

Witness Name: Tracey Ann Joyce
Statement No.: WITN3131001
Exhibits: WITN3131002 – WITN3131010
Dated: October 2020

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF TRACEY ANN JOYCE

1. I, Tracey Ann Joyce, will say as follows:

Section 1: Introduction

2. My name is Tracey Ann Joyce and my date of birth is GRO-C 1965. I reside at GRO-C. I have been married for 32 years. I have a son who has haemophilia and a daughter who is a carrier of the haemophilia gene.
3. I am providing this statement in relation to my father who had mild haemophilia and was infected with Hepatitis C as a result of his treatment with blood products. I have a brother, Andrew, who has also provided a statement to the Inquiry in relation to our father (WITN3208001).

Section 2: How Affected

4. My father, Alan Parsons, was born on GRO-C 1937. As child I was aware that he had haemophilia A but that it was only mild. He hardly ever had to go to the doctor. He was under the care of Oxford Haemophilia Centre at Churchill Hospital and always had dental treatment at the John Radcliffe Hospital.
5. I do not recall him having Factor VIII before 1982 when he was given it for dental treatment. I understand that this was not a tooth extraction and it was simply given as a precaution.
6. In a letter that he wrote to his MP in 2001, dad stated that he was infected in 1982 (WITN3131002). I do not know when he was diagnosed with Hepatitis C but I was still at school and living at home when I found out. I recall that he fell off a ladder in 1987 and Andrew and I knew before then as we knew that we could not touch his blood.

Section 3: Other Infections

7. I recall my dad getting a letter about vCJD. This was when my mum was still alive so it would have been prior to 2011. After he received it he was very down about it. He had seen something on the news about someone who had it and they were like a vegetable.
8. Dad was quite a jolly person but this was mostly for other people's benefit but we would see the impact it had on him when he was behind closed doors with us. Sometimes I would walk in and he'd just be sitting staring at the floor but when he saw me he would say "you alright Trace?" and put a big smile on his face.

Section 4: Consent

9. I do not know whether my dad consented to being tested for Hepatitis C. I did not attend medical appointments with him until a later stage in his life.
10. If the doctors wanted anything for research or for trials, they always asked him; he was always willing to be a guinea pig. I have found letters and consent

Section 5: Impact

Treatment for Hepatitis C and decline in health

11. Once dad had been diagnosed with Hepatitis C, he started attending the hepatology department at the John Radcliffe Hospital. He used to drive himself to the hospital and I often would not even know he had a hospital appointment. There was a big gap when Andrew and I were not really involved in matters relating to our father's health but I have set out below what I know. Andrew and I have applied for our father's medical records so that we can provide additional details to the Inquiry. To date we have received his UKHCDO records only.
12. Initially he was just being monitored and he had the odd endoscopy just to keep an eye on things. He was later diagnosed with fibrosis of the liver and then cirrhosis. This got him down and he thought about the end of his life.
13. He was under the care of Dr Jane Collier and in the 1990s she would take blood and he would sometimes have a CT scan or a biopsy. This went on for a few years before he received treatment for Hepatitis C.
14. In the early 2000s, my father got the opportunity to take a year-long course of Interferon. I am unsure of the exact date but I know it was after 1999 as he and my mother had moved house and he was in the new house when the course started. The letter he wrote to the MP in 2001 refers to *"intensive treatment over the next 12 months"*, so I assume he was referring to the Interferon treatment. He had already been diagnosed with cirrhosis by the time he started this treatment. Andrew and I were told he was on new medication. He said it was like having really bad flu; he was not able to get up and he hurt all over. He had to give up work due to the treatment, as discussed below.
15. He completed the whole course but it did not work and he seemed to decline from there; mentally as well as physically. My niece could be very tiring when she was young and he was always very calm with her until one particular day when she was about five or six years old he picked her up and shouted *"shut up, shut up"* at her and threw her out of the front door. I had never seen him like that before the treatment.
16. My mother had two strokes and the second one, which occurred in June 2004, led to her being completely paralysed and unable to communicate. She was doubly incontinent and had to be turned every two hours. Due to my father's health he was not in a condition to do this, even though he really wanted to be able to. She had to go into a nursing home and he went there every day from 9am to 5pm. The only day he was not there was when he was asked by a doctor to attend a meeting so that he could put forward a carer's view for aftercare. This had an impact on my father's health. My mother passed away in 2011 and I am glad she did not have to see my father at the end of his life.
17. Following my mother's death, I attended a routine appointment with my father at which Dr Collier discussed new medications for the treatment of Hepatitis C, Ledipasvir and Sofosbuvir. She told him how many people had been treated successfully and that the total cost of it was £36,000. She asked if he wanted it and he said *"I'm probably a bit too old; you'll want to save it for younger people"*. This was because she had told him how much it would cost the NHS. He did not like waste and did not want to waste other people's money. I got cross and said to him *"it was the NHS that gave it to you"*. I had to tell him to take it and that he was just as deserving as anyone.
18. Dr Collier was a lovely lady. She explained to him that if the medication cured his Hepatitis C, the damage would already have been done. She said that it would give him about 18 months more; he liked numbers. He decided to go on the treatment and did not have any side effects. One day while he was on the treatment, I found him crawling around on kitchen floor as he had dropped a tablet. He was insistent he had to find it as it cost £450.
19. He was amazed when the treatment worked. He was elated to be free of the virus due to the stigma attached to having it and the worry he felt about passing it on. Notes that my father prepared in relation to his medical treatment indicate that he started this treatment on 31 December 2015 (his "Notes") and test

