Wednesday, 1 May 2019

(10.02 am)

SIR BRIAN LANGSTAFF: Good morning everyone. Good morning Ms Richards. The first witness we have this morning wants to be known as Caz, does she?

MS RICHARDS: Caz Challis.

SIR BRIAN LANGSTAFF: Ms Challis, would you like to come forward.

CAROLYN CHALLIS, affirmed

Questioned by MS RICHARDS

MS RICHARDS: Caz, in 1992, if I can ask you to think back to then, you were undergoing treatment for cancer, Hodgkin's disease, and in the course of that you had three transfusions.

A. I had the first transfusion prior to diagnosis, because I was 24 weeks pregnant and I had pregnancy-related anaemia, and they did two needle biopsies in the months before that, in the February, trying to ascertain what was wrong with me, there was a lump in my groin and the two needy biopsies were not enough and so they needed to do a surgical biopsy which I had been resisting because I didn't want to have a general anaesthetic because I was pregnant. And finally I had to give in and, in order to get my haemoglobin up, they had to give me two units of blood.

Q. That was in March 1992?

A. That was March 3, I think.

Q. Then you had two subsequent transfusions in May 1993 and July 1993?

A. Yes, that was after two six-month rounds of chemo.

Q. I think it's also right that in the course of the treatment that you underwent for your cancer, you had a range of medical interventions: biopsies you've referred to, blood tests, Hickman lines, and so on?

A. Hickman lines. I had two six-month rounds of chemo; so there was a Hickman line permanently in place for about a year.

Q. Were you at the time of any of those transfusions given any information about any risks of infection?

A. Not that I remember.

Q. Now, in 1993, you were diagnosed with hepatitis C.

A. Yes.

Q. I understand around that time you also developed Jaundice. What can you recall about that?

A. I was screened because I had two six-month rounds of chemotherapy that were not enough. I was then screened for a bone marrow transplant. Had I never had to have the bone marrow transplant, I probably never would have found out that I had Hep C at all, but because they had to do intense screening ... so just prior to the bone marrow transplant, I was told I was hep c positive and after the bone marrow transplant, I was seriously yellow and very, very ill with jaundice.

Q. At the time you were diagnosed with hepatitis C, you obviously had a lot else happening in terms of medical treatment. You were about to have what you describe in your statement as a high dose of chemotherapy.

Can you remember what, if anything, was your reaction to being told that you also had hepatitis C?

A. As far as I remember, I was told by my bedside in quite a matter of fact way, but a serious way, but as far as I was concerned I was going into a bone marrow transplant room with 30 times the normal dose of chemo fighting for my life. I had a 50 per cent chance of coming out alive and hep c was the last thing. It literally went in one ear and out the other.

Q. Can I ask you then to describe how the hepatitis C began to affect you both physically and mentally?

A. It's hard to separate it from the recovery from a year's chemo and then a bone marrow transplant, but I did start to pick up in the years after the bone marrow transplant, probably until around 2000. So I sort of was on an upward slope and then I started to go on a downward slope with the hep c.

I started to -- I'd lost so much energy through all the cancer chemo and my bone marrow being suppressed through that, it was hard to know what was happening and I probably didn't give enough attention to the Hep C symptoms because I thought I'm still recovering from the chemo. But I began to lose even more energy and have dietary intolerances and brain fog and have to cancel plans, not make plans -- just chronic, chronic fatigue.

Q. Can I ask you a little about the brain fog. You described it in very vivid terms in your statement and I wondered if you could give some kind of sense of how that affected you, how it felt.

A. It would be hard to connect the synapses in the brain. It would be hard to find words. You'd know what you wanted to say but you couldn't find the words. I think I once described it as wading through treacle. You know, I've got quite a fast intellect normally but it was just like wading through treacle trying to make conversation sometimes.

One time I drove a couple of miles to my daughter and her baby and I had brain fog, and I was so poorly and I got there at a play centre and I sat and I remember my granddaughter was very small. She sat looking at me saying, "Grandma, why aren't you eating your ham sandwich?" And I just -- I couldn't eat. I couldn't think straight. I had to go home early and as I pulled into my driveway, I just smacked the car on the side of the driveway because my cognition was so out that I couldn't even drive properly and it was my home, but I pranged the car. In fact, I pranged the other side a few weeks later.

Q. What about the fatigue, the chronic fatigue? Again, are you able to give a sense of what that was like?

A. The fatigue is so deep and so profound that no amount of sleep fixes it. You wake up in the morning feeling jet-lagged, feeling as depleted as you did before you went to bed. People will say, "Well, just go and have a rest. You'll be all right", and it doesn't work like that.

Q. I think the way you put it in your statement, Caz, is the fatigue was not helped by sleep, it wasn't something you could push through. It was at times completely incapacitating, couldn't even get out of bed.

A. You couldn't push through it with willpower. I can remember coming home from art school. I tried to do an art course that I had to give up because of the fatigue. I remember coming home one day and having to

go upstairs and just lie straight in my bed, and we had people coming a round for a film night and I couldn't do anything about it. I couldn't move and I couldn't actually turn over in bed. I couldn't find the energy to turn over in bed. It was such a deep fatigue that I -- it's hard to explain it.

Q. As the symptoms progressed, I understand you began to experience a range of other effects of the infection, fibromyalgia, a sense of near permanent flu; is that right?

A. I had to stop going to yoga because I'd have muscle aches afterwards, for days afterwards, if I did anything strenuous. If I did 20 minutes' weeding in the garden, my arms would hurt for days afterwards.

Q. You mentioned digestive upsets, not being able to eat, weight loss.

A. Huge intolerances and not being able to eat after 6 o'clock at night. I couldn't have onions. I'm still -- have to be incredibly careful around food.

Q. What about the effects of the hepatitis C on you mentally?

A. I think once I registered it and realised that it was something serious, once I was recovering from the bone marrow transplant, I think I just felt ... just really frustrated that I'd got through something as serious

as cancer, and the cancer came back five years later, so I got through two life-threatening rounds of cancer only to be given another life-threatening illness. So I kind of -- I'm a bit of a not a "why me" but a "try me" person, so I just battle through it anyway.

Q. Can you tell us what the impact of this and of your infection was on family life? I understand it had a profound impact upon what you were able to do in relation to your children.

A. It was absolutely massive. Yes, my son (who's sitting here), who I was pregnant with when I was diagnosed, he was fostered out at six months old because of the cancer chemo. But the hep c impacted my energy so much that when I should have been recovering and taking my three children back and being a good Mum again, I was constantly having to -- not attending, I didn't attend my daughter (who's sitting here as well), I didn't attend her graduation, which broke my heart that I couldn't travel from Devon to York at that time.

The fatigue means you don't do so many things that you would like to do with your children and you don't give them the quality of care that you'd like to give them and, because of the cancer and then the hep c, they were farmed out. They were -- [he] was in

and out of foster care for years, backwards and forwards. We co-parented and we held it together but it was hard.

Q. I think there came a time when you became a grandparent but that the infection and the fatigue again impacted upon your ability to perform a caring role for your granddaughter.

A. It meant that I couldn't do the childcare that she would really have liked me to have done and sometimes she would read it that I didn't really want to.

Q. Then more broadly in terms of your private life and relationships, what impact did the infections and your illnesses and the fatigue have upon those relationships?

A. Absolutely massive. I was in a relationship when I first did the interferon treatment which I tried in 2004 but, because of my suppressed bone marrow from the bone marrow transplant, I only lasted 12 weeks on it. But my partner at the time was keen paraglider and kite surfer. We hadn't been together very long and I don't blame him but it was very, very hard that he chose not to stay with me, he chose to go off to kite festivals and to leave me to it, and with the Ribavirin as well, which causes depression, I was in a very, very, very dark place for some months. And having to make a two-hour trip to hospital every week as my blood counts were falling and I couldn't get treatment in the surgery in the village, so I had to keep going to Plymouth and, yes, him not being there for me ... and then --

Q. And then you subsequently married?

A. I subsequently married in 2006 and I was having some good days then and was completely honest about everything. But over the months and years, my energy dropped away more and more and more and more often he was working and he was coming in at 9 o'clock and saying, "Come on, let's go for a drink", and I couldn't move. It began to cause friction and finally I think in 2010 we separated but we were still trying to keep our marriage together by not living together.

Then in 2014 when I began the Epclusa trial, the clinical trial Epclusa, we agreed to officially part. So I kind of set him free to have children because I couldn't give him children, set him free. The bone marrow transplant had rendered it impossible for me to have any more children, and he was younger when I married him and then he decided he did want children. So I set the divorce papers in progress as I began the treatment for the hep c. So that was very sad but ...

Q. You also describe in your statement your infection and the associated symptoms impacting upon your career and your educational aspirations. Can you tell us a little about that.

A. Yes. When I got out of the bone marrow transplant, there had been no support for me. I was pregnant with cancer and I'd asked for support and there was no support at all. So as soon as I recovered from the bone marrow transplant, I set up a cancer support group in my nearest town which I ran for ten years. So in the course of doing that, I trained to be a counsellor and -- sorry, can I just ...

Yes, so I trained to be a counsellor and the placement on my course was working with people with alcohol dependency and so I continued doing that after my training and after I closed the cancer support group, because everybody in it was dying and it was just too painful, and the best -- the closest friend I was running it with was also going to die from her cancer, so we closed it before she died.

But then I carried on with the counselling and was working for an organisation called ALCAS and then for Addaction in the hospital in Bideford and I just loved it, absolutely loved it, but I'd come away and I'd see two or three clients in a morning and I'd come

away so drained that I couldn't function for the rest of the day. Then within a certain period of time I realised I just wasn't up to it anymore.

Q. You say in your statement it was about 2003 you had to stop all of your counselling work because of the strain on your health. You did some occasional work after that, I think, at a pottery studio but then you had to give that up in 2008.

A. And I did a holiday let cleaning for six months or a year or something. I used to go and do three hours cleaning. I couldn't move for the rest of the day and that caused friction in our marriage because he was free on a Saturday and I would do that all Saturday morning, I used to take my son with me to do it, and he'd get upset because I couldn't move. I literally could not move for the rest of the day.

Q. Then you've also talked more generally in your statement about making job applications and repeated rejections which you attribute to your health.

A. I applied for care work and never had any word back and, of course, I'd be upfront. I would tell them about my hep c. I'd never hear back.

Q. You mentioned earlier the art course that you were doing, art college. What happened in relation to that?

A. I'd always been torn in my life between going to art college, I had an unconditional place at art college when I was 18 in Ipswich Art School, but it meant living at home with my parents for another year and I wasn't -- I needed to spread my wings a bit. So I went to university and did a psychology degree.

So all my life there's been two branches of the psychology and the art. So at that point I decided to go back to art school and do my art degree. And I was just so, so tired. It was up two flights of stairs. It was a 25-mile drive, up two flights of stairs, and by the time I'd spent a day -- I loved printing. I was doing prints called "grin and bear it" or "put a brave face on it", all to do with my illness and how I present to the world and what's going on inside, how we wear a mask, and by the time I'd done a day in the print room I'd come home and I was good for nothing for the family. I couldn't move and eventually I had to give it up.

