

Witness Name: Brian Carberry

Statement No:WITN2328001

Dated:26th February 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF BRIAN CARBERRY

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 13th November 2018. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

I, Brian Carberry will say as follows:-

1. Introduction

1. My name is Brian Carberry and my date of birth and address are known to the Inquiry.
2. I was previously married and have an adult son and daughter from that marriage although my son sadly passed away. I have a son from my current second marriage who is 14 years of age.

2. How Infected

1. I am classed as Haemophilia A with a clotting factor of 0.001. I was aware from when I was a small child of this, because GRO-C

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has a similar condition. As a child suffering from haemophilia, I would regularly attend the Royal Victoria Hospital in Belfast.

2. As a youth, I had treatment for bleeding in my joints, which is a common complication that haemophilia sufferers encounter. The joints become very painful and I would need bed rest until the pain subsided.
3. I understand that I was treated with Factor VIII to help the process. It would speed up the healing process and ease the pain.
4. From the age of 11 to 16 I was in boarding school, Mitchell School House, Belfast. If I had a bleed in the joints there, I would be administered Factor VIII by the school physiotherapist. There were two physiotherapist's and it was the junior one who would deal with me. The more senior one didn't want to know.
5. I was given Factor VIII a number of times in school, usually as a result of a minor bump or scrape. They would cause swelling and pain. I would go straight to the physio and get treated.
6. Every few months I would still have to go to the Royal Victoria Hospital for a check up.
7. Around the age of 12 or 13 I had pancreatitis. I was in hospital for 10 days. It appeared to clear up. I now think it was a reaction to an infection which I must have had at that time. I believe it was around that time that I was infected with Hepatitis C.
8. As a young man, and then later, I would have regular check ups (still at the Royal Victoria) in respect of my haemophilia. After leaving school I had home treatment of Factor VIII.

9. It was at one of my regular check up's at the Royal, in 1995, that the Consultant Doctor Elizabeth Mayne said that she noticed from my notes that I had Hepatitis C. She told me I had been infected in the 1970's. This came as news to me and a great shock. She did not give me any details but it was obvious that I had been suffering from this for some time.
10. Dr. Mayne attempted to reassure me and said it would not cause any great problems and I was not to worry about it. She also mentioned that I was fortunate not to be infected by the HIV virus.
11. At no stage during this appointment was I offered support or counselling and was told that the risk of transfer to other people would be minimum.
12. I do not know why I was not told about this before, when they obviously must have known from my records.

3. Other Infections

1. As far as I am aware, the only infection I have contracted is Hepatitis C. Although several years ago I received a letter stating a blood donor had died from vCJD and I may have received blood products from this donor. I was asked if I wanted to know if I had received blood products from this donor but declined as there was no way to test if I was infected by this and therefore no treatment available.

4. Consent

1. As a child my parents were never given any information detailing risks associated with receiving blood products and as a young adult, I was never informed of any potential risks that may occur when receiving Factor VIII. I trusted my doctors!

5. Impact

1. My main issue, with having been infected with Hepatitis C, is it never leaves me. I never stop thinking about it and it has blighted my life.
2. Unfortunately, due to poor health I was unable to hold down a full-time job. When I left school I did some Youth Training Scheme type jobs. I suffered from fatigue. I found it difficult to concentrate. I lost all confidence. I now know it was the Hepatitis C affecting me.
3. Simple physical tasks such as just cutting the grass would wear me out.
4. From 1990 – 2010, I felt generally unwell and sick most of the time. It also caused me to become depressed.
5. I ended up being dependent on benefits which I found very degrading. When the benefits changed from DLA to PIPs, I found the application process very stressful. I felt like I was holding out a begging bowl. During this time, I became depressed and often on the verge of breaking down.
6. I had various drugs in respect of the Hepatitis C. For example, I had Volterol Retard. We discussed with doctors (in 1999) interferon and Ribavirin.
7. In 2000 I discussed with doctors having a year's treatment on Alpha Interferon and Ribavirin but as it would take so long and make me ill I didn't take this up.
8. I started Pegylated interferon and Ribavirin in 2006 but stopped after 4 weeks due to side effects.