20. However, it was around the time that he was having this treatment that he was told he had liver cancer. The hospital said they would "microwave the tumour" which worked for a while. His Notes indicate that he had an ablation to remove the liver tumour and a lymph gland biopsy on 11 February 2016. He was diagnosed with lymphoma on 22 February 2016 and was told this on 21 April 2016 that he was clear of liver cancer. He had kidney problems and suffered from ascites. His stomach was huge and rock hard; it hurt when he moved. He had to have his stomach drained on a few occasions. The first time he had it drained five litres of fluid was removed. There are references to his stomach being drained included in his Notes (WITN31131004).
21. My father was suffering from a number of conditions at this time; he had something growing out of his head and red welts on his leg. I had to take him to a specialist who said it was dermatitis. My father had suffered from dermatitis all his life and it was not that; I believe these symptoms were caused by the lymphoma.
22. In March 2016 he started chemotherapy at Milton Keynes Hospital. He had eight rounds of chemotherapy and following this he was told he was clear of lymphoma.
23. Shortly after this he complained of stomach pains. There are a number of letters in my father's papers which refer to him being in remission but making reference to him having pain in his stomach and to other issues he was having (WITN3131005). Andrew took him to hospital as he thought it was ascites and that it should be drained. They were only able to drain half a litre so Andrew took him straight up to the cancer ward where he was kept overnight.
24. The following morning my father made the doctors wait until I got there before they gave him any news. When Andrew and I were with him, he was told that he had colon cancer and that he only had a few weeks to live. We do not know how it had been missed when he was given the "all clear". It had been there at that time as it had stemmed from his liver cancer. We took him home that day and he died two weeks later on 3 July 2017.
25. He did manage to "eke out" his life quite remarkably. Some people with cirrhosis decline quickly but I credit the fact that my dad lived longer with the way he lived; he cut out alcohol and ate well.
26. Dr Howard did not know what to list as the cause of death on his death certificate as there were so many things wrong. The causes of death are listed as frailty in old age, cirrhosis of liver, Hepatitis C and cell lymphoma.
27. My father had organised most of his funeral, he was a very organised man and had a wicked sense of humour; he would talk with us about what music he wanted at it. I do not think most people knew what he died of and we did not go into detail.

Impact on social life and stigma

28. He was very placid, jolly and the life and soul of a party. He would not go to the pub but used to like to have a drink. When he was diagnosed with Hepatitis C he stopped socialising and stopped drinking. He would have a sip of something alcoholic if he attended a wedding but then would be in pain.
29. When I was younger and it hit the news that haemophiliacs were being infected by blood products, I remember someone saying, "*haemophilia, that's just a posh word for AIDS*".
30. Hepatitis C became conflated with HIV and people made assumptions. Even later in life if Hepatitis C came up in conversation and I said "*my dad's got that*", I would feel people shift away slightly. I would have to explain how he got it and could see that they thought he was either a drug user or gay.
31. His close friends knew that he had Hepatitis C but I never heard him mention it when we were out.

32. Up until he started chemotherapy he had been doing some work with the Stroke Club which was run by a local group of the charity Different Strokes. He had to stop this because he could no longer drive as the chemotherapy had affected the nerve endings in his feet. The Stroke Association later called him and asked him to do some treasury work and he agreed, saying it would only be a couple of hours a week. He always put on a jokey front and people would not know how ill he was.

33. He worried about infecting anyone else. He loved his carpets and when he used to have nose bleeds he did not want me to clean it up. I would say that I had gloves and an apron but he was protective.

Financial Impact

34. He was a civil engineer and worked on the railway but he could not go to work for safety reasons while he was on Interferon. He was running a consultancy at this time, having previously retired, and was making good money. This affected his income but not his pension, as he already had the maximum pension that he could have from employment with the railway.

35. He struggled to get insurance; he would always disclose his medical conditions on the form. For travel insurance there was an increased cost. I took him to Germany and the premium was much more expensive due to the haemophilia and everything else he had. This can stop people doing things but he just used to pay the increased premium.

36. I had to give I gave up work in 2017 to look after him. I used to run my own cleaning business and in January 2017 I gave up a few clients as I did not have time to keep them on. In April I gave up all my clients as I needed to be with dad. I moved in with him at the end as I was worried about the stairs and he would not have a stair lift put in. He needed someone there. I lived in Leighton Buzzard so I could be close to him. I moved to the countryside in February 2019.

Section 6: Treatment/Care/Support

37. My father was never offered any counselling by the NHS.

38. Following his diagnosis with cancer he had a lot of support from Mcmillian and he had carers for the last couple of weeks of his life; I could not fault them.

39. Willen Hospice contacted us following my father's death, as they ran a coffee morning in John Lewis to support those who had lost someone close to them. I attended one of these sessions in order to meet a few of the people my father had befriended there and to let them know how much we raised for the Stroke Club from donations at his funeral and various friends and family, but I can appreciate how it helps those who have lost a spouse, more so than a parent.

Section 7: Financial Assistance

40. My father applied for financial assistance from the Skipton Fund by himself; Andrew and I did not have any involvement in this.

41. I am not sure how my father became aware of the Skipton Fund, it was probably from The Haemophilia Society; it looked after him fairly well. I have however seen within my father's papers letters addressed to him from the Department of Health dated 26 January 2014 and 18 June 2014 which provided information about the Skipton Fund (WITN3131006). Dr Jane Collier would have helped with the forms; my father wrote to her on 20 July 2004 asking for her assistance with his application (WITN3131007). I was with him when Dr Collier told him he had cancer and he said jokingly "I am going to get another payment". She said, "oh yes, I'll write"; she took it quite seriously. The Haemophilia Society wrote to him on 20 January 2011 about a change in the payment scheme (WITN3131008) and he emailed the Skipton Fund on 22 January 2011 registering for the new scheme (WITN3131009).

42. As far as we know, he received an initial payment of £20,000 when he was first diagnosed, £25,000 when he was diagnosed with cirrhosis and a further £25,000 when he was diagnosed with liver cancer. He also received monthly payments; I am not sure when these started but the documents which my father retained suggest that it was after the changes to the scheme in January 2011. The paper work suggests that these initially amounted to £12,800 per annum and increased to £14,574 for the tax year 2014/2015 (WITN3131010). I believe before my father died the payments were approximately £1,400 per month.

43. I have since helped an elderly neighbour complete forms for the Skipton Fund and I know that they are lengthy forms.

44. When my father died we had to call the Skipton Fund to inform them, due to the fact he was receiving regular payments. They were very nice and referred us to the Caxton Foundation who provided grants. We did not really need one, but we applied to the Caxton Foundation and were given a grant to assist with the funeral costs which covered the main funeral costs and not the subsequent wake, flowers, cars etc, but was appreciated anyway.

45. We applied for a blue badge for him at time he was receiving treatment for lymphoma. We struggled to get it as they did not think that he would qualify. They called and said that they would have to interview him and he said *"that will be a bit difficult, I'm hooked up to chemo"* and he got it within a week.

46. As mentioned above, I stopped work to care for dad but I do not recall him getting an attendance allowance for me. There were probably a lot of things he could have applied for but did not do so. When my mum was ill, he applied for everything for her, although he had difficulties with this due to the points system that was used.

Section 8: Other issues

47. My father always said that he had had "good innings" in life; he was never bitter. I am probably more bitter about what happened to him than he was. In relation to the blood products I think, *"when you know something is causing harm, why keep using it and deliberately giving it to people knowing it is going to cause infection?"* I feel I have a duty to dad to carry on the fight for him. I do not expect to get anything out of the Inquiry but I want answers and to be able to say I got them for my dad.

Statement of Truth

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

Signed

GRO-C

Dated

26.11.2020