no, it's not connected with hepatitis, which was true but it was a half-truth in that it's directly connected with hepatitis because it's a result of the treatment for hepatitis.

So we felt there was definitely a conspiracy of silence about this. There was no acknowledgement. We were being treated or Gill was being treated in London, where we were then living, by the top skin doctors, the top doctors to deal with SLE, and no-one there mentioned this causal effect.

GILL: I find that incredible because every time I go to the dentist or the doctor I decided right at the beginning to tell people or we decided to tell people what had happened from the day we heard, because we wanted to tell the children, because otherwise we had to lie to the children or we could tell the children and say but you've not got to tell everything, and that was having them to lie to people, so we were in the fortunate position, and I have utter sympathy for people not in our fortunate position, that we were able to tell.

But it seems to me that if we could find out that causal link with no medical background whatsoever it seemed incredible to me that doctors working at the top of their field were not telling -- did they not know? You know, it's really difficult for me to believe that this is not common knowledge.

MS RICHARDS: You have exhibited to your statement various papers that you and Stan have found through your own research and we'll just look at one example. It's 363021, please, Paul. It should, in fact, be page 21 in the bundle you have there, Gill.

GILL: Thank you.

MS RICHARDS: We just need to look only at the first few lines of the article. It talks about a presentation in the Journal of Clinical Rheumatology, a case of severe SLE which developed during interferon alpha therapy for chronic hepatitis C and then it talks about:

"This case of life-threatening SLE adds to a growing body of literature about severe systemic autoimmune disease being induced in some individuals."

That's just one of the examples that you have provided to the Inquiry.

GILL: Yes.

STAN: The one that clinched it for us was an article we found and subsequently can't find, which said that children were being found to have SLE and the only children that they ever found to have SLE in America were children who had interferon, so that just clinched it for us, that was proof positive. We've seem to have lost that article now but we were still questioning and wondering but then that article said unequivocally children with SLE have had interferon.

GILL: Have been treated with interferon, usually for leukaemia I think.

MS RICHARDS: And finally and recently that connection has, as I understand it from you, been accepted by SIBS for the purposes of a stage 2 payment.

GILL: Yes.

MS RICHARDS: The interrelationship between your treatment with hepatitis C and the autoimmune disorder has been acknowledged.

GILL: Yes, it has and that was another astonishing day because having been unable to do anything about any of this for years and thinking there's a massive battle in court ahead of us that we probably can't afford, all a sudden a letter came through the post saying if you have these symptoms then we may be able to help you. I was like, "Oh my goodness, after 30 years suddenly it's accepted".

But so, yes, it does seem to be -- it's now much more in the medical literature than even when we discovered it five years ago.

MS RICHARDS: The financial and employment and career prospects, Gill -- sorry, consequences for you, Gill, have been very devastating. You've not been able to either pursue the career you would have wanted to pursue or, in fact, continue to work as a teacher.

GILL: Yes. After I was cured of hepatitis I was very lucky because the children's school offered me a job, because a teacher broke a leg and then that teacher came back but I was kept on and so I resumed my teaching career just almost as soon as I recovered and -- but and I was doing a lot of expeditions, which was sort of my thing, and teaching a full-time table but gradually I found I couldn't do the expeditions because I was -- I had this reaction after them and then other members of staff started offering to cover my games lessons because they didn't like to see the state I got in after them, and then I upset a couple

of heads of department by swapping classrooms every time the sun moved around and nobody knew where I was or the class was, but I got a lot of support from the school, particularly from the head and from lovely colleagues.

But then what I really wanted to do was to teach the oldest pupils, which was my natural sort of thing, and a job came up within the school so I applied for that, I had been there for five years and applied for effectively teacher of English in the senior school and got the job, and that meant I was spending -- I didn't have to do expeditions and everything. I thought that's good because I'm not really up to them now, but it meant I was spending hours on a computer and very quickly it became apparent that I could only spend about 15 minutes on a computer without my face swelling up.

We went through horrible few months where I just went about suppurating everywhere, and by then we were saying it's the light because we tried everything else trying to work out what was happening to me.

STAN: It's a bit like what the gentleman said this morning, where he said you reach a level and you go down to a level, then you go down to another level and then you go down to another level. Gill was a house

master in the prep school, which meant that we lived right in the school. I had a little office. I was self-employed had a little office in the school and looking back on it, in between classes Gill was nipping home and having a bath --

GILL: To calm it down --

STAN: -- to calm it all down.

