

Witness Name: Caroline Carthy

Statement No: WITN1140001

Exhibits: 0

Dated: 15th December 2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF CAROLINE CARTHY

I, Caroline Carthy will say as follows:-

Section 1. Introduction

1. My name is Caroline Carthy and I was born on [GRO-C] 1965. I live at [GRO-C] [GRO-C] Birmingham [GRO-C]. This statement has been prepared on behalf of myself and my two sisters, Jacqueline Golding and Jennifer Golding, who were born on [GRO-C] 1969 and [GRO-C] 1970, respectively.
2. This witness statement has been prepared without the benefit of access to my father's full medical records.

Section 2. How affected

3. My father, Graham Golding was born on [GRO-C] 1941 and lived at [GRO-C] [GRO-C] Birmingham [GRO-C]. He died on 2nd July 2015, at 73 years old, from cardiac and renal failure which I believe was attributable to his chronic Hepatitis C (HVC).

4. When he was born he was diagnosed with severe Haemophilia A and was treated at the Queen Elizabeth Hospital, Birmingham. In the 1970s he was under the care of Dr Franklin and from the 1990's onwards he was under the care of Dr Wilde.
5. My father had a twin brother, who was also a Haemophiliac. When they were teenagers, his brother died in a hospital bed next to him due to blood loss.
6. When he was a child, my father was treated with pigs' blood transfusions and plasma. When Factor VIII was introduced, he was treated with it on demand, so only when he needed it for a bleed. However, this happened to be quite often due to the severity of his Haemophilia. My father did not administer any treatment himself as he was not taught how to, so he relied on the hospital for his treatment.
7. When the medical professionals recognised the issues with Factor VIII, they then started treating some Haemophiliacs with Factor 8Y, which was supposedly from donors that had been hand-picked in the UK. My father was not treated with synthetic blood products, recombinant factor 8, to our knowledge, until the late 1990's, despite the fact that this was available before that time. Medical notes of my father will give more accurate times.
8. Jennifer and I [GRO-C] were aware of other treatment that became available over the years. [GRO-C]
[GRO-C] In 1995, [GRO-C]
[GRO-C]
[GRO-C] our father was still being treated with Factor VIII-Y. When we questioned this with the hospital we were told that synthetic blood products were too expensive and they were prioritising children that had never received other blood products.

9. My father was not given any information about the potential risks of infection from blood products. He had no knowledge of the dangers of using Factor VIII. In 1987 I knew a little about the dangers of using blood products, GRO-C

GRO-C

10. In 1977, my father collapsed at a family Jubilee party and was laying on the floor foaming at the mouth. He was rushed to hospital and was diagnosed with Hepatitis B from blood products. Fortunately, they were able to cure this. I believe he went on to develop jaundice and may have had Hepatitis B again, but I cannot recall when this was.

11. In or around 1998, my father attended his six-monthly routine clinic appointment with Dr Wilde. He came home and told us that he had been diagnosed with HCV, he was bewildered and none of us understood what this meant. This was the first he had heard anything about this infection and the first time he knew he had been tested for any infections. He showed us a leaflet that he had been given to take home and read, and I believe he was told to use condoms if he was having sex. Other than this, my father was provided with no information to understand or manage his infection.

12. We did our own research, but struggled to understand the infection properly. Even when my father passed away, we still did not properly understand his infection. Any information that was provided was not communicated properly and it was very basic, but was also not provided in a way that my father was able to understand. I acknowledge that they may not have had the information to provide at the start, but by 1998 they knew quite a lot so should have provided more information.

13. By this time, a lot of Haemophiliacs had been informed they had HIV and my father knew that there was a possibility that he had this as well. He was very concerned and it felt as though we were all sitting with a black cloud over our heads, waiting for this to develop.

Section 3. Other Infections

14. I am not aware of any other infections that my father contracted as a result of receiving contaminated blood products.