9. In around 2014 I became aware of a new treatment for Hepatitis C to a drug called Havoni. Unfortunately, in Northern Ireland there was a big waiting list for this. I had my MP raise the issue and eventually it was agreed that I would be assessed for a course of treatment on this.
10. However, during that assessment, I was diagnosed in 2015 with Non-Hodgkinson's Lymphoma. Over a period of six months I underwent RCHOP chemotherapy and successfully went into remission.
11. A month after chemotherapy ceased, I commenced treatment for Hepatitis C with Harvoni. It was a 12 week course. By late 2016 I was Hep C negative.
12. During subsequent hospital appointments I was tested and informed that the Non-Hodgkinson's Lymphoma had returned. I had to undergo a different chemotherapy called ESHAP, a stem cell harvest and subsequent stem cell transfer in which I was required to remain in hospital for five weeks due to my non-existent immune system. Thankfully at the appointment on the 6th November 2018 I received confirmation that my cancer is once again in remission.
13. Unfortunately on the 23rd November 2018 (approximately 2 weeks after my cancer remission appointment) I was readmitted to hospital with pneumonia. Due to my low immune system, my body did not recover and I was subsequently moved to the Intensive Care Unit (ICU) for closer monitoring, treatment and a higher level of oxygen. After six days in ICU, I was transferred back to the ward and started to improve. Regrettably, a few days later I suffered a spontaneous pneumothorax (collapsed lung). Although a drain was put in, the oxygen level in my blood continued to reduce and once again I was transferred to ICU. However this time, I was to be ventilated and sedated to allow a machine to help me to breathe whilst my body recovered. After 11 days the doctors were able to take me off the ventilation machine. My recovery has been very slow and at times I thought I was going to die

and never get home, but after six weeks in hospital, on the 3rd January 2019 and with the help of a walking aid and home oxygen, I was allowed to leave hospital. I still have a lot of appointments ahead but things are not looking quite as bleak.

14. Each day I become easily tired. Because of the Hepatitis C and more lately, the Non-Hodgkinson's Lymphoma, and then the pneumonia I cannot be particularly active. Each day I become easily tired and fatigued I am currently very weak requiring oxygen and having to use a walking aid. I am prone to muscle aches, bloating and abdominal pain. I often forget things (also known as brain fog) which can get tedious for my wife but very depressing for me and can cause me to be subject to mood swings. Since coming home from hospital on the 3rd January 2019 a bed has had to be moved to the living room as I am unable to get upstairs.
15. My youngest son has just turned 14 and over the past 7 years I have spent long times in hospital or at hospital appointments I have missed out on raising him and at times I feel he is looking after me, rather than me looking after him.
16. I have never been able to engage in the rough and tumble one might normally do with one's children or spend lengthy time with them supporting them with sports or the like.
17. Due to my ill-health I have also missed out on many family occasions, I am often ill and wiped out. Due to my last hospital admission, for the first time ever, I missed spending Christmas and the New Year with my family. Although I have missed other occasions, this time of year is particularly associated with family, leading me to become very angry and very depressed. It makes me feel like I am a burden on my family at times, rather than a help to them. It makes me feel guilty.
18. I always dread the fact that they are at risk of being infected by me.

19. My second wife is a very able and intelligent woman. She is an FCA (Fellow Chartered Accountant, Ireland). Yet again due to my poor health she had to leave her job in Belfast and is currently employed by a local accountancy firm. She has had to devote a lot of her time to helping and looking after me. Once again I feel guilty that due to me she has been probably held back in terms of her professional work and subsequent promotions.

20. I feel I have missed out on a full and active life. This has been denied to me as a result of something that should never have happened. It is upsetting that it has taken so many years for this to start to be investigated and I hope that the Inquiry is able to get to the truth.

6. Treatment/Care/Support

1. Counselling or psychological support has never been made available to me for my infection.

7. Financial Assistance

1. It was news of the Archer Inquiry that made me aware of the infected blood scandal. Also, around that time, the Haemophilia Centre informed me about applying for payments from the Skipton Trust. The Haemophilia Centre was very helpful and proactive in that respect. Therefore, I made the application and got a pay out in 2004 of £20,000.

2. In 2012 it was deemed there was a link between Hepatitis C and Non-Hodgkinson's Lymphoma and due to this link, I was entitled to apply for a higher stage payment from the Skipton Fund. I received a lump sum of £50,000 and a monthly payment of £1200 per month which has arisen to £1500 per month.

3. Because of Hepatitis C I find it difficult, if not impossible to get various financial services such as life insurance. With my second wife, we initially had problems organising a mortgage as the bank insisted on us both having life insurance to cover the mortgage. Unfortunately, I was unable to obtain the life insurance causing us both another stressful period in our lives. In the end my wife was able to purchase the house in her own name and I had to sign a waiver stating I had no claim on the house if we ever split. Once again I was made to feel useless. In recent years we have re-mortgaged and thankfully banks have changed their policies therefore the house is now in both our names but without my wife I don't think I would have ever been a house owner. Another example of financial services difficulty is travel insurance which is approx. £100 more expensive to purchase each time I travel abroad.

8. Other Issues

1. A few years ago, I was shown my files at the Haemophilia Centre. I had to sit there with a Staff Nurse. I saw Dr. Mayne's note of my consultation with her in 1991 when she told me about the Hepatitis C. What concerned me though, was that the records seemed to be missing for the late 1980's.
2. I know records used to be there as I had seen them when having earlier appointments. A couple of years ago I asked to see all my records. The file covering the late 1980's was missing.

Statement of Truth

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

Signed: GRO-C

Dated... 26/2/19