GILL: -- we thought that was sort of normal.

STAN: And the doctors were looking at, is it the eczema, is it your old fashioned eczema reared up. We were at a loss but because we were in a position to cope with it, my office was being put off mildly by the fact I was having to look after children while you were having at the bath and things, but we were coping with it. But then moving to the senior school --

GILL: Where I was -- you need hours in front of a computer because you are dealing with all their coursework and everything is sent by email and all the reports and all the marking, all the rest of it. So I just got in a mess. I looked awful for about three months and I went to get an appointment.

I said to my GP at that time in Edinburgh was trying to figure out what was going on and he said, "Well, I'll refer you to the hospital, but there's a six month waiting list", and I thought I can't, we

can't wait six months, so we paid for a private appointment and it turned out it was the same consultant so I effectively jumped the queue. I think it cost £200.

He said -- he did --

STAN: He knew immediately what it was.

GILL: He knew immediately. He did some tests. I can't remember if it was blood tests or what it was. I think we had to go back and when we went back, which was I think the same week, I remember he said, "Do you have medical insurance", and I said no and he said, "Well, I'm referring you back to my NHS caseload because you can't afford this. You're in this for the long haul". He said, "I don't want you to go off on Google and get scared", I said, "Well, you're too late because I've been Googling like mad", and he said, "But until we do further tests I advise you to avoid the light conditions that are causing this", which was just normal -- so I said, well, I'd have to resign to avoid light conditions that are causing this and I just remember he went *(Shrugged)*. He just looked at me over the desk. I was just stunned because I'd just, after the whole hepatitis thing, fought my way back up to where I would have been and so I remember I said to him, "Well, can you put it in writing", because all I was thinking was the head will think I've gone mad and so I have the letter saying, "Avoid those light conditions until we find out what's happening".

So then I just went to the head and said, "I have to resign", and he said, "It's all going so well". I said, "It's not really. Everyone's covering for me and I can't use the computer". He was sort of reluctant -- he said, "Well, Gill, you know we'll help you", and I said, "Do you know who's typing my reports", because it was the end of term, and he said, "No", and I said, "Your personal secretary", and he said, "Yeah, we can't have that", so that was me resigned.

But then I -- that was a major disaster for the family because that was our income halved again.

MS RICHARDS: You've not been able to go back to work --

GILL: No.

MS RICHARDS: -- because of the SLE.

GILL: Yes.

MS RICHARDS: Stan, what has the impact been on your work and your business of the years.

STAN: Well, it's -- it has varied over the years but, basically, it has changed the entire nature -- the nature of the business has been just to sort of

survive.

GILL: Yes.

STAN: It's been a hand to mouth existence and still is, in fact. When Gill had her job we were just recovering. We had loads and loads of debts from everything. We were just recovering, just got our debts paid back, we'd just bought a house, and we're just away to sort of say, "Okay, let's get going now", when Gill had to resign again and the children were just at the stage of going to university, in fact, Rory was at university in London and Lucy was heading down to university in Oxford. In fact, she was in London for a course at that time as well.

We could no longer fund their flats or their accommodation and our house as well and Gill by this time was determined not to take on debt, not to take university loans because we had been in debt. We'd just got out of it. It had been horrible.

GILL: I would like to explain, if I can.

STAN: If I finish that point. So basically we then moved down to London. I was fortunate, I got a good job in London. Through circumstances when the crash occurred I was charged with a very, very large Government project. When the crash occurred the project was axed so I was left -- I was made redundant so I was

starting up again self-employed in London, and it's been hand to mouth ever since, with myself, Gill, at some stage Rory, Lucy, Frankie, Zoe all living in the same two bedroom flat, me working in the kitchen or sleeping in the kitchen.

GILL: That doesn't make sense unless we explain that we -- when we knew there wouldn't be any help and I heard this yesterday or today I think, this happened to us, that we thought when this happened we thought this will take 20 years to sort. It's actually taken 30 years to sort, so we've got to plan a life, we can't just put everything on hold for 20 years.

So our big thing was we want to a soak it up, not pass it on to the children, and in a very strange way that made me feel they can't have student loans because that's -- if I'd had a salary I could have paid for all of this and so we just tried to find another way of paying for it. So that was the sort -- I don't know whether these are a good thing or a bad thing. It's like saying, "I will buy a fridge and put it in my bedroom just to put the medicine in it". I don't know if that helps you get through.