Section 4. Consent

15. I believe that my father was tested without his knowledge and consent. His blood was routinely tested every 6 months, as far as we were concerned, these were routine blood tests that monitored his blood levels for inhibitors, haemoglobin etc. Prior to being informed of his infection, my father had no idea he was even being tested for HCV or HIV.

Section 5. Impact

16. Being infected with HCV mentally destroyed my father. He did not understand it or know how to manage it, and he did not know what would happen to him. He did not know if he was going to die from the infection or if he would also develop AIDS. At this time, HCV was under the same umbrella as HIV and we had seen three of our cousins die from AIDS. Naturally, my father became constantly worried that he was going to die as well. You could see this fear in his face as he would sit and think about what might happen to him.

17. As he was always worrying, my father would sit at home all the time and not leave the house to even go to the shops. On the odd occasion that he did go out, he would get himself into a real panic and would think he was going to die. An

ambulance would have to be called for him and they would calm him down, because he was convinced that he was dying. Prior to this, my dad had been very sociable and enjoyed going out and keeping busy.

18. As a result of his constant worrying and the stress of his infection, my mum was put under a lot of pressure and their relationship broke down causing them to divorce in 2002. My mum was unable to cope with how down my father was all the time and because he was not having treatment or counselling, this only became worse over the years. He also had to stop working and relied on Incapacity Benefits, this put a financial strain on their marriage. As neither of them were working, they were around each other all the time and did not have any space from one another. I also believe that his fear of infecting her put a strain on their private time together. The divorce had a massive impact on my father and he became even more down afterwards.
19. Towards the end, my father lost a lot of faith in the hospital and did not even want to go in to be treated for a bleed. He had become very angry at them because he felt like they carried on his treatment with Factor VIII and were just watching him to see if he developed anything. We all feel that they put cost over life, as they refused to treat him with Recombinant Factor VIII for so long. This treatment was reserved for those that had not been infected, and it seemed as though he was in the 'condemned' group that were the last group to be treated with new products.
20. My father did not trust the medical staff or NHS anymore and would put off going to the hospital; he would rather suffer in pain at home. We would have to force him to go to hospital and it would usually take several days before he would eventually listen; for a severe Haemophiliac that would mean several days of sitting in terrible pain.
21. In addition to the mental issues that came with my father's infection, his physical health worsened. He used to be a painter and decorator, but had to stop working shortly after being diagnosed at around 60 years old. Although he loved working

and always enjoyed helping the family with jobs around the house, he could not physically manage the work anymore. He would get tired a lot and could not walk very far as he would get out of breath. He also became very achy and would complain of pains around where his liver was.

22. My father did not receive any treatment for his chronic HCV as we were told that it was incurable and there was no point trying to help him, because it could not be done. As far as we were all aware, there was no treatment available at that time.

23. In 2012, two weeks after we buried our mother, my father went into heart failure and he had a pace maker and a defibrillator fitted. However, in 2015 he went into multi-organ failure. His kidney function was really low and he was having issues with his liver, three months before he died we were later told that these had both gone into organ failure. Over the following three months, he was rushed into hospital about six or seven times. We had previously been told that when the liver starts to fail it causes other issues and towards the end he became very yellow. We believe that his multi-organ failure was due to chronic HCV, but we have not had any confirmation of this from the medical professionals. Only three hours prior to his death, my father had a liver scan and we have still not seen the results.

24. With regards to my father's private, family and social life this became non-existent. He used to love getting up on the stage and singing, doing karaoke and enjoying nights out with the family. After his diagnosis, he became quite reclusive and his personality changed completely. He stopped going out socially with my mum and would just sit at home and watch videos.

25. Due to concerns about the stigma associated with his infection, he did not tell anyone other than close family members. Although there was not much stigma around HCV, Haemophilia was linked to HIV and he was worried that people would assume he had this. The media had scared the public so much that if you

even mentioned Haemophilia you would be treated like a leper, and people would step back and become terrified.

