

Witness Name: Kenneth Cheley

Statement No.: WITN0175001

Dated: 30/4/2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF KENNETH CHELEY

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 23 January 2019.

I, Kenneth Cheley, will say as follows: -

Section 1. Introduction

1. My name is Kenneth Cheley. My date of birth GRO-C 1933 and address are known to the Inquiry. I am a retired long-distance tanker driver with two children. I am the widower to three wives. I intend to speak about my second late wife, Rosemary, being infected with HIV. In particular, the nature of our illness, how her and my illness affected me, the treatment received and the impact it had on me.
2. I am not legally represented and an investigator to the Inquiry has explained the anonymity process to me. I do not require anonymity, as I want my story to be heard.

Section 2. How Affected

How Rosemary's infection affected me:

3. My second wife, Rosemary Cheley, was infected with HIV from a hip replacement operation in September 1984 at Morriston Hospital. A consultant by the name of Dr [GRO-D] undertook the surgery.
4. Rosemary's wound was bandaged as opposed to stitched and she was recovering for almost five months. Unannounced, a new surgeon arrived and whisked Rosemary off to theatre without telling her or I what the surgery was for or why she needed it. I have been asked whether I can recall the surgeon's name. Unfortunately I cannot.
5. The next day, following the operation, the surgeon who had performed the surgery on Rosemary was standing by her bedside when I arrived at the hospital. He asked if we could speak and he proceeded to tell me that they needed to re-operate on Rosemary's hip as it was in a mess and the leg was out of alignment. The surgeon told me that it appears as though Dr [GRO-D] who had operated the first time had never operated on anyone else and died two months after performing Rosemary's operation.
6. He explained that he had to break Rosemary's leg from the knee down and inserted two metal pieces and four screws to re-align the leg. He said if it were up to him he would remove the lower half of the leg, but as of now she would have a limp but that he had done the best he could. I told him not to bother and that I would find my own doctor to fix her.
7. The surgeon advised me to get Rosemary a wheelchair due to her weight at the time, to take the pressure off her hip and leg. A few weeks later, Rosemary was discharged and was crying as I wheeled her out of the hospital; I was angry.
8. The next day I marched to our local GP wheeling Rosemary in the wheelchair, explained the problem and requested the GP do

something about the mess that Rosemary was in. She was crying and the GP acknowledged that Rosemary was in a state. Whilst we were in the appointment, our GP called his colleague in London requesting for Rosemary to have an appointment with a doctor at the Royal Marsden Hospital in London. The GP told me that if I hadn't received a referral letter within two weeks that I must go back and see him.

9. A referral letter arrived in the post before the two weeks were up from a Professor Bentley. Rosemary and I went to the first appointment, with him together, in May 1985, and explained to him that the surgeon at Morriston Hospital had told them about the alternative of either removing part of Rosemary's leg or walking with a permanent limp.
10. Professor Bentley told us that what that surgeon had told them was utter rubbish. He said that we had come to the right place as he could fix her leg and that she would not require a wheelchair or suffer from a permanent limp. I burst out laughing and when Professor Bentley asked why I was laughing, I told him that I had heard it all before. Professor Bentley told us to go home and think about whether Rosemary would want this further surgery.
11. Rosemary asked me what my thoughts were on whether she should go ahead with the surgery, to which I told her that she has to. I wheeled Rosemary into the Hospital for the operation in June 1985 and she walked out normally without crutches, within a month.
12. When we got home we saw our GP and he acknowledged that Rosemary was much happier than when he had last seen her. I thanked him and told him he had done us a huge favour by referring us to Professor Bentley.
13. There were no problems for the next nine to ten years following this operation. It was in 1994 however, that Rosemary was rushed to hospital with a suspected stroke. She was again admitted to Morriston

Hospital. The doctor, his name I cannot recall, asked me if Rosemary had received any blood in the past. I made the doctor aware of the operations that Rosemary had had in 1984 and 1985, but told him that I wasn't aware that she had received any.