Q. Now, you've mentioned the cancer returning. I think that was about 1998?

A. Mmm.

Q. You had to have various treatments, radiotherapy, surgery in relation to that. But there was an impact also, I understand, on your hepatitis C at that time.

Can you tell us a little about that.

A. It was about the same time probably that the hep c started to kick in but it was so hard to separate it all. Yes, I was doing my counselling diploma then because they gave me a room in the hospital (because it was so far for the radiotherapy, I used to stay in the hospital for the week days), somebody else looked after the children, and I wrote my essays in there. And, yeah, it was about the same time that the hep c started to really sap my energy. But it's very hard to separate.

Q. You tried various treatments in relation to the hepatitis C. You've mentioned interferon. Was it a 48-week treatment process?

A. I did -- I lasted for -- I think I did 12 weeks or 14 -- at 14 weeks they pulled me off because my blood counts would drop so low. So I went for acupuncture, I took traditional Chinese medicine, milk thistle, all kinds of herbs and supplements, researched it. I was buying in from America packages of herbs but I couldn't afford it. Because I was on benefits, I just couldn't afford it and I couldn't get the support from Skipton.

Q. We'll come on to the Skipton in a moment but just in terms of the side effects from the interferon

treatment that you attempted and had to give up, what kind of side effects did you experience?

A. From the interferon? Again, it's hard to separate from all the chemo damage but the Ribavirin knocked my blood counts really, really low. The interferon quite possibly had lasting cognitive effects, might have been connected to the fibromyalgia. It's difficult to know.

Q. You describe it in your statement in these terms:

"I would describe the effects of being on these drugs as like falling into a deep and terrifying abyss of pain and despair", and you told your doctor over my dead body would you ever take interferon again?

A. That was when I was on the treatment and my partner left me to go paragliding and, yes, I've never been -- I'm not a depressive person, I've never known depression, but it was like a crawling pit. I was seeing demons. I was hallucinating. I was doing artwork at night drawing monsters and ... horrible, horrible, horrible treatment.

Q. So it was about ten years before you were able to attempt treatment again for the hepatitis C?

A. Yes.

Q. You started a trial of Epclusa but discovered, I think, that you had been to start with in the

placebo group?

A. Yes, I was searching for trials. I tried for a trial, an AbbVie trial in London. My consultant knew I was searching and he was actually running a trial and so he said, "I think this would be good for you", and I said, "No, no, no, I want these drugs". He said, "These are better", so I was ringing the research nurse every single week so she wouldn't forget me and made sure I got on it. But, yes, I got the placebo run the first time round.

Q. But second time round you were --

A. I knew if I was the one in six that got placebo, I would get the real one but the problem was I wanted it done by the January, because my daughter here was getting married in Greece in the August and because I got the placebo and then three months' treatment, three months off, then I had to re-screen to be accepted again, it meant that I didn't finish treatment until about two or three weeks before the wedding, but I just got it in.

Q. With the second treatment course on Epclusa, how did you cope with that?

A. It was okay. I had quite a lot of fatigue with it. I don't know if that was just the body working hard to expel the hep c and I started to get tinnitus six

weeks in and I have mild to moderate hearing loss now and I still have the tinnitus. I can't say it's definitely connected but I think so.

Q. You say in your statement other members of the trial also experienced similar hearing problems in consequence of the treatment?

A. I have come across other people, because I work on a very big international hep c support group, I'm an admin, it's got 6,000 members so I see a lot of people on all the different medications and other people on one of the drugs, Sovaldi, do report tinnitus.

Q. Now, this treatment was finally successful in clearing the hepatitis C virus?

A. Yes, it's magic.

Q. I think that was February 2016. You say you were declared, cured and discharged. But the way you put it in your statement I wanted to ask you about, Caz. You say being discharged over the phone was a big shock. After 24 years of constant appointments and care, you felt adrift to start with.

A. I did, I did, because I was discharged by my research nurse in a phone call and she rang me up and said, "You're cured, that's it, and you don't need to come to the clinic anymore" and my hepatologist, Matthew Cramp, and my haematologist, Mike Hamnon, had been working together all those years in my care and I'd had felt very held and very safe, brilliant, brilliant, brilliant doctors both of them. I can't thank them enough for all their care but, yes, I suddenly felt very -- because I didn't have fibrosis I wasn't eligible to have the follow-up care.

Q. You have asked, I think, from time to time since then for there to be repeat fibroscans so that you can either find out if there's any liver damage or be reassured if there's not.

A. I asked a few months ago if I could have --

Q. You were told no?

A. I was told -- well, I went to my GP to ask and he said, "Well, where" -- he was brilliant he said, "Where would you like me to ask?" He didn't know anything about hep c. He didn't know anything about the scans but he was willing to learn. And I said, "Well, I'd like to go back to the liver unit", so he sent a letter there but I got the reply back with, "You don't need one because you didn't have fibrosis".

Q. Counselling: during the many years of treatment you had did you ever get offered counselling?

A. No. I did for the cancer but not the hep c.

Q. Do you think that would have been useful?

A. Possibly in retrospect -- possibly. I mean I had peer counselling as I was doing my counselling diploma but I don't think I particularly brought the hep c to it. I think it might have been useful.

Q. You mentioned in passing the Skipton Fund and that's what I wanted to ask you about now. You and the consultants who you've mentioned have had little doubt over the years that your hepatitis C was as a result of the transfusions and the treatment you received.

What happened when in 2004, when you were a single parent, you had your three children dependent upon you, you applied to The Skipton Fund for help. What was the response?

A. "No. You don't fit our criteria. Our cut-off date is September 1991."

Q. I'm going to ask for some documents to be put on screen, Caz, so we can have a look at some of the exchanges you had with The Skipton Fund. If you just give me a moment. *(Pause)*

So the first document, Paul, is 622007, please. Could you highlight the handwritten passage on the form, please.

Have you got that, Caz? This is in extract from the application form and the handwriting is that of your doctor, your consultant:

"This lady received a number of blood transfusions from 1992 to 1993 when undergoing chemotherapy for Hodgkin's disease. Whilst infection occurred outside the timings in this form, no other risk factors are present and the hospital treatment and transfusions are thought to be the cause."

So that was your consultant's supporting confirmation in your application?

A. Yes.

Q. Then if we could have document 8, please, Paul, so 622008, this is the letter you received from The Skipton Fund 14 December 2004, is it?

A. Yes.

Q. "It is with regret I must advise you that your doctor has advised us that the date of infection was in February 1992 and accordingly outside the scheme guidelines. In the circumstances I must advise you your claim to the fund has been declined."

What was your reaction and response on receiving that?

A. To fight them.

Q. I think if we go to document 9, 622009, we can see a letter from the Skipton to Dr Hamnon who is one of your consultants?

A. He was the haematologist who took me through the bone marrow transplant.

Q. We can see from the first paragraph of this letter dated 18 February 2005 that Dr Hamnon's obviously written in support of your application to the fund and the response is:

"As I am sure you will appreciate when the Department of Health established the Fund last year expert specialist advice was taken regarding the mechanical aspects of the Fund and this included the screening of blood products for hepatitis C. In this respect the information provided to the fund by the Blood Transfusion Service was that all blood products after 5 September 1991 used within the NHS will have been screened for hepatitis C."

Is that still on the screen because mine's gone down.

So that was again the rebuttal from the Skipton Fund to Dr Hamnon. You I think appealed that.

It is 6220010, please, Paul.

I hope you will see a letter from you dated 25 March 2005. Do you have that? It should be coming up now. So this was your appeal to The Skipton Fund. You've referred in the first paragraph to the letters of support from your specialist consultants and you've said this in the last part of the first paragraph:

"All three of these consultants are in full support of this application and share the professional opinion that my hepatitis C was indeed acquired from blood products received by me during treatment in 1992 for cancer."

Then you have talked about living each day with the malaise of being hepatitis C positive, the struggle to get through each day, single parent of three children unable to work. Then you say this with in final paragraph:

"To impose an arbitrary cut-off date which excludes legitimate cases such as my own seems merciless and mechanistic when dealing with people who are in real trouble with this insidious disease."

What was the outcome of that request for an appeal or review?

A. Another rejection.

Q. Then if we have document 11, please, 622011, Paul, so we're two years further on now, 2007, and you are still trying to ask The Skipton Fund, is this right, if they will reconsider their decision?

A. At this point I was desperate. There was no treatment for me and I was absolutely desperate to be able to buy these herbs in from America to try and cure the hep c myself because there was no treatment in the pipeline and the only way I would be able to do it

would be if I was granted the £20,000.

Q. If we can look and see you've set out here some of the supporting more recent observations from your consultants in this letter. You've set out an extract from what Dr Hamnon said and then you have said this:

"As my bloods were given so soon after the beginning of screening is it not likely that unscreened blood could still have been in the system or that infected individuals were still giving blood as they had not yet tested positive, i.e. they were not yet making antibodies."

Then you have referred to Dr Cramp and his letter:

"... well known that there are rare cases in which the Hep C- RNA can be present sufficient to transmit infection in the absence of an antibody result*(sic)*."

And then Dr Hamnon again:

"Specifically it seems quite likely that the transfusion was the source of your hepatitis C. It may be that one of the donors was indeed the source but hadn't yet made antibodies to prove positive on the screening test."

Then Dr Cramp also pointing out the possibility that you might have been given blood products that had

been frozen but donated prior to September 1991.

Now, you have made various arguments in that letter. Did you ever receive from The Skipton Fund anything which addressed in any kind of detail the specific points you were making there?

A. No.

Q. If we go on to document 12 -- 622012, please -- we see the letter you received later that month, March 2007. If we just look down the bottom of the first page, please -- just keep going down, the bottom of the page -- sorry, I'm not sure whether I'm seeing it on the screen in the same way.

"Your appeal was considered by the panel at its meeting on 23 March."

Have you got that? Then the Panel reviewed the entire file of papers. Can you see that, Caz?

A. Yes.

Q. So this was the rejection of your appeal.

"We noted that the treatment which you believe gave rise to your infection with hepatitis C took place after 1 September 1991. Unfortunately, this takes your application outside the terms of The Skipton Fund and we have no discretion to change the time limits ... we regret we must refuse your appeal."

Now, did you have any further dealings directly

with The Skipton Fund after that refusal of your application?

A. No, I don't think so.

Q. Subsequently, you had, I think, some interactions with the Blood Transfusion Service?

A. Yes, I was -- I had numerous letters with, I think, Dr Patricia Hewitt who was the head of the transfusion services, I think.

Q. You were told that the donors who had given the blood that you had received had been traced and that none were infected for hep c.

A. For a long time one was missing and eventually when that one turned up and appeared to be negative as well, she said that eliminates, effectively eliminates, the transfusions as a source of your infection. But she did say to me in a phone call, but, you know -- basically, she suggested that she believed that I had got infected through the treatment but it would be like searching for a needle in a haystack. They were her words.