26. Even at the hospital, my father's medical notes were surrounded by yellow tape that read 'HAZARDOUS' and he would be treated differently because of this. One instance of this poor treatment was when my father was being treated at Selly Oak Hospital. He was being treated like a normal patient, until I informed them that he had HCV. They instantly treated him differently and went into a state of panic; they frantically put gloves and gowns on. I found this very upsetting to watch and I know that my father did as well.
27. In the Queen Elizabeth Hospital, there was an incident where a nurse had pricked her finger whilst trying to take my father's blood. Unfortunately, during the incident my father had bled a lot and there was blood all over him and his sheets. When I arrived at the hospital hours later he was still sat there in bloody sheets as no one would change them. I was disgusted that they had let him sit in the bloody sheets all day and he was just sat there worrying. In the end, we had to change the sheets for him because none of the staff did it.
28. Losing our father has had a huge impact on the whole family. Seeing him going through what he experienced would annoy and upset us, particularly seeing how he was treated and seeing the fear that he felt. We also shared in his fear of the unknown, particularly when he was first diagnosed with HCV. At this time, Jennifer and her children were living at home with my parents. She was scared and worried for the children and is ashamed to say now that she was concerned about them becoming infected. She has said that she was being careful where he touched and was cleaning things thoroughly, like any kitchenware that he had used or even the toilet seat.
29. People were dying from AIDS and we knew that our father was being tested for HIV, so naturally we were very scared. We also did not want friends and family to

find out about his infection, because we knew that as a family we would be treated badly due to the connection between Haemophilia, HCV and HIV.

30. In the media you were either gay or a Haemophiliac if you had contracted HIV/AIDS. Haemophiliacs should not feel that they are going to be judged or stigmatised due to this. Even our children still face the stigma of this scandal and the media have only fuelled this. We would like the media to come out with more positive news stories about Haemophilia and encourage people to see those infected as victims, rather than thinking they were bad and have spread diseases. We also think there should be a small section in the news about the Inquiry to discuss how the treatment has progressed due to synthetic blood products.

Section 6. Treatment/Care/Support

31. My parents were not offered any support. At the very least, I believe they should have called both of my parents in and sat them down as a couple to discuss my father's infection and to ensure they really understood what this meant. My parents put their faith in the NHS and the doctors, and they believed they were making the right decisions for them.

32. My father had seen his brother die from Haemophilia and three of his nephews die as a result of contracting HIV, so he had been through a lot of emotional trauma and was very worried about what would happen to him. We believe that he required emotional support and counselling, but this was not provided to him.

Section 7. Financial Assistance

33. In 2004 my father received a Stage 1 payment of around £20,000 - £25,000 from the Skipton Fund. He heard about this from the social worker at the hospital, who then assisted him with all the paperwork. He did not receive any other payments after this.

34. We now feel that this was a payment to keep quiet. At the time my father felt grateful, but he should not have felt this way as it was given to him because they did not want to admit it was their fault.

35. When he died, he was in the process of applying for the Skipton Stage 2 payment. After he passed away the social worker told us that we could not continue to fight for it on our father's behalf.

36. Towards the end our father kept telling us not to worry about paying for his funeral, because there was someone that would help. When he died we asked the Haemophilia Sister at the hospital what this meant and she said that this would all be dealt with. We then received a grant of £3,500 for his funeral from the Caxton Fund.

Section 8. Other Infections

37. Due to his infection, my father could not get life insurance or travel insurance. He liked to travel to Tenerife, but he would have to do so without any insurance. He would take his treatment with him and when he had a bleed he would not go to hospital but would endure the pain until he got home, because he was worried how much it would cost without insurance.

Anonymity, disclosure and redaction

38. I confirm that I do not wish to apply for anonymity and that I understand this statement will be published and disclosed as part of the Inquiry.

39. I am willing to be called to give oral evidence if I can assist the Inquiry.

Statement of Truth

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

Signed..... **GRO-C**
Caroline Carthy

Dated *15th* December 2018