14. Within an hour, the doctor had gone away and looked at Rosemary's medical records. He invited me into the Sister's office and sat me down just us two. His words were, *"I'm really sorry Mr Cheley but your wife has got AIDS"*.
15. I asked the doctor how Rosemary would have got AIDS and he told me that during the first hip replacement operation, the one with Dr GRO-D, she received contaminated plasma.
16. I asked the doctor, *"What about me?"* and he responded saying *"Well what about you?"* I proceeded to tell him that I had been having unprotected sexual contact with my wife for the ten years that she would have been infected for. He replied saying, *"Oh, I forgot about you"*. The doctor took blood straight away, told me I would be alright and that he would have the results by the next day.
17. The following day, the a different doctor called me into the Sister's office away from Rosemary's bedside and sat me down. He told me that he was sorry, but that I have HIV.
18. The doctor told me that a HIV specialist nurse and doctor were going to take Rosemary to the HIV unit at Singleton Hospital. When the HIV specialists arrived to escort Rosemary to Singleton Hospital, I spoke with them briefly and informed them that I did not want Rosemary to be made aware of her AIDS diagnosis or the fact that she was going to a HIV unit. As far as she was concerned, she had had a stroke and she was being taken to a stroke unit at Singleton Hospital. The medical professionals respected my wish.

19. I was told that I wouldn't be able to find the ward if I didn't arrive at the hospital in the ambulance but I managed to get there before the ambulance arrived. We were taken to the eleventh floor at the top of the hospital to a ward that did not have a name. I was told to wait whilst the doctors examined Rosemary.
20. The doctor told me that the Sister would take me to his office once I had had lunch, but to make sure that I ate. I think he could tell that I hadn't been eating much. I returned after lunch and the Sister escorted me to her office to meet with the doctor. He told me that he had been on the phone to hospitals in London to see if they could do anything for Rosemary, as there were more advanced specialised units in London.
21. He told me that they had told him over the phone that based on the condition she was in, there was nothing they could do. The doctor then proceeded to tell me that he was sorry but that Rosemary only had a matter of days left. He told me that she had never had a stroke and that she had a tumour on the brain. He explained that typically, people in this state tend only to have a matter of days left to live. He told me that there was nothing more he could do but make her comfortable until she passes away.
22. What made this situation even worse was that she was going to die and I would be left alone and have to manage my HIV diagnosis. The doctor told me he would put me on medication but I told him I am not taking any medication until my wife had passed. He told me that he wouldn't force me but that I could begin a course of HIV tablets when I was ready.
23. The doctor mentioned that Rosemary must have contracted the infection from the September 1984 to which I told him that I knew this from a doctor telling me previously.

24. Ten days after Rosemary was transferred to Singleton Hospital in GRO-C 1994, she passed away. Her death certificate states that the cause of death was from Bronchopneumonia.
25. Prior to Rosemary's first operation with Dr GRO-D, I do not believe that she was made aware that she might have been given blood products during the operation that could potentially have been contaminated.
26. A doctor at Morriston Hospital, his name I do not recall, told me in confidence not to share with what he was about to tell me in fear of being sacked. He informed me that Rosemary was given contaminated plasma and that it was given to her in the 1984 surgery performed by Dr GRO-D. I believe that he had seen this information in Rosemary's medical records. I respected his wish not to tell anyone his name. I didn't even tell my solicitor.
27. No information was provided about the HIV infection. When a doctor told me that Rosemary was infected with contaminated plasma, he told me not to tell anybody that he had told me that. I was not however, provided with information in any form about HIV.

How my HIV infection affected me:

28. Approximately a week later, I returned to Singleton Hospital and saw the doctor who suggested that I begin medication for the HIV infection. I was prescribed the medication, the names of which I cannot recall. I had to dissolve four tablets of an evening over night and then take three different tablets every morning.
29. I took these tablets for a number of years until I began a clinical trial in 2009. There were only six HIV patients that were put on this medication, which I was told was the best tablets to be on to treat HIV. I do not recall the name of the manufacturer or the name of the

medication. All that I do recall is that it was an American manufacturer.

30. In the winter of 2009, my third late-wife Mary and I were in Spain. We spent the winter months there in our caravan. I became ill, couldn't keep my food down and lost weight rapidly. My then wife, called the doctor in the UK and he told her that I most likely just had a stomach bug, to just give me water and that it would go away.
31. I lost roughly around three and a half stone in weight. I decided I needed to get back home and began the drive, which lasted four days. I don't know how I made the drive back home.
32. Once home, Mary called the doctor again and he asked her to bring me in first thing the next day. When we arrived at the hospital, the doctor and nurses were waiting for me in reception with a wheelchair. I was wheeled up to a ward, undressed and they put a hospital gown on me. I recall my wife crying and that's when I knew what was happening. I was dying.
33. I recall being hooked up to a drip which was flushing a green liquid, the name of which I am unsure, into my system to cleanse my blood of the tablets. After three weeks, I was discharged from the hospital. I later found out that of the six people put on the clinical trial, one being myself, two people had lost their eyesight and one had died.
34. They stopped the clinical trial tablets, and put me back on the tablets I was on previously. I then had to go back every two weeks for appointments for a couple of months before I had fully recovered. It took me two months to completely recover and I had lost a lot of weight.

