

ANONYMOUS

Witness Name:

Statement No: WITN0874001

Exhibits: Nil

Dated: 24/07/2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 04 April 2019.

I, will say as follows: -

Section 1. Introduction

1. My name is My date of birth is 1957 and my address is known to the Inquiry. I retired as a Paramedic from the ambulance service in 2000 and currently live with my wife. We have one child and three grandchildren. My son has also provided a statement to the Inquiry. (WITN0875001)
2. I intend to speak about my wife's infection with the Hepatitis C Virus ("HCV"), which she contracted as a result of being given infected blood transfusions. My wife has provided a statement via her solicitors. (WITN1974001)

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3. In particular, I intend to discuss the nature of my wife's illness, how the illness affected her, the treatment she received and the impact it had on her life and the life of my family.
4. I confirm that I have chosen not to be legally represented and that I am happy for the Inquiry team to assist me with my statement.
5. I can also confirm that I have had explained to me the use of my statement form. I am happy to sign the consent form on the basis that it will be submitted when my statement is signed.
6. I would like to claim anonymity on the basis that my wife does not want to be identified. She has previously made a statement to the inquiry and has sought anonymity due to professional reasons involving patient care. (See WITN)

Section 2. How Affected

7. My wife was infected with HCV on 29 February 1988, at GRO-B GRO-B, when she received blood transfusions after suffering an ectopic pregnancy.
8. My wife and I had been trying for children for several years. During 1985/1986 we were having fertility treatment and eventually, had our son via IVF. He was born at GRO-B by caesarean section in 1987.
9. We continued to try for more children, until the following year when my wife started to suffer from abdominal pains. She was seen by her General Practitioner ("GP") and was then referred to a consultant, Mr. Scott, who arranged for my wife to have a dilation and curettage procedure. The following week she was in severe pain and following examination was diagnosed with having a ruptured ectopic pregnancy.

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10. My Wife was then rushed to the operating theatre on 29 February 1988, at GRO-C When she came around after her surgery she became aware that she had been given a blood transfusion. I believe she was given two units of blood in theatre and on the ward after her surgery. However, we were never told exactly how many units of blood she had received.
11. At no point did anybody tell my wife or I that there was a risk of developing an infection through blood transfusions or indeed that there was any risk at all.
12. Having recovered from the surgery, within a few weeks she began to suffer from fatigue and had the appearance of being jaundiced. I believe she had put it down to the general effects of having a transfusion, as she had heard from work that sometimes these symptoms might occur. Life then carried on as normal and my wife went back to work.
13. After my wife had recovered, we continued to try for another child via IVF. My wife did become pregnant but unfortunately, we lost that baby at about 11-12 weeks.
14. A few years later, around 1993, my wife went to donate blood. Some weeks later, she received a letter from the blood transfusion service at Southampton, informing her that she had contracted HCV. She was simply told in a letter. Not advised to see her GP or a hospital doctor where she could have been given such potentially life-changing news in person. She made an appointment to see a Consultant Haematologist in the Wessex Blood Transfusion Section at Southampton General Hospital. The Consultant Haematologist at the hospital was fairly matter of fact and, to be honest played down the seriousness of the virus. However, he did inform my wife that she had not picked up any other disease.

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15. We were not given much information in relation to her infection, including precautions to take or how to manage it. The Consultant Haematologist at Southampton General Hospital simply told us to have safe sex. This was a huge shame as my wife and I were again trying for another child at the time. At this stage no one would take us on at the fertility clinics. We stopped trying and thought that was it for our hopes of having any more children.
16. My wife was then referred to Dr. Snook, a local Consultant in Gastroenterology at [GRO-C]. Dr. Snook then saw her on 1 March 1993. He informed my wife that she had probably cleared the HCV and that she could go. She was then discharged from the clinic.
17. After seeing the Consultant Haematologist at Southampton, my wife had asked the hospital to do a 'look back' exercise to attempt to establish the source of the contamination. This would have proved beyond doubt the source of infection and also identified the donor so they could also receive treatment. She later received a letter back from a Consultant Haematologist stating that they were not undertaking a 'look back' exercise at that specific moment. I feel the fact they did not do a 'look back' is strange.
18. I would like to point out at this stage that I do think my wife should have been given more information about her HCV infection. As my wife was working as a nurse at the time, the seriousness of the infection should have been explained.
19. In 1995, around two years after being told that she was likely clear of the infection, my wife received an appointment from Royal South Hants Hospital to see a Hepatologist there who informed my wife that she had chronic Hepatitis C. We were never told why now, two years after being told my wife was clear of HCV, she was now confirmed as having Chronic Hepatitis C. There were no further blood tests following the appointment