I don't think it makes any difference to the result because the people who died were really, really brave, probably braver than me and they still died.

It's nothing to do with the result, it's just to do with how you get through and I do not know sometimes whether these things help you to get through or actually, you know, because they're -- they're not reasonable all of them but then you're not in a reasonable situation.

So anyway that was our -- we felt that we could have lived in -- we could have just said to the children, "Well, look, you're going to have to do without everything. It's not your Dad's fault. It's not my fault", but we wanted to try and make it that life would be the same for them if this hadn't happened, which led to some strange things like living in a two bedroomed flat instead of -- I remember Rory was in -- because I had a salary Rory was in a flat with the lads down at Imperial and when we phoned up and said, "We've had this great idea. We'll move to London and you come and live with us", and there was this long silence -- "and to pay for your sister", and there was a long silence, then he said, "Yes, it is a good idea. It's also the end of my social life", which it pretty much was but that's how we coped with it.

Lucy, I ought to say in that regard, we got -- so we paid for her accommodation in Oxford and we got through to her final year and there was absolutely no money left and so Lucy went to the proctor at the university and said, "Can I commute from London", where we did this little flat and they said yes, so every morning she got on the bus for two and a half hours, went to her classes and then got on the bus for two and a half hours and came back to London for a year, which was -- I remember she put porridge in her pocket. That's what I remember most, making porridge and then you putting it in your pocket.

MS RICHARDS: I wanted to ask Lucy, first of all, a little about the impact of all of this. Firstly, your observations about the impact of everything that your parents had been describing on your Dad.

LUCY: I think that, you know, who these infections have happened to, you know, they have just happened to a random bunch of people and not everybody's born equipped for facing these challenges. I mean, Mum is made of steel. Dad is a mere mortal and it's -- you know, it's sometimes been hard for him to deal with that emotionally and, you know, has triggered him being in bad moods and then everybody has to rally round and bring him back to his courage.

But I have to say that almost all the time Dad has shown extraordinary courage in response to this

situation and he has stepped up and just joined Mum in dealing with what has happened to her, to the extent that Dad lives in the dark too. He was saying earlier that the lights are giving him a headache because he wasn't used to it, and that's meant that Dad has -- especially supporting Mum financially, and he's said a little bit about the difficulties there, both my parents get I would say on average four to five hours sleep a night, and that's not necessarily in one block, just trying to deal with this.

So obviously Mum had fatigue as part of her -- the symptoms of hepatitis C and now gets this kind of flu like thing in response to light situation, but Dad falls asleep all the time.

I mean, I'm kind of quite proud of him staying awake right now. In quite distressing situations he can be standing talking and fall asleep. He can be at something he's been looking forward to and fall asleep. He can fall asleep halfway through a mouthful because his body is just under such pressure. He puts himself under that pressure to step up to the mark. I'm personally extremely concerned for, obviously, for how long Mum might live because we don't know at this stage but I'm also concerned about, you know, how long Dad might live as a consequence of pushing his body

for so long so hard.

GILL: I'd just like to say that Lucy is absolutely right that I know in the situation that we were in, particularly when we were young, as soon as I knew that I was infected I was determined that Stan wouldn't be infected either, although obviously your terror is for your children, isn't it, but I was determined that Stan wouldn't be infected. You can imagine what that meant for us and he has never, ever -- he's just always been right there and even though --

STAN: Not always behaving as well as I should.

GILL: Yes, but always there and that's amazing I think.

MS RICHARDS: Lucy, can I ask you about the impacts on you. You've gone into some detail in your statement and I can read any part of your statement if you don't want to talk about it.

LUCY: I'll give it a go.

MS RICHARDS: You have put it this way in your statement that because your Mum was transfused immediately after your birth you have never had a life pre-contamination.

LUCY: Yes.

MS RICHARDS: What's that meant for you?

LUCY: A few things. The story starts with me, started

with me this afternoon, it's started with me any time Mum's explained how she came to be transfused or any of us have, it starts with me in Mum's book, Lifeblood.

We found out about Mum's infection when I was seven years old so as a seven year old I was told Mum has this disease and Mum and Dad were always very upfront with us so they were very brave and told us exactly what was going on and tried to look brave so we wouldn't be scared by them being scared.

