

ANONYMOUS

Witness Name:

Statement No: WITN1974001

Exhibits: WITN1974002-WITN1974004

Dated: 4 February 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF

Section 1. Introduction

1. My name is My address and date of birth are known to the Inquiry.
2. I am white British and have been married for 37 years. I have one child and three grandchildren.

Section 2. How Infected

3. I was infected with Hepatitis C on 29 February 1988. I received two units of whole blood at when I was rushed to the operating theatre having lost a baby.
4. I became aware that I had had a blood transfusion when I woke up on the ward after surgery; the nurse was changing and putting up another bag of blood. No one informed me how many units of blood I had received in the operating

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theatre. I was in hospital until 5 March 1988

5. I was not advised at any time of any potential risks of being exposed to an infection through the blood transfusions.
6. I was informed I had Hepatitis C in 1993 by letter from the blood transfusion service at Southampton. A few weeks beforehand I had tried to donate blood for the first time since my transfusion in 1988. The letter was very basic; it simply stated that Hepatitis C had been picked up in the donation that I had given. There was a lot of emphasis in the letter that it was only Hepatitis C and that no other serious infections had been found. I guess they were saying that HIV had not been detected. The letter requested that I phone to make an appointment.
7. I think it was very wrong to just send a letter in the post informing me that I had Hepatitis C. I was extremely distressed on reading the letter, I read it over and over again. I just could not take the information on board I thought it must be a mistake. I had to wake my husband up, he was sleeping in the day time having just worked a night shift in the NHS.
8. Within two weeks I was seen in the Haematology/ Blood Donor unit at Southampton General Hospital by a Consultant Haematologist. After some discussion he informed me that the blood transfusions I had received in 1988 were the most likely route of my Hepatitis C infection. I felt that the seriousness of the infection was played down.
9. The only information that I was given in relation to the risks of passing the infection to others was in relation to sexual activity. I was advised to use the barrier method. This was difficult to hear as my husband and I had fertility

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problems and were trying for another baby.

10. On 1 March 1993 I was seen by Dr Snook, a Consultant in General Medicine at GRO-B, who informed me that all my liver function tests were normal. I was told that I had probably cleared the Hepatitis C virus, and that I should not worry any more about the diagnosis. I was then discharged from the clinic.
11. Approximately two weeks after my appointment in 1993, having had time to think, I wrote to the Consultant Haematologist asking the department to test the tags which would have been on the units of blood that I had received in 1988. As a nurse I knew these tags should have been stored and made available for testing for 10 years. I believed that these tags could confirm that the blood transfusions were the source of my Hepatitis C infection, and could enable the Blood Transfusion Service to trace the donor.
12. The Consultant Haematologist wrote back to me to say that they were not doing a look back exercise. Sadly I no longer have a copy of the letter but refusal of the NHS to take these steps is widely known.
13. The blood donor could have been traced and treated. They may still be out there, undiagnosed with deteriorating liver function and also risk of infecting other people. I find it so hard to comprehend why the NHS refused to test the blood transfusions I received or do a look back exercise.
14. In 1995 out of the blue I received an appointment at the Hepatology clinic at Southampton General Hospital. At the appointment I was informed by the Consultant I had Chronic Hepatitis C. They informed me of this without taking any blood samples.

Section 3. Other Infections

15. I have recently learnt that I am also at risk of having received CJD through contaminated blood. No one informed me of this risk at the time of the transfusion, or at the time that I was diagnosed with Hepatitis C. I found this out through my own research.

Section 4. Consent

16. I do not know whether I have been treated or tested without my knowledge, or without my consent, or without being given adequate and full information. I have had problems accessing my full medical notes; I have had to apply twice and even now key documents are still missing from around the time of my diagnosis and the early consultation with the Consultant Haematologist in 1993.
17. Several years after my diagnosis of chronic Hepatitis C I read a summary of my medical notes which included the sentence *RNA was detected but patient not informed*. I understand this to mean that I had a chronic Hepatitis C infection and that they had not informed me. This document is now missing from my notes.
18. I am sure this result would have come from the bloods that were taken in 1993 at the Haematology Department at Southampton General Hospital. However as mentioned above I was not informed I had a chronic Hepatitis C until 1995.