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where she was given the all clear at [GRO-C]. My wife had been told about her now chronic Hepatitis C without the hospital taking any blood samples. There was no information surrounding this in her medical notes.

20. My wife was offered treatment in 1997 as part of a research foundation. I believe that the foundation was called the Wellcome Foundation. She continued having treatment over the course of twenty years. The impact and effects of the treatments on wife and my family will be discussed further under Section 5 of this statement.
21. I can confirm that both my son and I were tested for HCV when my wife was first diagnosed and both our results came back as negative.

Section 3. Other Infections

22. To the best of my knowledge, I do not believe that my wife has contracted any other infection apart from HCV, associated with her contaminated blood transfusion. But because of vCJD transfusion risk, anyone who received donated blood prior to 1991 is not allowed to donate blood.

Section 4. Consent

23. I have been asked if I believe my wife has ever been treated or tested without her knowledge or consent and the answer is I don't know. My wife was called into Royal South Hants Hospital and informed she had Chronic HCV without being tested beforehand. As far as I am aware, my wife has always consented to her treatments.

Section 5. Impact

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24. The consequences of my wife being infected with HCV and the subsequent treatment she required has had a far-reaching impact, not only on my wife but on my family as a whole.
25. Physically, in the early years of having HCV she was quite well. However as previously stated, she was offered treatment in 1997 as part of a research foundation. She started her first drug trial in 1998 and was given Interferon. This was administered via injections in to her stomach. It lasted for a year. The trial was unsuccessful at clearing the HCV.
26. The Interferon made my wife fatigued. She had just started a new job. Previously, she had spoken to Occupational Health about her infection and was advised to work in non-invasive areas. She had thought of becoming a theatre nurse but was told that this was not possible because of her condition. She was unable to progress as she would have wanted to. This meant that her prospects of progressing through work were diminished. In view of this, my wife left the hospital and became first, a District Nurse and then a Practise Nurse in General Practise.
27. In 2001, my wife started her second course of treatment This consisted of Pegylated Interferon by injection and daily Ribavirin tablets. Once more the treatment was unsuccessful.
28. The side effects of the above treatment for my wife were awful. She suffered from fatigue, joint aches, flu-like symptoms, hair loss, loss of concentration and had difficulty working. She was trying to keep it all together but inevitably her work began to suffer. It appears that her employers may have thought that she was having domestic or social problems as a GP from my wife's work came to our house to interview her. My wife discussed what the problems were and the GP told my her to take some weeks off work. My Wife had expressed that during this interview, she felt as though she was obligated to disclose the information

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surrounding her infection to keep her job alive, even though she did not want to.

29. My Wife has suffered greatly with the stigma associated with HCV. The GP who came to our house stated that they were going to have to tell the other partners at the surgery about her infection. However, he also said that it would all be in confidence and my wife would not experience any problems. This was untrue: before the date of her interview, all the members of staff would go to my wife for vaccinations. After the date of her interview, none of the staff went to her for any medical treatments.
30. My wife started her third treatment in 2013; she was placed on twelve Boceprevir tablets a day, along with Pegylated Interferon and Ribavirin. Unfortunately, the third treatment was also unsuccessful at clearing the HCV virus.
31. The third treatment made my wife really ill. Now in a new job role, she knew that the current treatment would make her extremely ill, so much so that she would not be able to full-fill her duties. As a result, she had to give up her position. She was aware that if she asked for time off, everyone would soon find out about her infection and that she would be further stigmatised. The breach of confidentiality from her previous job certainly played a part in those feelings.
32. The symptoms experienced from the third treatment consisted of extreme fatigue and my wife's haemoglobin levels were so low that she required EPO injections. This treatment lasted forty-eight weeks. I remember times when she was physically shaking in her chair she was so ill. The treatments made her seriously ill. She had undetected virus half way through the trial and so the treatment continued to 48 weeks. Unfortunately, the virus came back after the drugs were stopped.