So what I was told was, "Mum's ill and she became ill after your birth", so what I heard being seven years old was, "Mum's ill because of you", and the trouble is that's so clearly not true that if I applied my rational brain to that, it doesn't even get a second -- it doesn't even -- it doesn't even need questioning. It's stupid. But that thought has lived in me and grown in me and everybody's heard the kind of the length of this story and the different parts of it and the financial difficulties and Mum's ongoing health concerns.

Every day growing up and exacerbated by the unusual conditions of mine and Rory's upbringing compared to the other children we knew I would live with this deep, dark feeling that I didn't know what it was, and it wasn't actually until like two years ago when everybody else was living up in Scotland and my husband and I were living down in London and we'd been to visit everybody and I was feeling kind of homesick when we went back down, I thought it was homesickness, and I was feeling very, very bad those two days.

So on the bus home from work -- I'm sorry, I don't know if I'm answering your question.

MS RICHARDS: You are.

LUCY: Good. On the bus home from work I called Mum to say, "Mum, I just feel awful", I had put into place things where I'd say if I think in this very bad way I'm just going to take 20 breaths, I'm just going to count to 20, carry on, but at the end of the second day I just had counted to 20 so many damn times it was very, very frustrating. So I called Mum and asked and said, "I need to speak because I feel awful", and she said can we call back later because Rory and Zoe are just popping round then they are going to the cinema and we'll be able to talk about it then.

But in the mean time I became so distressed, and this had never happened to me before, that I was trying to heat up some soup and I couldn't even get the packet open I just couldn't stay still long enough

to get the packet open and I ended up wailing in quite a lot -- I was alone, so quite alarming to me, I was just sort of -- it was like a disgusting sound coming out of me and I didn't know what was going on, so I was a bit scared.

So I called my husband who was meant to be going to the theatre and said, Please, can you actually just come home because I feel very unsafe and Mum's not available yet". I called Mum and she was upset because Rory and Zoe hadn't managed to go to the cinema because everybody was discussing the financial situation of Mum and Dad going forward, and this was before the little bit of support they are now receiving. I said, "No, you guys sort that out. You call me back", but I was very distressed. I was very upset that they were upset and I was very upset that I was so upset and I couldn't speak to them, and then this was whirling round my mind as my husband was making the soup and I was thinking and all of this, everybody's upset and it's all because of me, and then it just hit me like, you know, a eureka moment and I actually became quite elated because suddenly this sort of thing that had sat and grown, just through the chance of the different things that had been going on that day, had managed to get out and get an expression

and then I could see it and see how wrong it was but how real it had been.

So I don't know what your question was, so go again.

MS RICHARDS: You are absolutely answering it. I was asking you about the impact upon you.

LUCY: Yes.

MS RICHARDS: And your sense of there never having been for you a life pre-contamination and how that had made you feel and you've realised, as I understand it, from your statement and from what you have just said that you've been living with feelings of guilt.

LUCY: Yes.

MS RICHARDS: Irrational feelings of guilt, but feelings nonetheless for many years.

LUCY: Yes, and those coupled with the unusual circumstances of us growing up came together and triggered of when I was about nine years old, although I didn't know this was what it was at the time, a chronic case of social anxiety which I only really -- I only really started to be able to talk about about five years ago, but I'd never heard of it before so I was just describing my symptoms and we weren't really getting anywhere. Then when I had that eureka moment I stopped looking for what was wrong

with me because I thought I'd worked it out and I felt better for a few months but then the anxiety started to come back.

So I started searching again and then I just happened on a book about managing social anxiety and I thought well this isn't me but maybe it might elucidate something and I'd done that many Google searches trying to work out why do I feel so awful all the time particularly because I'm a very extroverted person so it becomes a bit of a vicious cycle of I want to be with people because that gives me energy and makes me happy but when I get to be with people I become very anxious so I want to be alone, then I feel very drained so I want to be with people, so I go round in a bit of a loop.

So I found this book by chance and it exactly described my situation. And I have to say that just the public inquiry happening and being asked to give a witness statement, I decided to put all this down, and then the Inquiry team suggested that I contact the British Red Cross, which I was a bit unsure about but I did, and then they suggested I speak to my GP which, again, I was unsure about -- you may not wonder why -- but I did speak to my GP because she's a very nice lady and she referred me for a mental health assessment and I'm just about to start CBT.

So all of the Inquiry happening has really helped me, you know, put words to this and receive the right treatment and it has been -- I mean, I'm just in a different place from a year ago with all of that.