Q. You've, I think subsequent to that, done a little investigation of your own in relation to the particular batch numbers that were examined as far as you're aware. Could we have document 622004 on screen. If you could just highlight the bottom part of that page, please, where it's got various numbers and handwritten entries. Thank you, stop there.

So we've got -- well, can you talk me through, Caz, please, what we have here and the next page as well.

A. What we have here is the original letter that was written by my haematologist in 1997 asking for the batch numbers to be checked, and I obtained copies of the actual blood reports (which I have copies of and you have copies of) and I cross-referred and the batch numbers have not been transcribed exactly right.

So in the first one, all the ones with an asterisk are slightly out. You can see the first one reads 68906TT9 and the actual number is 689067T9.

Q. If we go on to the next page, please.

A. The first four which were all given in one transfusion on 5 May '93, the zeros have all been transcribed as 2s.

Q. So, having ascertained that for yourself -- thanks, that can go down --

SIR BRIAN LANGSTAFF: There is a further error, isn't there, in the first one because it's 83 --

A. Yes, you're right. Yes, I forgot that one, yes.

MS RICHARDS: Having found those discrepancies out for yourself, did you take any steps in relation to them?

A. Yes. This was about two years ago. This is after the Inquiry started happening. I thought, well, I might as well try once more, gather my energy and try once more, and I got more copies of bits of my blood records and I rang the Blood Service and asked them if they could -- you know, I said I'd found these discrepancies, could they please check the numbers, and I was told I didn't have the authority to ask for that and I would have to go back to the original haematologist who asked for these checks back in 1997, who I know is retired.

So I went begging to my brilliant haematologist, Professor Cramp, who is such a busy man and I hate bothering him. So I went begging to him with a letter saying, can you, you know -- transcribed, sent all the copies of the original letter and the blood reports and another copy with my red number changes on it and that was November, I think, 2017.

He sent that off internally to a haematologist at Derriford, because he's a hepatologist, to ask his advice and he said he'd get back to me, and I haven't heard any more and I just haven't got the heart to bother him because he's such a busy man and he's doing such brilliant work.

Q. In your statement, as well as describing this possible

mismatch between the batch numbers listed and the units that were subsequently tested, you've identified in your witness statement other possibilities that may explain why it is that you were infected, as you and your consultants believe, in consequence of the blood transfusions. You've said this:

"The possibility that a donor with hepatitis C could have evaded the screening process, the antibody tests used at the relevant time are renowned to be fallible and, in addition, early on in any viral infection an individual can be infected yet have negative tests for the virus. Alternatively, possible for someone to have been infected at the time they gave blood but not at the point of the next donation."

Those are the very points that Dr Hamnon and Dr Cramp were effectively making on your behalf in your correspondence with the Skipton?

A. Yes, I'm not any kind of a scientist. I took my words from what they said in their letters, and actually Patricia Hewitt had also said the same thing.

Q. Having had your application rejected those years ago by The Skipton Fund, are you able to claim anything from the replacement scheme, the IBSS?

A. Not a ha'penny, no. I've tried twice. The first time I was told no. Then I tried again and she spoke to

her manager and she rang me back and she said, "Well, I could send you the form", she said "but I really don't want to put you through filling them in for no reason". And then a very dear friend here, who's come to support me, pushed me again to do it again. So I have actually got the forms at home but I can't see the point of bothering any doctor to fill them in because they've still got the same dates on them.

Q. You've said in your statement that the rejection of the application for any assistance from The Skipton Fund has meant you've had to rely upon welfare benefits, and you've had to endure the humiliation of work capability assessments to get those benefits. Could you tell us a little about that process.

A. The work capability assessments, about five or six years ago I think I had the first one and there were five false alarms before I finally got one.

The first time I went -- it's a 50 mile round trip -- I went with a friend, I was so nervous, and we waited for about half-an-hour and then they told us that the computers were down and sent us away. There were five more attempts before I finally got one, by which time I'd asked for it to be recorded.

Then I was found fit for work. Then I had to appeal that. Then, after a mandatory reconsideration, they put me back in the support group where they should have put me in the first place and then, as they sent me the letter that I was back in the support group, so there was another bundle of forms to start the whole process again because apparently they'd lost my files. So they wanted me to start all over again.

It's so, so, stressful. I have one of these every three years. The last one, I took a friend with me. It will be nearly three years -- it's coming up soon -- and we waited about 40 minutes, I think, and we went in and it was completely different, actually. It was a nurse and she said, "I'm so, so sorry that you've had to wait so long". She said, "I wanted to read all your notes and your letters". I'd sent five or six supporting letters from my family and I'd written a document describing my life and my history, a potted history. She said, "I wanted to read everything". She said, "I can see that life is really, really difficult for you" at which point I just burst into tears because I'd been heard.

She was brilliant. She, of course, put me in the support group and she finished the interview early. She was a gem amongst many who are not as compassionate.

Q. Your statement raises a concern based both on your own experiences but also your wider experiences as part of a hepatitis C advocacy group about the continuing lack of knowledge in the medical profession about hepatitis C, its effects and its symptoms. What experiences have you had with doctors that have led you to form that view?

A. I had a doctor when my son was about seven years old, he was feeling quite unwell and quite tired all of the time, and so I took him in to my GP who had known me since the cancer, known me all the way through, and said, "Do you think he could maybe test him for hep c?" He looked at me and he said, "What makes you think he might have hep c?" He was my family doctor.

The same doctor, many years later with the work capability test, I asked him to write a letter for me to help me with the work capability test. He looked at me and said, "Well, I think you could work".

I repeatedly went to doctors and said, "I'm so, so tired. Please can you run some tests. I don't know what to do". "Oh, the hep c won't be making you tired".

The people who heard was the hepatologist. He always backed me and heard because he understood hep c. But the GPs, they just have no understanding. The one I had when I was going through the Epclusa trial, he was kind of interested but not engaged. He'd listen to me rattling on a bit about being on the trial but he wasn't really -- he wasn't engaged.

Then the one I've got now, even though he's a much younger one so he will have trained more recently, he's very eager to learn but he didn't know what a fibroscan was. That's the one that I went to see to ask for a fibroscan and had to explain what it was.

So they're still not being taught in medical school what to look for or -- and they're not testing people and that's my big, big, big mission is to get more education and awareness and get people tested. Now that we know that there's a finger prick test called OraQuick that's available for £12.

Q. Thank you. You produced some documentation in relation to that. Can we just put that on the screen whilst Caz is talking about it. It's the NICE document.

A. So it cost £12. It could be provided to every single patient. I want every single person in the UK tested and treated. We have a 12-week cure now. If every person is tested, then we'll find the missing thousands and we can eliminate hep c. They're talking about eliminating hep c here by 2025. They're not going to do that unless they test everybody and find everybody. They can do it. It's cheap.

Q. Caz, those are the questions I had for you. Is there anything else you wanted to say?

A. Thank you. That was one of the things; so I've covered that now.

My big thing is I want more advocacy, more education and awareness to reduce the stigma and the fear. I know people who got hep c through hospital treatments who still haven't told their family. The stigma needs to be resolved and that will only come with more education.

More education for the prevention of transmission so that hep c doesn't get -- slip through the net like it did for me somehow, somewhere, not through deliberate negligence maybe but somehow it got through. So I want more awareness and I want, yes, the third thing was everybody, every single person, tested and then treated.

I was speaking to Rachel this morning from the Hep C Trust and she said they've had a huge increase in calls from people infected post 1991. So I want more awareness around the cut-off date of September '91 because it's still going on. It's still slipping through.

I want inclusion for all affected. It's taken me a couple of days here to realise why I've been feeling a little bit, like, outside of the group because of my dates and a little bit, oh, I don't know if I should really be here. And it's just clicked: it's because Skipton told me I was not worthy. They made me feel unworthy. I wasn't worth any kind of compensation, any kind of financial support. And so I'm very angry about that and I want those criteria changed. So I want inclusion for everybody affected.

And that's it really. And I want to say thank you to my children for being here and my wonderful friends who have come to support me.

Q. Thank you.

A. Thank you.

SIR BRIAN LANGSTAFF: Don't worry, I've nothing to ask but I do have my thanks to you for coming, which plainly everyone here appreciates. Thank you very much, Caz.

Ms Richards, shall we continue or shall we take a break?

MS RICHARDS: Sir, I think it might be slightly easier if we were to take our break now early. Mr Nicholls is the next witness. Ms Fraser Butlin will be asking him questions; so we need to rearrange things and also see if the monitor can be repaired. So perhaps if we take

the break now and then we will hear from Mr Nicholls after that.

SIR BRIAN LANGSTAFF: We will take a break. To make sure the coffee arrives in time, shall we take a break until 11.30.

(10.53 am)

(A short break)

(11.30 am)

SIR BRIAN LANGSTAFF: Ms Fraser Butlin, the next witness wishes to be called Steven?

MS FRASER BUTLIN: Steve.

SIR BRIAN LANGSTAFF: Steve, thank you.

STEPHEN NICHOLLS, affirmed

Questioned by MS FRASER BUTLIN

MS FRASER BUTLIN: Steve, you were diagnosed with haemophilia B when you were about one years old.

A. That's correct, yes.

Q. Initially, when you were diagnosed you didn't have many difficulties with it in the very early days.

A. No, I think it was a classic diagnosis of a haemophiliac. Before one, you were bruising a lot under your arms and the parents became alarmed and you were going to the GPs and to the hospitals and, again, there's the classic parents coming under the radar of is this child abuse, is this baby battering, before

the diagnosis because obviously it's very unusual for a child to be bleeding and have things. But about one years' old is when the formal diagnosis of haemophilia came through, yes.

Q. But from about the age of four you had more regular and severe bleeds?

A. Yes, I think as a haemophiliac starts growing and growing fast is when the joints are developing and that's when the bleeds really come fast and furious, yes.

Q. You were treated with cryoprecipitate until you were about six?

A. Yes.

Q. Then changed over to Factor IX concentrates?

A. Yes.

Q. As far as you're aware were there any discussions with your parents of any risks involved in that change?

A. Absolutely none at all.

Q. About that time you were also put on to home treatment?

A. I was, yes.

Q. Now, can you describe for us what the impact of haemophilia B was having on you by the time you were about age 6 or 7.

A. Personally, my memories of pre-five would just be pain

and hospitals, that's all I can remember, and dread of going to the hospitals, upsetting my parents. At five, school age, trying to attend the mainstream school, being sent to a mainstream school, missing more than what I was able to attend because I was bleeding. Pain, yeah, pain and constant bleeding really constant bleeding.

Q. You mentioned missing a lot of schooling?

A. Yes.

Q. At about six or seven your parents applied for you to go to Treloars School?

A. That's right, yes. They'd heard through a personal friend who was given a teaching placement there of this school in Orton Hampshire that was recruiting a lot of haemophiliacs and there they were getting a really good education and it was geared up and the medical treatment was freely available on site.