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19. I do not know what triggered the letter from Southampton General Hospital asking me to attend an appointment in 1995. I have requested my notes which include a letter from Dr Snook to my GP following my appointment in 1993. This letter states that I was not a candidate for interferon therapy and that he had not made me a further routine clinic appointment [WITN19740002]. There is then a copy of a referral form sent to my GP asking her to refer me to the Hepatology Department for formal review in the liver clinic [WITN19740003]. I have no idea who sent this to her. The letter sent to my GP following my appointment in 1995 states that the Hepatitis C was picked up when I had tried to give blood earlier that year, however this was found in 1993 and not 1995 [WITN19740004].

20. In 1997 I did take part in consented research studies when I was under Hepatology department at Southampton general I did this as it was the only way I could receive any treatment. All of these notes are missing or unavailable.

Section 5. Impact

21. In the early years Hepatitis C had little physical effect but as the years passed it began to take its toll. In 2013 I developed liver cirrhosis and day to day life became increasingly difficult. My limbs ached and felt heavy. My liver ached sometimes, either a very sharp pain or a dull ache that lasted for days.

22. I started to suffer from extreme fatigue and poor concentration, at times even simple conversation was difficult. I often used the wrong words when talking or said sentences back to front. This had a dramatic emotional effect, leading to a lack of confidence and frustration at not being able to hold a sensible

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conversation. I got to the point when I did not feel confident to even drive my car and only drove short distances.

23. I found it very difficult when I lost concentration at work during consultations with patients. I became fearful that I might make an error. At times it felt like my brain just would not function. At home I was withdrawn from social life and found just going out for a walk exhausting. I was not sleeping well and found tasks around the home increasingly difficult to maintain
24. I had three awful treatments for Hepatitis C between 1998 and 2013. Each treatment lasted a full year, each failed to clear the virus.
25. In 1998 I had to inject myself with standard Interferon three times a week for one year. In 2001 I took Ribavirin tablets twice per day and a Pegylated Interferon injection once per week. This caused fatigue, anaemia, and difficulty with day to day living. I developed double vision. In addition this treatment caused me to go through early menopause at age 44.
26. In 2013 I was started on Pegylated Interferon injections again once a week, Ribavirin tablets twice a day, and twelve Boceprevir tablets a day. This was an absolutely awful treatment. I suffered from severe anaemia and fatigue. I was unable to cope with day to day living and could not sleep at night. I required twice weekly injection of EPO to help with anaemia.
27. Each time a treatment failed it would take me at least a year to recover both physically and emotionally. During each treatment the viral level in my blood would drop but would then rise again after failure. After each failed treatment I felt as if I was being infected again.

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28. After the third treatment failed my liver deteriorated considerably. In February 2013 I commenced six monthly screening for liver cancer. This involves a liver scan and a blood test every six months for the rest of my life. These tests cause considerable anxiety each time they are due and day to day I live with the constant stress of the risk of developing liver cancer. I have had four very painful liver biopsies and also a gastroscopy
29. In 2016 I started my fourth treatment for Hepatitis C. I took a combination of Sofosbuvir, Ribavirin and Ledipasvir. This was a trial for people with Cirrhosis. This treatment was successful and I was informed that I had cleared the Hepatitis C Virus on 23 February 2016 after being infected for 28 years.
30. I had to wait 15 months to commence the fourth treatment as the government was rationing treatment due to cost. Southampton Hospital like many others was limited in how many patients they could treat each month.
31. After the fourth treatment I was very happy and could not believe I had finally cleared the virus. However soon afterwards I developed bowel problems, and an intolerance of lactose and artificial sweetener. I have been informed that this could be linked to immunity problems resulting from my prolonged Hepatitis C infection. I have been referred to a specialist for further investigations.
32. The symptoms can come on very suddenly, they are very painful and can be socially difficult. I have also developed an intolerance of caffeine which causes a pounding heart, sweating and insomnia. I scan food labels but many foods and soft drinks contain artificial sweeteners and caffeine. It is difficult to avoid these hidden ingredients specially when eating out.