I probably should say on this point that most people who know me know nothing about this. I guess that's one of the things of social anxiety, is the last thing you want to -- because you feel that people can see that there's something wrong with you, so you think. I suppose for me it was maybe this guilt thing that I didn't want anyone to see. The last thing you want to seem is not totally fine. So I have spoken to some very good friends about it recently but, you know, that's 20 years after it started and many friendships have been that long and they've not known anything.

MS RICHARDS: One of the observations you have made in your statement, I think in one form or another all of you have made it in your witness statements, is the effect of what you've described as the silence of officialdom. Can you explain a little more about that.

LUCY: Well, there's two sides to that, I think. The first one is that, as a seven-year old, taking that on

my own shoulders, Mum's illness and everything that followed, I think if somebody else had taken responsibility it might have been clearer to me that it wasn't my fault.

Then ... I forgot my two things but something else I would say is when the public hearings in London started, I had this feeling of, "Well, I can't have caused all of these stories". So that was relieving to me.

It will come back to me, my other point.

MS RICHARDS: One of the points -- and it may or may not be the one you were thinking of Lucy -- but one of the points you make in your statement is there's been an inability for you to talk about this because other people know nothing about it.

LUCY: Yes, that's exactly it. Because it's not been officially acknowledged, it's very difficult to bring up because you sound slightly, as Mum was saying, kind of crazy, like nobody knows what you're talking about, which is very isolating. And I think that was why the beginning of the London hearings was a bit of a watershed for me because then I could refer to it, I could seek, you know, other people to know about what was going on for me, which I couldn't do before, because I felt that if they hadn't heard of it,

I could say, "Have you not been reading the news?" whereas before it just -- you know, what do you refer to? It's not happened.

MS RICHARDS: Rory, can I ask you, you've again described in your statement very vividly the impact of again everything that we've been hearing about on your upbringing and indeed on your young adulthood and you've put it this way, that every decision that's ever been taken in your collective family lives has in some way or another been affected or driven by the fact of your Mum's illness and the consequences of that illness; is that right?

RORY: Yes, that's absolutely correct. I've been throughout my life utterly blown away, astounded, by the fact that in this situation of adversity Mum and Dad's driving force has been to not let this infected blood impinge on the next generation and that's an impossible task. It is not possible.

It's influenced every decision they have made, the bigger life decisions. You know, we've spoken about the smaller mundane daily decisions which are also affected and I've -- every decision I make now is in some way trying to live up to the standards that they set for themselves and trying to pay back the opportunities they've given me and my sister.

And, you know, that night talking about the finances and planning that Lucy referred to a moment ago is an example. We make these plans about the future and finances and life and jobs and family and we make all these plans but they don't work. There's not an answer. There's not enough money, there's not enough time. There's not enough support.

So I know that really upsets my parents that my wife and I are -- sorry. My wife and I are trying to start a family and plan our lives but we are -- you know, we are also planning how to support my parents in their retirement which I know they find incredibly difficult to hear but it's just the reality of the situation we're in.

So every decision you make is affected by the infected blood.

MS RICHARDS: You feel a sense of responsibility to look after your parents.

RORY: Absolutely.

MS RICHARDS: But a lack of confidence in your ability to do so.

RORY: Yes. As I say, it's a problem without a solution and the only solution that I can offer is to raise the standards a bit higher or to try a bit harder, to put more effort, to just keep battling away and just try and make it work and so that -- the consequence of that is that one never succeeds. One never achieves anything.

I really struggle with confidence because -- well, that's the outcome of it.

GILL: I obviously -- my children -- I think Rory is right. You cannot cope with something like this and obviously that's really upsetting for Stan and I because Rory has achieved so much. If I told you his CV, it is astonishing. He's put on concerts in Buckingham Palace. He did the Queen's Jubilee. It's astonishing. But he feels that it's not good enough and when any time we say to him "that was really well done" he won't -- it hurts him to hear it because it just presumably, I'm assuming, this feeling wells up of "but it's not good enough" and that's because -- and I think that -- and what Lucy says is absolutely right as well that Lucy has suffered on her own for 20 years and none of us knew. And all our efforts to say, "Right, we're going to soak this up and it's not going to hurt the children" have totally failed because you cannot cope with something like this.

And so I think what Rory and Lucy say is absolutely true, that had there been an official recognition, we would have had more normal lives

because we wouldn't have had to set high standards. We could have said, "Oh, yes, we're those people" and then the bar would have come down. But nobody said that. It was just match your friends with both hands tied behind your back and you can't do it. It doesn't work.