Q. When did you start attending?

A. I started attending when I was about eight years old.

Q. So about September 1976?

A. Yes.

Q. And you still believe that Treloars was the best place for you to go?

A. I do. I understand why the decision was made for my parents because obviously they wanted to give me a good education, they wanted me to have the best medical treatment and at that time you would report to my local hospital which in that case I was living in Portsmouth, which was St Mary's and you were literally fighting for treatment because the treatment wasn't readily available, you wouldn't see the same doctor more than once. It would usually be a houseman.

The general consensus was go home, bring him back in the morning to see if it's any better. Obviously, you quickly learn it will never get better so the bleeds got worse because the treatment just wasn't as freely available, but at Treloars it was made clear that if you had a bleed you would be treated within hours.

Q. In terms of your schooling and being able to attend school?

A. Obviously, yeah, and Treloars, yes, it was educational. I'll tell you a little bit about the geographics of Treloars. There was three establishments of Treloars within about three and a half miles of each other. There was what was known as Lord Mayor Treloar College, which was a very grand old-style school, which was purely boys from the age of around 11 upwards; there was Florence Treloars School which was just down the road, which was

predominantly girls, and haemophiliacs, boys and other boys under ten were put in that unit for the first two years until they were able to move up; and there was Treloar Hospital which again was about a mile down the road where first -- where all the treatment was administered in the early years.

Q. When you first went to Treloars you were receiving both cryoprecipitate and freeze dried Factor IX?

A. I have memories of having cryoprecipitate at Treloars but very quickly they pushed for everybody to be changed on to factor concentrate. It became apparent that I was one of the first ones to be put permanently across, yes.

Q. When you were put permanently across to the factor concentrate, again, was there any discussion with either you or your parents about the risks of that treatment?

A. Definitely not to my parents. To myself and the other boys it was being sold to assist this is a miracle to you guys. To have cryoprecipitate would mean you would be lucky to get out the treatment that day. It would take two or three hours to administer. You'd be under a drip with your arm out, two to three hours, and then they invite you to rest for two hours before you went back to normal life. Sometimes it was long,

depending on the size of the dose. This was coming in a 60 ml syringe which could be administered within quarter of an hour/20 minutes and you could get up and walk away. And, of course, this was in little bottles which you could take home with you, administer yourself at home. So cryoprecipitate couldn't be administered at home. You had to report to hospital.

Q. When you were about 11, so about 1978, you went on to prophylactic treatment?

A. I did.

Q. Can you describe how that was carried out at Treloars?

A. Prophylactic treatment is basically they would give you treatment every other day, usually, maybe two to three times a week on a routine basis, which would prevent bleeding virtually because, obviously, your factor levels were high so you didn't bleed. There was a really, really big push in those years to get as many haemophiliacs as they could onto prophylactic treatment.

Again, there was no risk assessment done to me. They didn't say this stuff contains a risk. Obviously the more you have, the greater the risk. That wasn't explained at all. It was just sold to you purely, "This will give you a more normal life. You'll have more free time. You'll be fitter, so take it".

Q. You've described the treatment room at Treloars?

A. Yes.

Q. Could you describe that for us in your own words.

A. As I say, go back the very early days, all the treatment was administered at Treloar Hospital and that would mean that every morning there will be transit vans pull upside Treloar School or College, the 12 haemophiliacs would get in because that's how many they seated, and they would be ferried to the hospital where the treatment was administered.

In those days, it was mainly cryoprecipitate. You would be down there three hours and then they would ferry you back to the school and these vans were running three or four times a day. After I had been there about two years, the actual haemophilia centre moved to the school; so it was administered actually on site.

Q. What was the room like on site?

A. The room on site was -- contained, I would say, it contained the sink, eight to ten tables, eight to ten chairs and a doorway which went through to where the storage area where the factors were being stored.

Q. When you went in for treatment what did you find?

A. In the early days --

Q. In the treatment room on site?

A. In the treatment room on site, physically what was in there? When I was having treatment you mean?

Q. You described when you arrived pre-mixed doses would already be out on the tables.

A. Yes, at Treloars there was, in the heyday when I was there, there was probably up to 50 haemophiliacs in attendance and you think if they were pushing for these most people were having three doses a week so every morning there would be 20/25 haemophiliacs queuing up for their treatment.

The treatment room itself contained eight tables, when you went in there it was very regimented at Treloars, you were known by your surname, you were given a number, a laundry number and your surname there was no Christian names. Again, these were all pseudonym names, like Big Ears, Joe Smith and Bloggs written on a white Luxon sheet on the table with pre-mixed doses. So there would be syringes with just a clear substance in it, some may have peoples' name on, around the room. So you'd report there, look for your name. If your name wasn't in there, you may wait until your name was called.

Q. You've described that in the early days if a boy hadn't turned up for treatment and there wasn't a syringe ready with your name on it you could simply

be given someone else's dose?

A. Exactly. If Thursdays they knew it was again pseudonyms, Smith, Bloggs' and Harry's day, if you turned up and your name wasn't in there and they said, "Where's Harry today?"

"Didn't you know he's got an exam?" They'd say, "Well, you may as well have it", because he was coming back later, so there was absolutely no way you knew what was in that particular syringe, what product was in that syringe. All you know is it had been pre-mixed and it had your name on it.

Q. You describe that it was very much like a cattle market for a particular period of about four years.

A. It was. It remained that way for around four years, yes.

Q. In about 1982 when you were about 15 the push for prophylactic treatment you say seemed to slow down.

A. It did, yes. Obviously, boys being boys there we wanted to play football, be out riding bikes. The last thing you want is to keep being called up for prophylactic treatment all the time and there was -- yes, we didn't like it but if you could stand it they would push for it.

But as the boys got older obviously refusals started to happen, "I'm not doing that, I'm not doing

that". But it wasn't because of the risk of infection because it wasn't known then. It was just purely because your veins, your physical body couldn't take it.

Q. You also say the way in which treatment was organised from the when you were about 15 changed completely.

A. Absolutely, yes.

Q. Can you describe what changed?

A. There was locks put on doors. You weren't allowed in the treatment room on your own. A mixer was installed in the treatment room. The bottles were in the treatment room. The treatment product was mixed in front of you in the mixing machine. It was pulled up in front of you. Records were kept. It was clear that every batch number was being taken off the product and you noticed a change there, yes.

Q. Was the reason for this change ever explained to you?

A. No.

Q. In about 1983 you recall media reports circulating about a link between haemophiliacs and AIDS.

A. Yes.

Q. In your statement, you describe that around this time some of your friends at the school started showing symptoms of illness.

A. Symptoms of illness, yes.

Q. Can you describe what was happening?

A. There was always -- I mean, this will sound very flippant to you but there was -- people were ill at Treloars. We accepted that, that there were ill people there. There would be cases of hepatitis there, many, one of the haemophiliacs would go yellow, he would get no special treatment at all, he would attend school as normal, he would play football as normal. In fact, he would be teased about being yellow. That's just the way it was.

Q. I think you said there was a name used to call them?

A. Yeah, he just used to be called banana or something like that. A month later he'd be better and it would be someone else. It was just so normal. It happened on a monthly basis.

Q. But 1983 you've indicated that it was a little bit different?

A. With, sorry --

Q. In 1983 there had been rumours circulating about AIDS and you said that --

A. There was rumours circulating about AIDS, yes, and the link was being established between AIDS and haemophilia.

Q. You said that:

"Around this time some of my friends at school started showing symptoms of illness that was nothing to do with haemophilia bleeding. It was an incredibly scary time for us."

A. It was, yes. People were becoming flu-like symptoms. People were going home for the half-term break and they wouldn't be returning. Yes, there was a lot of people, glandular fever, throat infections becoming a lot more prominent. Everybody was worried because the link, it was the press story was just breaking that there was a link between haemophilia and HIV, yes.

Q. You've described a pact that you and four of your closest friends made. Do you feel able to tell us about that pact?

A. That was probably a year later. I was either in my very last year or the first year that I'd left when the first haemophiliacs were starting to die and everybody was really scared and, yeah, four or five of us in the room and we realised that this is serious and this is killing us or killing haemophiliacs and we said, "This is going to happen to us, we can see it", and we said, "Right, we've stuck together right through our childhood. If it happens and it kicks off we're going to rely on the person still alive to pursue it and find out why and what went wrong", and

I'm the only one left. That's tough. I think about that every day and ... it's tough.

Q. What was the school's response to the rumours and the increasing illness of the students?

A. Okay, in Treloars we've established that the school and the haemophiliac centre they were on the same site. There was just big double doors between them. This side was the school, the education; that side was the haemophilia centre.

They didn't hide it but the way it broke at Treloars was the newspapers. No-one had mentioned the word AIDS or anything. It was just all over the newspapers. Obviously the haemophiliacs wanted answers and started to ask questions.

I think, first of all, I think they said, you know, "Don't worry, don't worry, just carry on as normal just carry on", and we sort of accepted that. So Treloars was -- we were exposed to mortality at a very young age at Treloars. Obviously, there was some very sick people there and through the -- I was then for six/seven years so I saw a handful of people die. I will give you one example where we were playing football and one of the lads just dropped dead on the floor. Obviously, we're 13/14-year old lads, so one of us jumped on the bike, quickly rode round to

the haemophilia centre where the doctor was on call, he came running down with a bag, got there too late. He'd gone.

Q. So that was somebody before the AIDS --

A. Yes, this was before.

Q. In terms of how the school responded and talked to you about what was going on, was there any discussion from the school about what was happening?

A. Not when I was there, no, not when I was there.

Q. Now I want to move on to look at some of your records and your own infection. You've obtained your records from Treloars. How did you come to receive them?

A. I've received patchy records. They're not complete by any means. There are large sections missing. Three to four attempts were applied for because Treloars is no longer. It's now all moved to Basingstoke. Initially on request they said, "No, They've all gone. We haven't got them anymore". Kept trying, received dribs and drabs through and then one day I went to Treloars -- over to Basingstoke to the thing, they said, "Oh, Stephen, you were after records". There's a new haemophilia doctor had arrived. He said, "We've just unearthed boxes of records in a cupboard of the Treloars days. Would you like them?"

Of course I said, "Very much I would, yes."

They weren't complete but there was three or four guys who got a reasonable set of notes there, found in the cupboard, yes.

Q. Paul, can we have document 1432006, please.

We should be able to highlight, thank you, the date here is January 1977. You can see that on the left-hand side of the screen and you've been identified in the bold letters as a hepatitis risk?

A. Yes.

Q. Were you told about this at the time?

A. No.

Q. If we can go to document 1432005, if you look down the middle column you first tested positive for hepatitis antibodies in January 1979. Were you told about this at the time?

A. No.

Q. Were you even aware that you were being tested?

A. No.

Q. Please can we have 1432007. Could we highlight that second paragraph, please. It says your SGOT was slightly raised and had been since January 1979. What's your understanding of what that means?

A. I have no idea.

Q. Okay.

A. Honestly. I'd imagine it's something to do with the liver function test, I would assume.

Q. You said in your statement you understand that raised SGOT is an indication of damage to the liver?

A. Yes, liver function test, but I do not know what SGOT actually stands for.

Q. That's okay. Were you told about this at the time?

A. No.

Q. Now, you remember being told to avoid alcohol while you were at Treloars?

A. Yes.

Q. But you say you were certainly never advised that you had or were at risk of hepatitis.

A. No, the first time they ever discussed liver problems with me was when a highly respected haemophilia nurse and it had been mentioned at this stage to avoid alcohol because of liver problems and they said, "Your liver's under enough strain as it is coping with the amount of factor you're having; so don't give it any extra pressure by drinking alcohol".