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33. Hepatitis C has and still does cause me unimaginable emotional and physical stress. I still get severe acute liver pain, tiredness and limb aches. I still have some difficulty in conversation. I often find that I am using incorrect or opposite words and sometimes lose the thread of a conversation. Every time an email or letter arrives I get stressed. Every appointment with doctors or at the hospital brings on anxiety: will I be treated right and with respect? Do I have to explain everything again? Will they believe me?
34. From the date that I was diagnosed I worried about infecting close family members, at the time my husband and young son and later in life my grandchildren. Every little cut or scratch worried me and I was always thinking: could I infect someone? I hated my own blood.
35. The diagnosis had a massive impact on me and on my family. My son was 6 years old when I was diagnosed and he had to have blood test to screen for Hepatitis C, how do you begin to explain to a 6 year old why he needs to have a blood test? My husband was also tested but fortunately they both tested negative to Hepatitis C Virus.
36. I was advised to use contraception barrier devices. This was very difficult to take on board as we had infertility problems and were trying to conceive. Once the treatments started I had to confirm that I could not or would not get pregnant during treatments as Interferon and Ribavirin are toxic and are known to cause foetal abnormalities.
37. We were very lucky to have one child, our son, by IVF. After the Hepatitis C diagnosis we decided not to go for any more IVF attempts. Only specialist

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centres would offer treatment to me given my diagnosis of Hepatitis C, and we were concerned about the risk of passing on Hepatitis C to the baby.

38. Hepatitis C not only affected me but my whole family who worried and watched me suffer over the years. Sadly my mother passed away not knowing that eventually I did manage to clear the virus on my fourth treatment
39. From diagnosis onward, at nearly every clinic appointment I was asked these three questions:
 - Have you ever injected any drugs or taken recreational drugs?
 - Have you any tattoos?
 - How many people have you slept with?
40. Time and time again I have had to inform medical staff that I was infected via a blood transfusion. It is documented in my notes that a blood transfusion was the most likely source of infection. However I often felt that medical professionals did not believe me when I said that I had been infected via contaminated blood, and I was asked repeatedly about my sexual activity and history of drug and alcohol abuse. If I had not had to explain myself at every appointment I am sure that I would have coped better with my infected status. Maybe it would have given me the confidence to be more open about my infection.
41. This is how the stigma and the shame began. I could not talk about my Hepatitis C or the treatment with friends, colleagues or neighbours. I tried to cover up how ill I was feeling for fear someone would ask about my health. Only close family knew and they could not share this information with anyone. I was very anxious that my young son would tell other people. It was very difficult

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for my family not to be able to talk about my condition to others, or to explain why I was looking so unwell when I was ill or on treatment.

42. Hepatitis C has affected all areas of my life. Dentists have refused appointments or have forced me to attend at the end of the day. My GP and hospital appointments notes had red warning stickers on them. GPs have been reluctant to prescribe analgesia because they have linked my diagnosis of Hepatitis C to drug abuse. For example when I broke my arm the pain was terrible; I am intolerant to Ibuprofen but my GP refused to prescribe me anything stronger. At that time GPs seemed to have little understanding of Hepatitis C or the treatment available. I do feel that attitudes have changed as there has been more publicity of the contaminated blood.
43. The stigma meant that I could not share my diagnosis with colleagues, and taking time off sick was difficult. For example once after having a liver biopsy I returned to work the next morning when I should have been resting. I worked for the whole day in considerable pain.
44. The stigma continues even after death. I went to co-op to arrange my funeral plan as I had read that the Caxton Foundation would pay £3,500 towards it. I was informed by the funeral directors that due to the Hepatitis C they would not be able to touch my body or to embalm me. They said that I would be sealed in a black bag marked as an infection risk and that no family members would be able to see my body. I cannot begin to express how emotionally distressed this makes me feel. This has also had a huge emotional impact on my husband and my son.
45. I qualified as a registered Nurse in 1978. Hepatitis C had an effect on my

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career and on the areas where I was allowed to work. I would have liked to work in operating theatres, but moved into general practice as this was thought to be a safer area for me to practice in.

46. Through my first treatment in 1998 I managed to continue to work in my position as a Senior Practice Nurse, but it was so hard. In my Practice Nurse Clinics I had a patient who was undergoing the same interferon treatment as me. It was incredibly difficult to listen to them tell me that I had no idea how hard it was to go through the treatment.
47. During the second treatment in 2001 I was in the same post as a Senior Practice Nurse. Working through this treatment was even more difficult. I looked pale and unwell and had lost some of my hair and lots of weight. Colleagues noticed how ill I looked and often asked if I was feeling OK. Although these questions were normal I found them very stressful and would try my best to lie and say that all was well. The rumour at work was that I had emotional problems, I could not tell colleagues the truth.
48. Eventually my occupational health GP forced me to take two weeks leave. On my return I had to reduce my hours to 21 hours a week, meaning that I lost a considerable amount of money each month.
49. When I started my third treatment in 2013 I had to leave my job as a Senior Practice Nurse as I knew the triple therapy treatment would be impossible to work through. Again because of the stigma I could not let my colleagues or the patients I cared for know about my Hepatitis C status. I had to lie about my reasons for leaving my job, I handed my notice in and left. Leaving my job left me on the bread line.