So both Lucy and Rory and Zoe and Frankie have been absolutely amazing in continuing the collegiate way we make decisions and the way we support each other which started -- well, I think it was sort of the way we naturally inclined, but when the letter came we told them straight away, "Now we're going to decide everything together, if you've got to be tested, you know, and here's a chance to do all the things in the school that you can't do anymore and what do you want to do?"

So we made all these decisions together and I remember when we first met Zoe and Frankie, we were having one of our family discussions trying to decide, which is always how we can cope on not enough money, and I always remember -- so they tend to go on and on and on because there isn't actually a solution and I always remember -- I hope you don't mind my saying -- but Zoe getting out of bed, saying, "Oh, what's happening? I'd better join in" and I felt,

I've never forgotten it, I felt so supported. And now the boot's on the other foot. The next -- Lucy and Rory and Zoe and Frankie certainly supplying all the emotional support that I hope we used to supply them.

And, as Rory says, we make plans because we now have a little support as of last December, we were able, having sold our house twice to cope with the situation over the years, we were able to buy a little house (very far away to keep it cheap) and the plan is that Stan will work until he's 75 and that will -- by then, we'll have -- I mean, it was amazing. We found a bank at Christmas that would give us a mortgage and Stan is 63 and he will have paid for the house by the time he is 75 and then he can stop and that is -- we're able to do that. We were going to do it anyway but, as Rory said, the plan did not work. It just didn't -- it depended on me writing a bestseller, which is, like, not going to, but now we think we might just squeeze through if we basically do nothing but work as -- I mean, Stan just works every day of the week and every evening.

He actually said when we were driving down to Edinburgh last night, he went, "We've got a day off tomorrow". I'm not sure you're meant to look at it like that but what he meant was "I'm not stuck in the office as I have been month in, month out".

STAN: Switched my phone off.

GILL: Yes, he meant I'll switch the office phone off.

MS RICHARDS: Gill, it may not be a bestseller yet but you have written your family's story in this book Lifeblood. What was it that drove you to write this?

GILL: Really resigning because that drove me to write any book because I'd -- I've always written on and off. My aim was in creative writing with Douglas Dunn. He won the Queen's Medal for Poetry about two years ago/three years ago. He's my supervisor.

And so it's always been -- one never writes for money because you would literally be better off buying a lottery ticket but it's always been something I wanted to do and then, when I resigned, it was something I could still do because we found -- well, initially the family helped me because I couldn't use a computer but you can write in a dark room. In fact, it's amazing. You can't read in a dark room but you can write in a dark room and when somebody puts the lights on, they can read it. And then we found -- initially, the family helped by typing it and then I found a student who was sufficiently adept on a computer that she would type it up fast enough that we could afford to pay her. So we paid her by the hour but she could do -- what I could write in a day, she could type in about three-quarters of an hour. So we could afford her and she was scrupulously honest.

That's how I wrote Lifeblood: in the dark with Amy typing it up. Well, with the family to start with and then Amy typing it up.

And -- so I've forgotten your question now. Sorry, could you remind me?

MS RICHARDS: I was asking you what prompted you to write it.

GILL: What prompted me to write it. So before I started writing Lifeblood, I'd resigned but I could still write and so, as Rory said, we've got a plan, it's a really sketchy plan but the plan is that Dad will keep going and Mum will write a book and if that works, Dad can stop. I'd wrote a novel which actually got -- I mean, I got an agent quite quickly but, to my family's despair, I write -- I don't write -- I can't do scary stuff. I've had enough scary stuff and so I'm not the most commercial of writers. But anyway the agent, I was despairing to the agent one day and she said -- and I actually heard myself say, "You see, the thing is because of this blood transfusion I haven't got anything to write about" meaning my life has been so constrained. And she said, "What blood

transfusion?" and when I told her, she went, "Well, why don't you write about that?"

So I went home and said Jenny wants me to write about all that's happened but I don't really want to, you know, write about that. And immediately all the -- I don't like to call you the young people -- but said, "Mum, you have to write that. You have to write that" and --

RORY: For all the people that can't, for all the people that aren't here to write it.

GILL: Yes, exactly. So I started writing it. I wrote our story and that got a publisher. So just the family story got a publisher but the publisher said you have to put that in a wider context, so you have to rewrite the second half with putting it in the context of what's happening.