Q. And you weren't told about your hepatitis infection until 1991 which we will come on to --

A. Okay.

Q. -- in a moment.

Now, you are aware that your blood was being tested regularly while you were at Treloars?

A. Absolutely.

Q. Why do you think that was?

A. It was the norm to have blood taken, I would say, on a fortnightly basis, if not a weekly basis, sometimes every other dose you would have it would be, "Oh, Stephen, we just need some blood from you", and you would literally stick your arm out, they would pull 60mls back in a syringe, start squirting it into bottles, connect your factor up and you'd have your factor and you'd go. You didn't question it. It was normal to every -- not just me. As I say, I'm speaking for the whole of the Treloars boys. It was normal for people to be giving blood on a weekly to fortnightly basis, large quantities, not test tubes, tens of test tubes.

Q. You have said:

"I am convinced that many of the pupils at Treloars were monitored very carefully and that they did all the tests that they could possibly for commercial interest and/or financial gain."

A. I do. I think Treloars had access to virgin haemophiliacs, so to speak, pups is another word. They had boys there from 8 years old who had obviously never been exposed to any drugs, sex, alcohol, any other of the ways any of these infections could be

contracted and they were monitoring us. They were taking blood and looking how things were developing, how fast is this progressing, who is getting what, what is happening here. We didn't even know anything was happening. It was just the norm for blood to be taken in large quantities to all the boys there.

Q. What impact has that had on your willingness to attend medical appointments once you left Treloars?

A. I don't have much faith in the medical -- I find trust very hard because sometimes they're not telling you exactly as it is. There's an ulterior motive for what they want you to do and that is the beauty of the internet now. You can research things and the good thing about Treloars was, as I say, 89 boys went there and I'm one of the 16 still left. But we still talk. We can confer with each other, even at the other end of the country, "What is happening to you, what is happening". He's been told something totally different to me and you can question it.

So I'm very fortunate to have those companions, those people who are going through exactly the same thing as you to confer with, so we're a tough bunch to be because we can talk to each other.

Q. In those early years after you left Treloars, what was the emotional impact on you of what was happening to

your friends?

A. Oh, it was astounding. The bonds that were built, Treloars, as I say, you know, we ate together, we learnt together, we were treated together, so the bonds that were built become like brothers. They weren't just like school mates, you know. Close friendships, close bonds were built there and to see your friends dying one by one and it's always in the back of your mind there but for the grace of God go I, I could be next.

That was -- obviously we were feeling it but people handle it in different ways. My way was I just blotted it out, just focussed forward and told no-one and that nobody included -- obviously, my parents knew I was a haemophiliac but they didn't know the problems that was going on with it. I sheltered them from that.

Q. You were first told that you had hepatitis C in about 1991.

A. Yes.

Q. How were you told?

A. I was told face-to-face by the doctor flippantly, I would say is a good word. It was in a routine examination, "Oh, Stephen, by the way, you've tested positive for this". I didn't really know what it meant. I was fully aware of the HIV because that was in full flow by this time. I thought, "What are you saying?" He said, "You know, not too much to worry about but life expectancy could be affected here but my advice to you is just carry on as normal, carry on as normal", and that's what I did.

Q. You've said that the doctor was extremely guarded and simply told you to be careful.

A. Yes.

Q. Did he tell you anything about the possible routes of transmitting the infection?

A. No, not then.

Q. How did you feel when you were given that diagnosis?

A. Obviously, you know, the death of haemophiliacs when this was happening was really, really massive scale. You know, it was one a month and I attended many funerals and I suppose when you attend so many and you see 30/40 of your friends die, it's always in the back of the mind there but for the grace of God go I, but you do become slightly hardened to it, you do, and I thought there is could be it, this one. And, yeah, I was shattered. I really -- it took a while to sink in and for me to decide how I'm going to cope with this and what am I going to do, and so I decided to just crack on with what was left, don't look back.

I became very anti-Treloars for a while because I thought it's not worth going back there. There's none of us left, but I pulled myself together and thought just live for the day, just keep going, just keep going and that's what I did.

Q. One thing you did after you were told about your hepatitis C is you became worried about your own financial position; so you found a job at the parks department of the local council?

A. Exactly. I mean, again, it was well aware at this stage that haemophiliacs couldn't get life insurance and, therefore, couldn't get a mortgage. I thought, "Well, how am I going to get around this?" and I think, logically, let's pursue going for jobs with accommodation and that's what I did. Again, I didn't declare it. At that time, I was a reasonably well man. I was -- I told nobody and got a job.

Q. So you particularly went for that job because of the tied accommodation that came with it?

A. That's what attracted me to it, yes.

Q. After about two years in that job you left the role.

A. Yes.

Q. Can you tell us what happened.

A. Somebody spotted a disabled sticker in my car and obviously started to dig and first thing I knew is you've got an appointment with human resources, I think, and she was called in and there was a lady sitting there I'd never met before and started asking questions, and I was totally flabbergasted by the questions she was asking. But somehow she got the information. She knew I was a haemophiliac. She didn't ask me directly but I could see exactly where she was coming from. Obviously, I couldn't deny it.

So I listened to what she had to say and they were -- made it very clear they were uncomfortable me being there. They wanted to know what I wanted to do. They made me feel very uncomfortable. They wanted me to resign or -- which I wouldn't and it was sort of left for about a day and I thought where's this going to go? Then I was called back and, you know, "Have you had any thoughts about the thing", and they said, "We'd like you to leave and leave quietly", and I said, "Well, but my accommodation's tied what am I going to do?" They said, "Well, short-term we'd just like you to go sick for up to a year. There will be no questions asked and during that year we'll find you a council house".

Q. So you and your first wife moved into a council flat?

A. Yes.

Q. You became a service engineer for household goods?

A. I did. When that happened I felt broken again but I was still reasonably well at that time and I thought, "I can pick these pieces up and start again", and I did and I thought, "Well, how are you going to hide it again?" I thought, "You're going to have to do it". So we had plans, we wanted a family, we wanted a normal life and I thought, "Well, I'm going to have to go and get another good job here", so I thought, "I'm going to have to reinvent, basically", which is what I did. I went for another job, didn't tell them, got a good job.

We wanted to buy a house. I knew you couldn't get a mortgage, a haemophiliacs got no chance but, you know, I admit it, I applied for a mortgage and I didn't tell them. I lied. I got a mortgage and life went on for ten years, I suppose, ticking along quite nicely. I was earning well, we had a family.

Then my health started to suffer. I was getting tired a lot and I was struggling to do the job and I'd gone up and I was training the engineers at the time. I sort of worked the day around it and thought you're not going to be able to do this for much longer and I wasn't ready to throw the towel in. So I thought, "Well, what can you do?" So I thought, "You're going to have to reinvent again". I thought I'll even set up my own company doing exactly the same thing where I'm in control.

Q. Before we talk about that, can you just describe for us a little bit more about the symptoms you were experiencing towards the end of your time when you were employed.

A. Fatigue. Fatigue was the main one, tiredness. It's hard to explain. It's a brick wall at 2 o'clock in the afternoon. It's not tiredness. Your body is just telling you you've got to sleep, not you need rest. You've got to sleep. You've got to. I was driving around and I knew I had to pull over and I had to sleep and then try and get through the day.

That's what it -- it creeps up fairly gradually and probably had been creeping up for many years before that but that's the time I realised it's getting dangerous now because you're working with electricity, you're working in people's houses, this isn't fair. The risk is getting too much and you can't carry on like this safely and that's why I chose to leave that employment, yes.

Q. So you set up your own business.

A. Yes.

Q. It did very well --

A. It did, yes.

Q. -- to start with.

A. Yes.

Q. How did you manage your symptoms while you were running your own business?

A. Obviously, I was fully aware that my health was declining and it was declining reasonably fast. So I wanted to be able to cope and manage my day to -- so at that time I had two young children, a mortgage deal and I knew it had to succeed. So I used to get up at 8 o'clock and I may work until 11 o'clock and I would work hard flat out.

The business I had was a service engineer. I used to go round peoples houses fixing cookers and washing machines, et cetera. I'd cram four in an hour, get them as close to each other, bang, bang, bang, and then by 12 o'clock I'd just come home and go to bed because I was exhausted. I may get up at 7 o'clock for something to eat and go back to bed again and then do the same the next day and that went on for years.

Q. Now, you gave that business up during your treatment for the hep c which we will come to shortly but can you describe the financial impact that the hepatitis C has had on you.

A. Up until -- all the time I was working I adjusted.

I forced myself. I had to provide for my family. I had to. I went for as long as I could and worked for as long as I could but there got a point where I just couldn't work anymore, the fatigue was so much. Not only was I endangering myself, I was endangering other people by doing the job I do in it.

So it was hard and at the time where it was really bad, which was just prior to the hep c treatment, that was the time I decided, "You can't work anymore and you're going to have to stop and throw the towel in", and I did.

Q. You said:

"My career and earnings potential was on target for an above average person and I would have been able to provide financial security for myself and my family, including pension arrangements."

A. Exactly, yes.

Q. "Sadly I can't do this."

A. No. What money I managed to save has obviously gone now, yes.

Q. You didn't tell your children about your infection until your eldest was about 16.

A. Yes.

Q. Can you tell us why that was?

A. Obviously I'd seen it happen to so many other

haemophiliacs. I'd seen the devastation it can cause, the trauma throughout the families, the discrimination, the ignorance of some people and how it can upset -- if it was just me myself I could cope with it but I wasn't prepared to put my wife and my family, and especially my children at risk; so I decided yes, they knew I was a haemophiliac. They knew I had bad legs. They knew I had injections. They knew I had to sleep a lot, but I kept it at that. I didn't go into the full details, no.

Q. You remained quiet because you didn't want your sons to be bullied at school?

A. Yes, exactly, yes.

Q. You also tried to shelter your own parents from it?

A. Exactly, yes. My coping mechanism was, well, I pulled into myself and thought, "I know the truth. I know what I can do and what I can't. Why burden anybody else? Nothing's going to change. It's not going to change the past. It's probably not going to change the future", so I cope with it, my problem, I deal with it my way.

Q. So you only ever told people who were closest to you about your infection but then three years ago you met your wife and you told her pretty much straight away about your infection?

A. Yes.

Q. What was her reaction?

A. Absolutely amazing. I think she said, "I don't know how you told me that but it makes absolutely no difference to me at all, nothing", which amazed me, amazed me.

Q. Before 2012 you were not offered treatment for your hepatitis C through the NHS?

A. No.

Q. Can you tell us what you were told about this by the doctors?

A. Treatment was mentioned, you know, "Of course, we can treat your hepatitis C, we can treat your hepatitis C. Your liver is getting bad. We may have to think about". But they made it very clear because of my genotype that the treatment was very severe, the success rate was 60-ish per cent and I was seeing other haemophiliacs going through this treatment and it nearly killing them -- sitting next to me, exactly the same -- and I thought at the moment until someone says to me, "You've got to do it or you should do it", I avoided it.