35. I told my doctor to never change my tablets again and the doctor responded by telling me that I had fought well. I told him, I didn't want to die.
36. I was not given adequate information to help understand or manage my infection. I was given one pamphlet when I was first diagnosed but I believe that I should have been provided with information at the earliest possible stage.
37. I am pleased that the test results were communicated to me. However, had I have known earlier that Rosemary had contracted HIV, I wouldn't have had unprotected sex with her.
38. I have been told about the risks of infecting others by having sexual intercourse, through bodily fluids and to be careful if I cut myself, but to try and live the best life I can. I haven't been told how to dispose of bandages or plasters; I just throw them in the bin.

Section 3. Other Infections

39. As far as I am aware, I have not been tested for HCV, only HIV.

Section 4. Consent

40. Aside from the clinical trial I took part in, mentioned above, I do not believe that I have been treated or tested without my knowledge, consent, without adequate information or for the purposes of research.

Section 5. Impact

41. When I found out that my wife had AIDS, I was angry there was no doubt about it. At the time however, I knew I had to come to terms with it. I was aware that HIV was a regular thing in the 1990's. When I was told, I didn't have time to think about it, I just needed to make

sure that I met my wife at Singleton Hospital where she was being transferred.

42. I have since felt like I was fighting the temper inside. I had never played about with other women and I had always kept myself to myself. I felt a whole range of emotions and didn't know how to process them. My priority at that time was Rosemary.
43. Rosemary's diagnosis made me feel frightened for her. I tried to keep all the wrong things away from her. I wanted to protect her by not telling her that she had AIDS. I felt as though everything was building up inside me and the pressure was mounting. I couldn't tell her the truth, which is why I told her that she was being transferred to a stroke unit at Singleton Hospital.
44. I believe in telling the truth and so lying to my wife was a heavy burden. I don't like lying; I have never lied to any of my late wives. I do not regret it but on reflection, I do not like the fact that I felt as though I had to lie to her.
45. Although I do not discuss it, I am depressed. I can't bring myself to tell people at the hospital because I feel disgusted with myself for having those feelings. I once brought it up to one doctor and told him how I felt. He responded by telling me to pull myself together.
46. Following Rosemary's death, I attempted to commit suicide. I was on a train headed to Inverness to visit my son. I got as far as Glasgow and something inside me told me that it's time to go. I opened the window on one of the doors and put my hand through the window to grab the handle to open it. A member of the train staff saw me and I felt him put his hand on my shoulder. He told me that I don't want to do this because both he and I will get sucked out.

47. I told him to keep walking, he refused and so I responded by telling him that I didn't want to take him with me. He told me to pull my hand back into the carriage and I did. He put his arm around me and walked me further down the carriage. He sat me down near a woman and asked her to talk to me and told her that I wasn't feeling well.
48. The woman spoke to me throughout the rest of the journey to Inverness. I nodded in response. Once we had arrived, the same member of staff came and found me and asked if I was meeting someone. I told him that I was and he told me that he wouldn't tell the person that I was meeting, what happened.
49. I got off of the train and walked towards my son. The member of staff came over to us and asked my son if I was his dad. He responded by saying that I was and the staff member told my son to look after me because I hadn't been feeling well on the train. I have only told my daughter-in-law and now the Inquiry team this experience of mine.
50. The physical effects I have due to being infected with HIV are that I sleep a lot; I have a small appetite but drink a lot of milk. I have trouble with my blood pressure, although I am unsure as to whether this is linked to the HIV. At present I am unaware as to whether my viral load is low but they seem quite happy with me at the hospital.
51. I have been open about my infection and not hidden a thing from anyone. All of my neighbours are aware that I am HIV positive and I'm happy with that. I've never had problems with telling people.
52. I have not felt any stigma from the wider community in regards to my infection.
53. Initially, following my diagnosis, I was required to attend the hospital fortnightly for appointments. This changed to once every four to six months until the clinical trial treatment made me very unwell. I was

again required to attend the hospital for appointments once every fortnight until they were happy with me and so I now continue going only once every four to six months again.