It was really difficult to work out how to do that. I rewrote the second half four times and eventually I just thought, well, the only way to do it is as I discovered it. So that involved just telling the story of -- because when she said "you'll have to put it in a wider context", I went off to the British Library and I had some references to newspapers so I thought I'll start with that. So I went to the British Library and it's not there -- now it's all

computerised in Euston Road, so I can't access it, but I caught the last six months of everything still being on microfiche in Collindale, which meant a very long tube journey, but as Rory will explain, tubes are dark. Rory understands that our eyes adapt to light. He's explained to me our eyes adapt to light, so it's actually very dark in this room compared to being on the ground floor but your eyes adapt so it doesn't seem that different.

The scale -- I mean, the eye is amazing. So on a sunny day it's about 20,000 lux and and on a grey winter's day it's about 40 lux and yet your eye just adapts and you think, "Well, I can see, it's daytime" which is why I'm much more able to go out in the winter than in the summer.

So on the tube, I was saying, "Oh, there's loads of lights" and Rory went, "Mum, the tube is dark, you can travel on the tube" and it transpired that was true. So I could go to the library and everything was on microfiche, which is very dim. In fact, you can't read all of it, it's so dim. So I was able to do the research for the book. And then I thought -- I mean, I tried photocopying newspaper articles and peppering the book with them. That was the result I wanted because it was done really quick but the publisher

said, "No, that's not a story".

So I thought, "Well, the only thing to do then is just tell the story of finding out" and, in fact, that worked very well because I didn't know that -- I'd no idea of the scale of this contaminated blood disaster until I did that research. I didn't even know -- I mean, I didn't know the numbers, I didn't realise it had been in the press long before I had my transfusion. I was coming home every day saying, "Listen to this, look what I found". And, I mean, it was very haphazard research because I'm not actually physically capable of doing proper research now but it was very suited to me and produced a sort of time-line of events which allowed me to finish the book.

MS RICHARDS: That concludes my questions for you but I wanted to ask each of you if you had anything to add and starting with Lucy.

LUCY: I just wanted to read the following.

The truth of what has happened will be littered with missed opportunities for thousands of doctors and civil servants to take responsibility to ameliorate the situation in thousands of different ways. I had a similar opportunity today. I could share the impact Mum's blood transfusion has had on me to add to the complete story to help the public inquiry team.

This was hard to do, not least because of the stigma surrounding mental health issues in our society. But I have taken responsibility and done it.

So I have two questions. How different would the total story have been if every opportunity afforded to all doctors and civil servants to ameliorate the situation had been taken and where are their voices now, clamouring to admit their own faults and apologise? I would like to single out the Scottish Health Board who, speaking at the opening of these hearings, failed to apologise.

So in summary, and possibly outwith the public inquiry, just human to human I would like to ask all doctors and civil servants who have in any way been connected to the infected blood disaster to consider, "Could I have done more?" Thank you.

MS RICHARDS: Rory, is there anything you would like to add?

RORY: Yes, thank you. I'll just read this out.

Growing up as a member of our family, the culture of silence from the NHS left us feeling truly alone and that we somehow were supposed to shoulder the guilt and hardship of our situation and to take responsibility for rectifying it, an impossible task. The only outside support we received was huge

generosity and care from a handful of educational institutions. Once we received the letter, we became aware of the figures surrounding the numbers of infected people. But this was not examples of shared experience and was of little comfort.

I'd like to thank the Inquiry for bringing this disaster out of the silence and acknowledging publicly what has happened and for focusing on people's stories. However, every article I read always quotes the same figures that were so meaningless to me for all those years. Let me try to give you a more meaningful sense of scale.

The estimated number of people who have died as a consequence of infected blood is akin to the number of British soldiers killed during the evacuation of Dunkirk and is akin to the number of people killed when the Twin Towers came down. To appreciate the scale of the number of people infected and affected, one must deal with disasters such as Chernobyl. I give these examples not to shock or sensationalise -- the evidence is shocking enough -- but to help those in a position to make a change to quantify the levels of ongoing suffering.

I want to take this opportunity to plead with the State, Department of Health, the NHS, hospital

staff, GPs, and the Inquiry to show the same levels of support and care that those educational institutions showed our family and to implement the medical, emotional, mental health, and financial care that has been missing for all these decades. Thank you.

MS RICHARDS: Thank you. Stan.

STAN: This is a day I thought I would never see and this Inquiry is more than we ever thought possible. So thank you.

There's only one course of action when you make a mistake. You should admit it, you should face up to it, you should rectify it and you should do it immediately. With respect to infected blood, Britain -- not just the NHS, Britain -- did not do this and, as a result of this, thousands of lives have been irrevocably altered and, in some cases, destroyed.

This Inquiry and Sir Brian are Britain's best hope that this lesson will be learned.

MS RICHARDS: Thank you. And Gill.

GILL: I'd like to start by paying tribute to the families for whom my worst nightmare is true: people who have lost their children. I cannot think where their courage comes from and I admire them so much for helping the Inquiry.

And I wanted to lead on from that and talk about the absolute terror that one feels in this situation and, as you know, as you've heard today, I was terrified I'd infect my children. In fact, I nearly killed them when I crashed the car. I was too ashamed to go for help when I burned my daughter. None of that -- well, all of it was either made worse or caused by the official silence that my children and husband are talking about and that is unforgivable.

I don't know how the mistakes came about that brought this disaster (that's for you to decide, Sir Brian) and it may be that there are certain circumstances or excuses that I don't know about.

But I can't see any reason for the silence that we have lived with. I can't see any reason that we have lived alone as a family until now. And when people ask me if I'm angry, that's what I'm angry about, that we were put in danger when we didn't know to take precautions, when I didn't know not to drive the car, and we lived in fear, fear that we weren't coping and our children would be taken away because we didn't know why we weren't coping.

All of that was made worse or brought about by a lack of responsibility at high level by the Government or by the NHS. I'd like to thank my family because they took that responsibility. For all the nice things they say about me, they took it and they never let it go when everybody else, government after government said in my research that it was too big a responsibility for a government to take on. Well, since my son was three and my daughter was a baby, they've taken it and my husband, despite the distress it's caused him, has never let it go. And thank you everyone involved with this Inquiry for relieving them of that because I have seen the happiness that they have felt when this Inquiry was launched and that happiness has grown as the Inquiry proceeded.

And I feel now that I haven't managed to cope with this but that you have brought them the relief that I -- already you have brought them and we hope for the future the relief that I so much wanted to bring them but I just couldn't. Thank you.

MS RICHARDS: Gill, I am just going to ask Mr O'Neill if there's anything further.

GILL: Thank you.

(Pause)

MS RICHARDS: There are no further questions. Thank you. Sir.

SIR BRIAN LANGSTAFF: Can I make three observations. The first is that I have read a lot of statements --

I have by no means read them all but I will -- and a lot of those statements are from those who suffered from hepatitis and who almost to a man or woman had interferon treatment to cope with it. I have kept no particular count but there are three or four certainly who have described light sensitivity as a consequence, but I thought you ought to know of that.

GILL: Thank you.

SIR BRIAN LANGSTAFF: If it should be the case that it is substantiated, as it may well be, that interferon treatment may in some cases give rise to light sensitivity, I certainly would regard it (and I would be difficult, I think, to shift from this point of view) that it is a consequence of having been infected with hepatitis C, and if that hepatitis C was a consequence of infected blood, it was a consequence of that.

GILL: Thank you.

SIR BRIAN LANGSTAFF: That's the first.

The second is that you have each in your own way made a powerful plea for those who might have said sorry at an earlier stage to have done so. It is right, I think, that I mention again to you, and in fact to those who are listening, that I heard Eleanor Grey QC for the Department of Health say that wrong

had been done when she addressed me in September last year and that I think just needs to be said as a matter of record, although it already is.

But, thirdly, can I say that you, Lucy, described you, Gill, as a woman of steel. You described the whole experience of having hepatitis as scary. I suspect it may have been quite scary, despite your welcoming the Inquiry and wanting to be here, to decide to come here as a family and lay bare what are your own different perspectives on what has taken place, and that seems to me to take a huge amount of courage. It has affected you all. I suspect it probably has affected us all.

Can I just say thank you. We can't achieve what we would like to do in this Inquiry and get a proper perspective of as much as we can without the evidence of people like yourselves who are prepared to take the scary step that you have. Thank you.

GILL: Thank you.

SIR BRIAN LANGSTAFF: That concludes the evidence for today. Excuse me for talking while you are going back to your seats. Tomorrow 10 o'clock and what do we have in store tomorrow?

MS RICHARDS: We have three witnesses tomorrow, sir: Pamela Pennycook, Alice Mackie, and then our third

witness is anonymous.

SIR BRIAN LANGSTAFF: Thank you. 10 o'clock.

(5.15 pm)

(Adjourned until 10.00 am the following day)

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