And then I was getting mixed signals from the doctors, sort of thing. I couldn't figure out quite how serious this was. I knew my health was going down

fast and I still wasn't getting the sort of answers I was looking for from the NHS. So I started to research it. With the beauty of the internet, I started to learn. I thought these symptoms are looking bad. So I thought I want an honest opinion here and I want a complete layman that's not going to be biased in any way. I researched it and I saw this the guy in London, Mr Richardson, who I knew was "Mr Liver". He was the guy who pioneered the first liver transplant. He was George Best's liver specialist and he had a practice in Harley Street and I researched it and they would do an hour consultation, including scans and everything. You could just walk in off the street and people did in London, they just walk in off the street to have a general health check, so I thought what I'm going to do is I'm going to book an appointment and go there as a complete layman and take all my blood results with me and ask him for an honest opinion, which is what I did.

Q. What did he say to you?

A. "I'm amazed you're still walking", was the first thing he said. He said, "Looking at your results, I'm amazed your still walling here". He said, "I know a little bit about the scandal with the haemophilia

thing. Why have you not been treated? I just don't understand how you've got this bad".

I explained to him I'd researched the treatments and the reason was for him to advise me what treatments were available, when they were available the news for the new interferon treatments was just breaking and he said, yes. He said, "The problem with you is you haven't got time". He says, "You need treatment within the year otherwise you're going to die". That hit me hard. I wasn't expecting that one. Obviously, they done scans and tests and I thought, well, where do we go from here. I said I've heard about these new interferon treatments. You know, I was literally willing to travel to a different country to get them and he said, "No, they are not going to be on the NHS for at least three years". I said, "Well, how about privately? Is there any chance we can get them private?" He said, "I'm not going to see them for probably two", and he said, "You haven't got that long".

So I felt, I thought, "That's the final blow. This is it". He said, "Leave it with me", took my details, obviously my hour was up. I had the scans; had the results; I went away.

Within a week I had a phone call from the Royal

London saying, "We've had a referral from you from Mr" -- I didn't know anything about a referral. He said, "We'd like to meet you straight away". So it was literally, "Come on down", sort of thing. So I jumped on the train and they said, "We've been told that you need treatment straight away. We'd like to refer you to a drugs trial, to our trial unit", and at that time they were just trialling the Gilead sofosbuvir treatment, put me forward for that trial and I applied for that trial.

Q. You couldn't join the Gilead trial in the end because of your liver condition.

A. No, I was turned down. Yes, I applied for it. My hope was built up, I thought this was it because they were all saying this is the one that's going to cure you. I waited about a week and had the phone call and said, "I'm sorry, because your liver's so bad they won't accept you on the trial".

Q. But instead you joined a different six-month trial. You can't remember which drugs that involved but you do know that it didn't --

A. No. A week later, yeah, the phone rung again. He said, "We've found other another trial. Come on down again". So I came on down. They said, "We've found another trial that will take you" and they said the problem with this trial is it's still Ribavirin and another drug, which at that time was a test drug and just had a long numerical number.

Q. What were the side effects of that treatment?

A. It was made perfectly clear to me that this drug wasn't aimed at the UK market. It was aimed at the foreign market, with people with a darker skin because the main side effect was it was photo-sensitivity, sunburn. You couldn't stand the light. But I knew at that stage it was going to save my life; so I'd have taken anything.

Q. And you did manage to complete the six-month trial --

A. I did three months, with the side effects were -- I say it was designed for people with darker skin. There's me, a red-haired fair skin; I had no chance. So literally I couldn't even look out the window. You had to have factor 50 on indoors, three months, blisters like you couldn't believe. But I was determined to do it and I did it, yes.

Q. And you cleared the virus?

A. Yes.

Q. Having cleared the virus, what's your health like now?

A. The damage has been done to my health. Obviously, the cirrhosis doesn't change. My liver's still cirrhotic, it hasn't got any worse, and there are signs of

improvement. I feel -- in myself, I feel better now than I ever have done but after clearing the hep c virus, it takes time. It's not you clear the virus and within six weeks you're going to be feeling better. Within six months you may start to feel marginally better. It takes two years before the energy comes back. I mean, I can go a day without sleeping through the day now. That's only been for the last two years. It takes time.

Q. Before you started the treatment to clear the virus, you went to the GP suffering with depression?

A. Yes.

Q. And you went to see a counsellor?

A. Yes.

Q. I think you say you found that counselling helpful to you.

A. I did. This was pure -- I've got an excellent GP, totally understanding. He knows me and he knows if ever I go to see him, I'm in trouble. I don't go there all the time. And I think I was just after a routine prescription for painkillers or something and he said, "It's time for me to say to you I'm only going to give you this prescription if you will go and have counselling". He said, "I think it will really, really help you". I said "okay" and I went. Yes, I

went for a couple of sessions. I think, for me, it helped me because it was a complete stranger. I told her everything and I'd never done that before to anybody.

Q. You were also exposed to hepatitis B?

A. Yes.

Q. And you've received three letters warning you of your risk of vCJD?

A. Yes.

Q. In your statement, you have explained that two years ago you wanted to have ankle surgery at the Royal Surrey Hospital but this was refused because of the risk of vCJD, and you ultimately had the surgery at Basingstoke Hospital.

A. Yes.

Q. In a very recent explanation, the Trust have said that the reason why they couldn't undertake the surgery was because they received advice from your haemophilia centre that the surgery should take place there in the interests of your safety.

Do you still hold to what you believe to have been the situation in relation to vCJD?

A. Absolutely I do.

Q. I want to move on to the issue of financial assistance. After you saw the private doctor, you

applied to The Skipton Fund and received payments from them?

A. Yes.

Q. And you now receive payments from the EIBSS?

A. I do.

Q. Do you have any particular views or experiences in relation to the process and nature of the schemes or the payments that are made?

A. For me, it was all done purely on blood results and scan results and it was just done automatically; so I had no issues with it. It was done quickly and they received the paperwork.

Q. You have said that you've got -- you have had no problems getting payments from The Skipton Fund but you do think the payments you've received are unfair?

A. I do. It's not -- when you have a family, if they just took it as the average UK family, the average UK wage, the average working man's wage, I was earning more. I wouldn't consider myself as an average wage and I worked hard to get it and now -- I paid into the system for that time and my earnings are about 20 per cent of what I used to earn what I get, I think. It's barely enough to survive on. I'm still totally dependent on benefits now I can't work. It's not particularly ideal. Now I've remarried, I've got two young stepchildren; so we find it hard to survive financially on what's provided, yeah.

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

A. I think one thing I would like touched upon is haemophilia treatment, as it stands now, it feels we're penalised for our infections where I feel we should be being prioritised, rather than penalised. Whatever you do, wherever you go, you'll see the -- for example, when I had my ankle and I researched this guy hard and I knew he was the best. And he said -- I explained to him and he said, "Steve, I've got no problem. You're exactly the same to anybody else. I would operate on you tomorrow but there's going to be a lot of red tape to go through. I myself have got no problem".

But as soon as it goes through and it goes through to the different departments, you're flagged, you're flagged, we want to know more about this, we want to know more about the vCJD, we want to know and it just does -- and this takes months, in my case two years, to actually come to fruition and then they say, "I'm sorry, we can't do it". And I was told before it had all been agreed, it was just a question of you saying when you want it done and I will do it within

two months, and when I say two months, two years down the line they eventually said no.

It's not fair. You get exactly the same for dental care. I struggle for dental care. If you can find an NHS practice that will accept you, which is hard. It's not great but I found my personal thing if you go to a private dentist they are a bit keener because they will say, "We treat everybody the same. We use disposable instruments. You're the same as anybody else", but unfortunately that costs a couple of hundred pounds. But it should be -- if anything we should be being prioritised through operations and general procedures rather than being penalised, which we are now.

Q. I am just going to turn my back and ask Mr Snowden who, as you know, represents you if there's anything further.

A. Sure. *(Pause)*

Q. Just one point that Mr Snowden asks me to raise. We were discussing earlier about the press story breaking in about 1983 of the link between haemophilia and HIV.

Did the school ever say or suggest at the time anything about a link between the treatment you were receiving and HIV?

A. Not to me personally, no. Not at that time.

MS FRASER BUTLIN: Thank you.

SIR BRIAN LANGSTAFF: When you say, "Not to me personally", do you happen to know from what other boys were saying that it was raised with them?

A. Obviously, I couldn't speak for every haemophiliac there but I think the general consensus would be, no, not at that time.

SIR BRIAN LANGSTAFF: Thank you very much.

Steve, thank you very much for coming to give your evidence. That's it but thank you.

Ms Fraser Butlin, we are, I think, a shade earlier than planned. Would you suggest that we begin with the next witness?

MS FRASER BUTLIN: No, I suggest we take a break and start after lunch.

SIR BRIAN LANGSTAFF: That seems very sensible to me. So shall we begin at, let's say, 1.45.

(12.20 pm)

(Luncheon Adjournment)

(1.47 pm)

SIR BRIAN LANGSTAFF: Our witness this afternoon wishes to be known as Kate, does she?

MS RICHARDS: That's right, sir, yes. So if Ms Ashton, Kate, would come up.

KATE ASHTON, sworn

Questioned by MS RICHARDS

MS RICHARDS: Kate, in 1988 you were diagnosed with a type of cancer of the blood, acute myeloid leukaemia; is that right?

A. Yes.

Q. You started chemotherapy in the autumn of that year?

A. Yes.

Q. You had a number of courses of chemotherapy and then you underwent a full bone marrow transplant in May of 1989?

A. Yes.

Q. Now, I understand from your statement that in the course of your treatment for your cancer, you had multiple transfusions; is that right?

A. Yes both during my treatment, most people probably know that your blood counts go down whenever you're given chemotherapy and so on so you have to have transfusion support in the form of, in my case, whole blood and platelets and that also went on for about 12 to 15 months after the bone marrow transplant. I needed weekly transfusions for about a year afterwards.

Q. I think we can see that from some of your medical records.

Paul, could we have 1416003, please.

That should come on the screen in front of you, Kate, I hope. You should, I hope, see a letter 9 November 1998. In the last sentence it referred to you being given a transfusion of platelets?

A. Mm-hm.

Q. 1988. Then if we could have the next exhibit 1416004, please. This takes us through to -- I will wait until it comes up on the screen. So this takes us through to July 1989 and we can see at the end of the first paragraph it says you were still requiring platelet support at least once a week and you'd required a couple of blood transfusions since your discharge.

A. Yes.

Q. Then if we could go, please, Paul, to 1416008, which should be a letter of 28 September 1989, in fact, it seems to be essentially to the same effect. It might be the same letter. Ah, the second page of that, please. There's a letter 28 September 1989. That should be coming on the screen in front of you now, Kate. So we can see from that in the second paragraph it refers to you being on regular blood and platelet transfusions?