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50. The stress of this difficult situation along with the fear of bumping into people socially is too difficult to begin to express.
51. The career I loved as a Senior Practice Nurse was ruined and cut short. In accordance with the Nursing Midwifery Code of Conduct I no longer felt fit or safe to practice as a Registered Nurse. I gave up my State Registration with the Nursing Midwifery Council in 2014, at least 10 years before my official retirement age. My ill health forced me into early retirement and caused considerable financial difficulties.
52. If it were not for the Hepatitis C I would still be employed as a Senior Practice Nurse. The average salary for this position is £43,850 per year, which is approximately £22 per hour. Retiring 10 years early due to ill health gives me a potential loss of earnings of approximately £438,500 in paid salary, plus a loss of 10 years contributions to my NHS pension. This considerable lost income has put pressure on family finances and has meant that we have always lived on a tight budget. My husband was diagnosed with cancer aged 50 and was unable to work, this meant for a number of years neither of us had a regular income.
53. I have received no funding for the costs of travelling to appointments at Southampton Hospital. I would not have had to travel to these appointments if it was not for the Hepatitis C. Each appointment is a 60 mile round trip, with parking fees of a minimum of £3 on each visit. During treatment I was having 20 to 26 appointments per year, this is at least 1200 miles and £60 in parking fees for each year that I underwent treatment.

Section 6. Treatment/Care/Support

54. I attended counselling sessions paid for by the Caxton Foundation. I had to organise these myself and to choose a local counsellor, however there was a very limited supply of counsellors in my area. I stopped after seven sessions as I found the counsellor's comments unhelpful. She remarked that it did not matter how I got the Hepatitis C Infection but to me it certainly did matter. I had done nothing but become seriously ill; I went into hospital in 1988 with one thing and came out with a life changing infection.

Section 7. Financial Assistance

55. I first heard about the Skipton Fund on the radio. I looked them up and applied for the stage 1 payment which I received in January 2005. I used this money to pay off some of our mortgage in order to reduce our monthly outgoings.

56. I was later informed by a hepatology nurse that I should contact the Skipton Fund to find out about applying for the stage 2 payment. I phoned the Skipton Fund and was told by the person on the phone not to bother applying as I would not qualify for the payment. I applied by email anyway, the payment was authorised within 30 days.

57. I received the stage 2 payment in August 2013. I still have this money in the bank. I am too scared to spend it and feel that I have to keep it for future security. I now receive monthly payments from EIBSS. I have also received the funeral grant of £3,500 from the Caxton Foundation.

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58. I think that the foundations should have contacted me to inform me of what funding or financial support was available. I only found out what I could apply for through my specialist nurse and through the support groups. I think it is unfair that there is a disparity in the financial support given to people in the different countries of the UK.
59. I would like there to be a final settlement of compensation awarded to those who have been infected through contaminated blood, rather than ex gratia payments. This has been going on for far too long, I would like to see an end to it so that I can try to move on emotionally and financially.

Section 8. Other Issues

60. I looked into joining a group litigation in around 1995 through a solicitor in Portsmouth. However at that time they would not offer us a no win no fee agreement and we would have been risking our home if we joined, so we decided that we could not proceed.
61. I am happy with the terms of reference set by the Inquiry. I hope the inquiry can find out why so many people were infected and why the infection of people was allowed to continue even when evidence of the risk was available. I would like to find out why blood was imported and why donations were taken from prisoners and people in high risk groups.
62. I was infected on 29 February 1988. At that time I believe there was plenty of evidence of the risks of spreading Hepatitis C through blood transfusions. The units of blood that I received could have been tested for Hepatitis C before they were given to me.

63. I was infected at the age of 30. I am 61 now; I would just like to have answers before I die. Some family, friends, neighbours still do not know of my Hepatitis C status. The last 30 years of my life would have been very different if I had not contracted Hepatitis C via contaminated blood. The impact it has had on myself and on close family is unimaginable and impossible to put fully into words.

Statement of Truth

I believe that the facts stated in this written statement are true.

Signature..... .....

Dated04.02.2019.....