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33. In 2016, my wife was finally cleared of HCV. This was after she was placed on a combination of Sofosbuvir, Ribivarin and Ledipasvir. The treatment lasted three months and my Wife remains clear of HCV to this day.
34. The effects of this treatment were again fatigue and flu type symptoms. As a result of the various treatments she has undertaken, my wife also developed bowel problems. No doctors have ever linked this to her infection with HCV and the medication taken to combat it but she has been told there is a possibility that the two could be connected.
35. My Wife has also developed cirrhosis of the liver. She is having six-monthly ultrasounds and blood tests. She is also having the occasional fibre scan.
36. I remember my wife had a fibre scan last year, where it took the nurse fifty pulses to complete. Normally, these scans would take between ten and twenty pulses. This made it extremely painful for my wife. A previous scan had come back with a score of 10.2, so we were shocked to find the results of this particular scan had come back at 4.9, which was ridiculously low. On the basis of my wife's score being so low, the Consultant Hepatologist discharged her from Southampton General Hospital.
37. Having raised a question about her discharge and having been recalled, she went for further fibre scans last week and we were faced with another shock when the score came back as 10.9. The timeframe between the two scans was around nine months. It is not likely that the scores from the tests could change so drastically. It is not normal for this to happen and it is likely that the previous scan that produced the low reading was conducted incorrectly. As a consequence of the scan last week, my Wife has been placed back onto to the liver scan programme. Currently, she suffers with borderline cirrhosis.

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38. During the treatments my wife was so ill that she could barely get through work. She was so tired when she came home that her social life was non-existent.
39. As previously stated, she has had to deal with a lot of the stigma associated with her infection with HCV.
40. Last year my wife had arranged funeral plans through the Co-Op. She had heard that the Caxton Foundation would put some money towards these arrangements. The funeral directors told her that she would not be able to be embalmed or put on display. She was told that she would be put in a biohazard bag, in a sealed coffin and that would be that. This was devastating news for us to hear and especially for my wife.
41. As a result of my Wife's diagnosis we have always been faced with the same three questions when seeing consultants or doctors in relation to the infection:
 - i. Have you ever used drugs?
 - ii. Have you had any tattoos?
 - iii. How many sexual partners have you had?
42. Being asked such questions was extremely upsetting for the both of us. To be married for such a long time and for my wife to be asked how many sexual partners she has had made us feel extremely uncomfortable. This further added to the feelings of being stigmatised. A lot of people were relating HCV to drug use and a "dirty" lifestyle. Having to go through life trying to fight that stigma and my wife having to justify that she was infected through contaminated blood, which was almost never believed, has been very difficult.
43. My Wife has also been told that she will be put on the end of the operating list, as she is a 'dirty case'. She has also been refused dental treatment in

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the past due to her HCV infection. There are people who my wife and I have told about her infection and who we no longer see. We have lost friends as a result of the infection. We had to tell our son not to mention it to his friends as it could well have caused issues for him.

44. The impact of my wife's infection with HCV has had a huge bearing on my life. When she was first diagnosed it was hard to take in. I thought to myself what is this all about? Why us? I thought that it must have been a mistake. My wife was naturally upset, so I had to come to terms with it fairly quickly in order to support her through that.
45. When my wife was told she was finally clear in 2016, I thought to myself that this was great. Life carried on but there always seemed to be a shadow there. There is always a worry in the back of my mind, there has been for the past thirty years.
46. We have carried on as best we can since my wife's diagnosis. When she was told that she had chronic Hepatitis C, my life became a whole different ball game. We went from being a normal couple, to me supporting a patient. This was particularly difficult, especially supporting her through her treatments and witnessing the pain and anguish she suffered. I believe that this put a strain on our relationship. My Wife would come home from work and be so fatigued that she would simply fall asleep. Communication, displays of affection, intimacy, were all affected. It was hard; it felt like I was losing part of my partner.
47. The fatigue my wife was faced with put extra strain on me. I was working full time and had to take on extra duties in the household. I had to adjust my working patterns to accommodate her appointments. We had to keep my son busy and occupied; often we just went out, him and I, to let my wife rest.

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48. I have suffered a number of emotional effects since my wife was diagnosed with HCV. Her infection, combined with how bad the side effects were from her treatment, has made me prone to anxiety. I am always concerned about how she is feeling; it was so hard to watch. On a couple of occasions, she collapsed and that caused me a lot of concern about her general health; I always had to factor it in if we were thinking of partaking in any activities. These feelings and emotions were made harder to deal with when I was diagnosed with Prostate Cancer at the age of 50. At times we were both in treatment at the same time. This made life very difficult as we were both feeling unwell. I was also unable to continue with work at that time.
49. One of the hardest things associated with my wife's infection and subsequent treatments, was watching my partner suffer and not being able to do anything about it. Just the feeling of helplessness. We lost out socially as a couple, especially at family functions where my wife was too ill to attend. Everyone would always ask where she was and I would have to tell the family that she was not feeling well. We would also have to consider if my wife would be able to eat due to her bowel related issues. This had also curtailed many social events and had a huge social impact on us.
50. The fact that we could not have a bigger family was hard. We both wanted more children; with IVF treatment we may have been successful again. However, IVF treatment was no longer an option because of my wife's infection with HCV. We did not want to put her or the child at risk. This in turn meant that having an only child was hard. We had to make sure that he had a good social life and ensure he could always play with other children. Keeping him entertained was hard work at times.
51. My wife's infection with HCV has also had a huge financial impact on our lives. Initially, she had to go part time, which was a big loss financially and on her pension. After the third round of treatment my wife had to give up work altogether. We did have assistance from the Caxton Foundation for

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a while, when my wife's wages were non-existent. As she has had breaks during her working career she could not apply for benefits. Fortunately, we did received money from the Skipton Fund. There would have been a big step up in earnings if my wife could have progressed in her career, but all of that stopped and was taken from her. Due to her brain fog she struggles to concentrate and hold a conversation, this was one of the factors in her decision to stop working. My wife has also had to give up her registration, which means she can no longer work as a nurse. This again has had a significant financial impact on our lives. I believe that my wife has conducted some calculations and worked out that her potential loss of earning equates to £438,500 over ten years.

Section 6. Treatment/Care/Support

52. I can confirm that my wife was offered funding for counselling via the Caxton Foundation. However, she had to find her own counsellor and arrange all of the appointments herself. The range of options available was limited. My wife went to four out of the seven sessions but had to stop as the psychologist upset her. She felt they did not understand; she was treated the same as other people with HCV, even though her infection arose through completely different circumstances not of her making. The counselling did not take this into consideration.
53. I can also confirm that during my interview with the inquiry, I have been informed about the support mechanism that the British Red Cross provide.

Section 7. Financial Assistance

54. I believe that my wife first heard about the Skipton Fund through an online forum. I remember that she received the stage one payment but I cannot remember exactly how much this was. I do remember that it was not a lot.

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55. I believe that it was not too difficult applying for the payments from Skipton, but it may have been difficult trying to get the consultants to sign the necessary letters.
56. My wife was told that she would be eligible to apply for stage 2 under the Skipton fund as she was suffering from liver cirrhosis. This information came from a nurse involved in her treatment. However, when she rang the Skipton Fund, they advised her not to apply for stage 2, as she would not receive any payments.
57. Undeterred, my wife applied for Stage 2 and her application was accepted.
58. Currently she receives Stage 2 payments from EIBSS.

Section 8. Other Issues

59. I would like the inquiry to know that I think it is dreadful what people have had to endure as a result of being given infected blood. The more you dig into it and the more you find out, the worse it gets. In 1987, when my wife had her ectopic pregnancy, there should have been screening for blood donations in place by then. Simple things like checking the donor's liver functions could have alerted medical staff to possible liver disease. I know that other countries were screening by this time. My wife's infection with HCV has completely taken over our lives for the past 30 years. It dominates everything we do and yet we struggle to even talk to the people closest to us about it.

Statement of Truth

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

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Dated 24/7/19.