A. Yes.

Q. That carried through I think pretty much well into the end of 1990?

A. Yes, yes.

Q. Could we just have up on screen, please, Paul, 1416006.

That's a letter 10 December 1990 and we can see there the reference to platelet transfusion but if we just go to the second page of that letter, if you could just highlight the second sentence, please. Thank you. There's a reference there, Kate, to "screening for hepatitis C is in hand"?

A. Mm-hm.

Q. So this is December 1990. Were you at that time told either that screening for hepatitis C was in hand or told the results of any screening?

A. No, absolutely not, no.

Q. You can take that down, please.

In terms of the transfusions themselves that you had had over this prolonged period, '88, '89, 1990 were you ever given any advice or information or warnings in relation to the risks of being exposed to infection?

A. No, not at all. I sometimes had reactions to transfusions that were sort of immediate. That tends to come sometimes when you have a lot of blood transfusions but certainly nothing regarding risk of infection or anything like that.

Q. Now, in consequence of one or more of those transfusions, you developed hepatitis C?

A. Mm-hm, yes.

Q. Can you recall when you were first told that you had hepatitis C?

A. It's very difficult going back over the years. The medical records that I was able to pin down mentioned I think it was 1997 when a doctor first recorded that in a letter and, as far as I remember, that was the first time that I knew that was the case.

Q. We'll have a look at that, Kate. It's 1416009, please. That's a letter 15 April 1997?

A. Yes.

Q. If we have the second paragraph highlighted, we'll see it says:

"Investigations from her last visit have unfortunately shown that Kate is hepatitis C positive and this almost certainly relates to her intensive blood product transfusional support post autograft in 1989 prior to routine screening of blood donors."

So that is, as far as you are concerned, the first time you were told you had hepatitis C?

A. Yes, yes.

Q. Then if we could just see the whole letter again please. There's a paragraph towards the bottom of the

page which you have circled which says this:

"I discussed with her the implications of the finding of hepatitis C including the risk of developing chronic liver disease and risks of transmission."

What can you remember as to what you were told?

A. I actually remember very little. I do remember there was a discussion of sorts and I think I was told that I shouldn't share my toothbrush with anybody. I can't remember if any risks of sexual transmission were discussed or not. They may well have been, but the actual implications medically of having hepatitis C either weren't discussed or I don't recall them because certainly I don't recall there being any impact at that time and it was a bit like I knew I'd picked up cytomegalovirus from transfusions and it was kind of nothing. Who cares if you are CMV positive or negative, sort of thing.

I think at the time I had no reason to think it was anything different from that. It was just, "Oh, well, you've got this, by the way".

I don't think -- the doctor was subsequently criticised actually but, I have to say, I don't think there was any fault. I think it was just he was apparently going to refer me to a gastroenterologist who would have discussed things further but, no, my understanding at the time was very limited.

Q. I think the way you've put it in your witness statement was that you didn't comprehend what the diagnosis meant in terms of your medical condition or your life?

A. No, no, not at all.

Q. You are absolutely right the doctor whose letter we have just been looking at, the letter makes reference to there being an intention to refer you to a gastroenterologist.

You say in your statement that you were essentially lost to follow up from 1997 through to about 2004.

A. Yes.

Q. Do you know what happened in relation to that referral?

A. I don't know. I think, you know, it's one of those things that happens. I don't think I -- as far as I can recall that I remember being told I was going to be referred and I think when I didn't receive a letter of course I didn't know that I was expecting a letter so I probably didn't follow it up from my end, and I was not required any further follow up at that time by the haematologists who I had been under for

treatment.

So life just went back to normal. I didn't have to -- it wasn't until a few years later that I think I said to my GP once, "Oh, I was once diagnosed with hepatitis C, does that need following up or anything?" And that was quite a number of years later.

Q. You have got some recollection of some form of medical interactions potentially in 2004 but it's really only in 2012 that we see matters relating to your hepatitis C being picked up and discussed?

A. Yes.

Q. Can we have a look, please, at another document. It is 1416011 this is a letter King's College Hospital, July 2012. We can see just down the bottom of that first page under the heading "Diagnoses", at point 4 it says:

"Hepatitis C diagnosed 1992? Transfusions acquired."

As far as you're aware that's mistake and the diagnosis was made the 1997 as we've just seen.

A. Yes and there were several other letters that say 1997 so I think this was probably just a mistype or something.

Q. If we go on to the second page of that letter, please, the second paragraph, we see there a liver biopsy was

done in 2012 and stage 4 fibrosis there identified. Then if we could look further down the page, near where that handwriting is, please, Paul:

"We discussed the risks and benefits of hepatitis C treatment. She has clearly looked into this. I have encouraged her to do as much reading into this as possible."

Is that your handwriting on the side?

A. It is, yes.

Q. Your note when you looked at your records is:

"First time Hep C really discussed with me."

A. Mmm.

Q. I think you were also told around 2012 that the genotype of your Hep C, which was genotype 3A?

A. Yes.

Q. In fact, if we get that up on screen, please, it's 1416012, first paragraph, please.

We can see there the confirmation of the genotype and then it says this:

"In particular the HIV test which is done routinely in all patients before starting hepatitis C treatment was negative."

Were you aware that you were being tested for HIV?

A. No, I don't think I was.

Q. Now, I wanted to ask you about the treatment for the hepatitis C and the various different treatment experiences that you underwent. You first underwent treatment with interferon and Ribavirin in 2012-2013 --

A. Yes.

Q. -- for about 28 weeks was the intense course of the treatment?

A. Yes, yes.

Q. What can you tell us about that experience?

A. The experience wasn't as bad as I hear from some other people. I generally felt a bit unwell and an issue that I think has come from the hepatitis C but we'll probably touch on a different point as being depression and tiredness generally, and I think it was made worse during that period. But I was able to keep on working so, you know, I wasn't laid low by it. Unfortunately, the treatment didn't work and I was told that that was not so uncommon with my genotype, that it didn't always work. So that was it, pretty much.

Q. Yes, you described in your statement that you felt poorly and had flu-related symptoms but, as you say, you were able to keep working throughout that treatment?

A. Yes.
Q. There was then in 2014 a clinical trial that you were involved in using Sovaldi --
A. Yes.
Q. -- one of the newer drugs?
A. Yes.
Q. But you had to abandon that for unrelated reasons?
A. Yes. I only had one dose of that and I couldn't carry on with the trial.
Q. Then it was finally in 2017 that you embarked upon a third course of treatment?
A. Mm-hm.
Q. That was successful in the sense that it cleared the hepatitis C virus?
A. Yes, yes.
Q. What you've said in your statement after that three months of treatment you were finally pronounced clear of the virus in February 2018 but you still have the liver damage?
A. Yes.
Q. And you still have to have regular checks in relation to that?
A. I do, because the degree of cirrhosis is enough to warrant six-monthly checks.
Q. Were there any particular side effects in relation to that course of treatment, that last course of treatment?

A. No, the final course of treatment seemed to be free of side effects, as far as I was aware.
Q. I want to take you back to the effect overall of the hepatitis C on you, both physically and mentally.

What was the main physical effect of the infection? What's it been for you?
A. It's very hard to specify or quantify. Certainly over the years I feel I've become more fatigued in daily life, tired, than I would expect at my age and so on. You know, you don't know what to compare to.

I would say fatigue was really the main thing. I haven't had any jaundice or any other sort of overt symptoms from the liver damage that I can actually point a finger to and say that's definitely the hepatitis, so yes.
Q. What about the mental impact?
A. The mental impact, I would say that in terms of, again, directly relating to the fact that I have got hepatitis C and these are the consequences, this could happen in the future, I can't say that I've suffered a great deal of stress from just the knowledge itself and being a survivor of bone marrow transplants and that sort of thing tends to make you feel, well, gosh, you know, that's -- you know, you've got through that sort of thing.

However, over the time since becoming infected and as the years have gone by, I have suffered more and more from depression, really quite badly at times, and I have been told by the liver specialist that depression is something which is quite often linked with hepatitis C, so I'm guessing that that's probably the main cause insofar as anybody can tell, yes.
Q. You've been very candid in your witness statement about how that's affected you in particular from 2011 onward --
A. Yes.
Q. -- when you said the fatigue and the depression that you were experiencing, as it worsened you began to plan suicide.
A. Yes, yes, I did. I had a business. I ran a shop, a needlework quilting shop with a good friend of mine for -- we started in 2005, so we had been running it for about seven years and so on and that was my situation in mid-2012 when the depression reached a point where I really felt that I couldn't just keep going or, you know, envisage another several decades of feeling the way I felt and I was also, although I'm not married and I don't have a family, I've got very good friends and I realise that the impact of my depression on them was really not good at all, including my business partner, and you kind of feel like you want to release those around you from having to worry about you.

But I felt I couldn't do it, couldn't do the deed, while I still was running the business with my friend because I didn't want to leave that responsibility on her, so I waited until we'd sold the business and, you know, sort of really planned it out and I actually made an attempt on my life when we'd sold the business in February 2013.
Q. You gave yourself an injection of insulin ten times in excess of the normal adult dose.
A. Yes, I did.
Q. But you don't know whether you changed your mind or whether you were concerned that you hadn't given yourself enough to be effective?
A. No, about five hours after the injection, I still wasn't as bad as I thought I ought to be. I was only beginning to have symptoms and I -- yes, I began to think, "Oh no, I haven't taken enough. I'm going to end up with irreversible brain damage. That's going to be even worse for everybody around me", and I called an ambulance. I didn't consciously change my

mind but who knows subconsciously maybe I did, I'm not sure.

But actually when the attempt didn't succeed, it was a bit of a turnaround point because I thought, "Well, I'm not going to try again, I'm living, I'm still alive, and I've just got to go on and find the best way of doing that that I can and put things into place that will, you know, make life better or ..." yeah.

Q. You did receive some assistance after the events that you've described, in fact, through the intervention of a police officer.

A. Yes, yes. When I left the hospital a couple of police turned up on my doorstep a few hours later saying the hospital had sent them out for me to bring me back because once they done the blood tests they realised I'd taken an awful lot more than they thought I had at first. Unfortunately -- well, fortunately I'd chosen a form of insulin that was longer-acting and it had taken a while to act and although the hospital didn't offer me any mental health support, this very nice police officer took it upon himself to refer me to the mental health services and I saw somebody fairly quickly. It was three and a half years before I finally got to see a councillor on the NHS but

that's another story.

But, yes, so after about three and a half years I got to have some therapy for a few months.

Q. So you had I think initially your GP prescribed you some antidepressants?

A. Yes.

Q. But it was about October 2016 when you first got to see a psychotherapist?

A. Yes.

Q. And you had for a period of time I think quite a lot of sessions.

A. Yes, a year, a year's worth.

Q. Ultimately, was it helpful?

A. I suspect not. I'm not sure that it was. I think more long-term help has been my very good friends, my Christian faith to some extent, although I've struggled with that probably because of the depression, you know, everything's bound up together. But I don't know whether it was of help or not. I was grateful to receive it because some people don't get that far but, yeah, I'm not sure.