54. Every time I go for an appointment, they check my blood pressure, my weight and take blood. I am unsure as to whether my viral load is checked every time. Since last April I have been in hospital a couple of times as I keep falling over which may either be related to my high blood pressure or my infection. My current medication for the HIV infection is Ziagen, Ritonavir and Darunavir.
55. With regards to my career as a long distance tanker driver, I had to resign due to Rosemary's ill health at the age of sixty-one. I became tired, exhausted and I wanted to leave with my manager's authority and consent. Leaving this way would entitle me to depart with my full pension allowance intact. I believe that had I of told my manager what the real problem was, I would have ben put on sick leave or made redundant which would have lost me twenty-two per cent of my pension. Following three meetings with my manager who had the authority to sign this off, he granted it. He quizzed me as to what was going on, as I believe he could tell that I wasn't feeling myself.
56. As a result of retiring at sixty-one, I was deprived of four years worth of work.

Section 6. Treatment/Care/Support

57. I have not faced difficulties or obstacles in obtaining treatment. When I disclosed to my dentist that I have HIV, it was around the same time that I believed that I required dental treatment. He wasn't happy about it but he put his gloves on. He looked inside my mouth and then proceeded to tell me that there was nothing he could do. I wasn't happy because I was in and out very fast.

58. I have not received any counselling at all. The Inquiry investigator explained how the British Red Cross are working with the Inquiry and gave me their card. I don't feel as though I'd want it because I would feel embarrassed. However I will think about it.

Section 7. Financial Assistance

59. Not long after my diagnosis, the hospital informed me of the Eileen Trust. Although I cannot remember applying I have received some financial relief from them.
60. I believe that I now receive payments from Wales Infected Blood Support Scheme ("WIBSS"), which is more than I received from the Eileen Trust. There were no preconditions imposed on the ex gratia payments I received. I am unable to recall the dates of when I began receiving payments.
61. The Eileen Trust ex gratia payments was a little over £1,000 per month whereas now from WIBSS, I receive just over £1,500 per month.
62. An investigator to the Inquiry explained to me what an ex gratia payment is, as I was unsure.
63. In regards to the amount of financial assistance that I receive, I am happy that I get something. Something is better than nothing however I do wish it were more.
64. I became Rosemary's carer and the receptionist at Singleton Hospital would pay me £5 every time I went for parking.

Section 8. Other Issues

65. Soon after Rosemary passed away, I instructed a solicitor from the local firm, Douglas Jones and Mercer ("DJM"), to prove my point about how Rosemary had become infected with HIV. I explained to the solicitor what had happened over the years in regards to her health and he told me he would start writing letters to the right people in London. I saw him one week later when he made it very clear that I can't fight Morriston Hospital for compensation. I was given a form to sign stating that DJM would only represent me if I agreed not to take action against Morriston Hospital.
66. The solicitor, his name I do not recall, told me I needed to take action against those whom supplied the blood, The National Blood Transfusion Service ("NBTS").
67. It was a lengthy process but three years later, the solicitor told me he had been in contact with the NBTS. He had told me that it had taken the NBTS three years to track down exactly what blood product(s) Rosemary had received. I was sent a letter by the solicitor, which stipulated that Rosemary was clear of infected blood and insinuated that either she or I had been unfaithful.
68. I reached out to the solicitor and told him that Rosemary wasn't given infected blood, she was given infected plasma. I hadn't previously informed my solicitor of the type of blood product Rosemary had received (plasma), as the doctor that told me in confidence originally, that I should not share this information, otherwise he would lose his job. The solicitor was angry that I hadn't shared this information earlier.
69. The solicitor came back to me three days later with two cheques from the NBTS. One for the amount of £40,000, which was awarded to me as a result of Rosemary's treatment and subsequent death. The other was for the amount of £20,000 also awarded to me, in relation to my

infection. I paid DJM £1,400 for their services and that was the end of it.

70. I am very happy for DJM to allow and share with the Infected Blood Inquiry the contents of my litigation, regarding Rosemary and myself, against the NBTS of which I received a payment in 1997. This may provide useful information to the Inquiry.
71. Dr **GRO-D** who died two months after my wife's surgery hid my wife's predicament from me and another surgeon had to take over after delays; I feel my wife was murdered by being given contaminated plasma. Despite repeatedly asking, no one would explain a thing in the early days. Nobody would talk to me; I never received an honest answer.
72. I believe that Dr **GRO-D** cut himself on the pin that he was trying to remove from Rosemary's hip, became infected with the HIV infection from the plasma they had put in her system and subsequently died two months later.

Statement of Truth

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

Signed GRO-C

Dated 30/4/2019