Q. Can I ask you to describe the effect, the toll on your daily life, of the fatigue and depression that you experienced in consequence of the hepatitis C infection.

A. It's sort of increased over the years, I suppose, to the point where it's affected work. Certainly, despite my period running a shop for nearly eight years, I've spent most of my working life as a medical secretary, having originally trained as a doctor many years in my youth but not practised medicine, and I began to struggle a lot with concentration and that kind of thing.

Because I was struggling to deal with people, and an opportunity came up for me to work from home, I opted for that and I probably not very healthily sort of withdrew a bit into my shell and I could work from home and not have to deal so much with other people, I guess.

But I started working for an Australian company downloading medical dictations and typing them or proofreading them and I was actually fired from one of those jobs just about three years ago now because of lack of concentration. I sent a couple of the letters back to the wrong client; so obviously that's got data protection implications and was quite a serious thing to do.

Most of my working life I've been really highly thought of and, in fact, even sought after. You know, once I've left a job the employers have contacted me

and said, "Oh, could you possibly come back and help out", so that's quite humiliating really to come to a point where my work has reached a thing where I have to be fired and that's really due to concentration issues, motivation working from home.

Q. You said in your statement that that fault for which you were fired, not something you would normally do?

A. Yes.

Q. You were very upset by it, you were suffering from fatigue and concentration problems because of the hepatitis C and then that dismissal had a knock-on effect for you in terms of how you then progressed with your work.

A. Yes, yes, that's right and that's obviously a long-term worry. I'm still doing some work from home but financially obviously there are implications as well and although I have an income from The Skipton Fund which I'm very grateful for and it covers my mortgage payments, it's not enough to cover bills and food and, you know, all the normal things that we need. And, of course, because of having had hepatitis C I can't get any kind of insurance, certainly not indemnity to cover my mortgage or any kind of sickness insurance should I have to stop working or take too much time off work sick.

So for the future that's a difficult thing as well, to work out how to kind of make way financially.

Q. You had a period after the cessation of the employment you have described, you had to apply for universal credit for a period of time --

A. Yes.

Q. -- which you didn't particularly want to do but --

A. No.

Q. -- but you felt you had no choice.

Then you were able to get some temporary work and then you began to work for another company which had different systems --

A. Yes.

Q. -- that you felt comfortable with that you weren't going to, through your hepatitis consequences and symptoms, make any mistakes?

A. Yes.

Q. But I think you have had to adjust the way in which you work in order to accommodate that. Can you tell us a little bit about that?

A. Well, I am working for another company now, also Australian (they tend to pay better than the British companies) and so I do work for them. I am actually still registered with Universal Credit because my hours are still quite limited and that really is

linked to the depression and the associated concentration, motivation issues and fatigue and how long I can work each day. So some months I do better than others. The work tends to be pretty much, other than Christmas and so on, always available but I am limited by how much of it I can take off from them and that's sort of the current situation.

Q. So you are essentially working part time doing what you feel physically and mentally able to do?

A. Yes.

Q. You are working purely from home?

A. Yes.

Q. And that has both the benefit that you don't have the pressure of interaction with others but the disadvantage for you of isolation?

A. Yes, yes, and I've taken steps. I've given myself a kick up the backside and, you know, I've taken steps to try and get out a bit more. I've joined a choir again, I used to sing a lot, and that kind of thing to sort of help that.

Q. You say in your statement that you have a longer term worry about the future, that your future is unclear and you're concerned that there will be a serious ongoing impact on your ability to obtain or sustain employment.

A. Yes, I think so and that's a bit of a mixture, not just of how I feel within myself but applying for a job outside of the home requires references and I've not done so well having been fired from a job and so on, and last time I did have an outside job where I was employed as opposed to self-employed there were some issues there with the occupational health discussing the hepatitis C infection and the depression and so on and they -- I did get the job but there was quite a lot of kind of queries and questions over it. So I'm not sure how that will play in either. But, yes, it's mostly how well I think I could cope with it or whether I could get a job or if I got a job whether I could keep it.

Q. I understand again from your statement that there was an impact upon your education because there was a particular qualification you were studying for.

A. Yes. I was doing a proof-reading qualification because I mean I've worked informally as a medical proof reader, but I wanted to get a formal proofreading qualification to allow me just to extend what I could do a bit and also because I was working from home possibly get work outside of -- when I'd done the proofreading work it was mainly for the consultants I was working for and I thought if I had

a qualification I could offer myself as a proof reader to possibly medical journals and the like or in a non-medical area.

Many years ago I went to theological college as well and I thought maybe I could offer myself in that area which has got some quite specialist language and so on, but I had to give up the course before -- I just couldn't study properly or get to finish that so I had to give that up.

Q. I think a number of years ago before you were infected you spent quite a lot of time travelling?

A. Yes.

Q. Been to a number of different countries?

A. Yes.

Q. You've described the change for you through the hepatitis C and the consequent depression as a change from being a highly self-motivated individual who taught herself languages to having no motivation or interest in doing anything at all?

A. Yes, I think that's fair to say. I mean, if you are somebody who knew me even, I don't know, 10/15 years ago they would probably describe me very differently. I was well respected at work. I was very busy. I did a lot of singing as a soloist and in groups, in opera and other areas. I taught, I got together groups to learn to sing as a choir of singers. I taught singing. I taught needlework and so on when we had our shop and before that. I was involved -- you know, I went overseas doing relief and development work. I was quite involved in the church I belonged to with caring for homeless people and I was a lay preacher and all these sorts of things and liked being able to participate and be of -- you know, give back to the community, as it were.

Yeah, I've reached the point where I really don't do anything and sort of try not to hide from the world. I've been trying to not to, especially for the last few months, but making positive steps there but, yes, it's been a real turnaround from the kind of life and the sort of person I was, I suppose, yes.

Q. You've got a close community of friends --

A. I've got -- yes, some close friends.

Q. -- who have been a tremendous support to you?

A. Yes.

Q. But you also say in your statement that your infection has had an impact upon that relationship because you have been a worry to them and you haven't been able to do with them some of the things you would have wanted to do.

A. Yes. Again, I think that's more the outcome with the

link to fatigue and depression. At one point a few years ago my very best friend, and she said it kindly, said, "You know, sometimes when you're in the room, it's just like having a dark cloud in the room", and that was really painful and I've learnt ways over the years. I now call myself a cheerful depressive because quite a lot of people wouldn't know how I sometimes felt inside and, actually, sometimes I think, well, it's a choice how we, you know -- or a good friend of mine says you fake it to make it and, you know, there's some truth in that if I choose to be cheerful, you know, it feels better and that's obviously better for my friends.

So you're right, it was very painful to see the effect I was having on people that really cared a lot about me and, you know, as I said, that was one of the things that really made me think about suicide because I didn't want to do that to them. I think since then I've found ways of actually being better when I'm with people so that that hasn't got such a big impact on them.

Q. You've told us about the financial impacts through your employment and The Skipton Fund which you say it's helpful, covers your mortgage, but isn't enough to cover bills, food, other outgoings?

A. No.

Q. Can I just ask you about The Skipton Fund application.

A. Yes.

Q. You made an application in about 2012 and you got the stage 1 payment, which was the lump sum payment.

A. Yes.

Q. Then in due course it was recommended to you by your doctors I think that you should apply for a stage 2 payment?

A. Yes.

Q. What happened in relation to the progress of that stage 2 payment?

A. Yes, well, I'd been diagnosed with stage 4 fibrosis and the word cirrhosis was sort of bandied about and the consultant said that's definitely enough to qualify for the second stage payments. So I sent in the application form and, you know, the doctors filled that in and that was refused and when I tried to find out why, it appears that in the NHS they use in pathology they use the Ishak Staging System to classify levels of fibrosis of the liver and, apparently, at that stage, it was borderline cirrhosis. It turned out that the Skipton Fund people used a different staging system which was also borderline but whereas in the NHS system I was over

the border, with the Skipton system I'm not sure what they called it, the classification system, I was slightly under and my consultant wrote back to them saying, you know, to all intents and purposes, Kate has this degree of liver damage which is, you know, and she is eligible for this, but they refused it again.

I just left things at that point and it was I think, I'm not quite sure of the timing, maybe it was a couple of years after that that I had a fibroscan which showed that the damage had increased quite a bit and so it was suggested that I reapply and at that stage The Skipton Fund granted me the second stage payment.

Q. Which I think you finally got in February 2017.

A. That sounds about right.

Q. That's the date in your statement.

A. Yes.

Q. Although you eventually got that, you spent some time trying to get it?

A. Yes.

Q. But, in fact, I understand there was quite a significant period of time, you're not exactly sure when but between your diagnosis in 1997 and more recent years in which you simply weren't aware of the existence of The Skipton Fund at all and so didn't make an application.

A. No, I wasn't aware of it and I was just rereading my notes earlier and last night, and there is a note somewhere -- I did write it down if it is important in a letter, 1416011, which is 2012, where the doctor there is actually confirming the diagnosis and he says he encouraged me to apply for the Skipton funding.

Even once I knew about it, actually, the initial payment I decided not to apply for it because at the time I didn't realise what the implications would be financially. I didn't -- I wasn't in financial trouble at that time and I'm a bit -- I don't like the idea of applying for compensation for the sake of it, sort of thing. I wasn't quite sure if it was compensation anyway but, you know, I'd raged on about UK is going to become like America. We're going to demand money for, you know, falling over a pin or whatever.

So it was, I think, a couple of years later when I really realised that I was struggling financially and that it was reasonable that I receive the money and fair and I applied for it then. That was the initial one, the initial stage payment.

Q. The way you put it in your statement is after you did

finally find out about The Skipton Fund, and the precise dates don't matter, Kate, you didn't apply for some time because you felt like you didn't deserve it?

A. Yes, yes.

Q. And then when you finally made your application for the stage 2 some years later, you had debts and that's the point at which you realised you shouldn't be ashamed to take this money?

A. Yes, yes.

Q. Is there anything else, Kate, that you would like to add?

A. I don't think so.

MS RICHARDS: I am just going to turn my back and ask Mr Snowden who, as you know, represents you to see if there's anything he has.

No, nothing.

SIR BRIAN LANGSTAFF: It remains for me to say thank you very much indeed, Kate, for coming to share your story with us.

A. Thank you.

SIR BRIAN LANGSTAFF: That is the last witness for today.

MS RICHARDS: It is, sir.

SIR BRIAN LANGSTAFF: Who do we have tomorrow?

MS RICHARDS: Tomorrow we have three witnesses. We have, first of all, Clair Walton, we then have an anonymous witness, witness 140, and then we have a change to the schedule. We have had to reschedule a witness until later on and so we have instead Lesley Brownless who has very kindly agreed to give evidence at short notice.

SIR BRIAN LANGSTAFF: That is very good of her. Thank you very much. So we shall start then at 10 o'clock and I look forward to seeing you and anyone else who wishes to be here at 10 o'clock in the morning. By all means, stay for tea, if there is any.

(2.29 pm)

(Adjourned until 10.00 am the following day)

INDEX

F: