

20 FEB 2019

Witness Name: Joyce Deakin

Statement No.: WITN0119001

Exhibits: Nil

Dated: 18-2-19

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF JOYCE DEAKIN

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 24 October 2018.

I, Joyce Deakin, will say as follows: -

Section 1. Introduction

1. My name is Joyce Deakin. My date of birth is GRO-C1942 and my address is known to the Inquiry. I am retired, but previously I worked for 35 years in a village newsagent, before assisting my husband in running a shop. I live on my own and have one daughter.
2. I intend to speak about my late husband Kenneth Kidd Deakin (GRO-C1941 – 5/10/2014). He had been infected with Hepatitis C virus ("HCV"), as a result of being given infected blood through a blood transfusion.
3. In particular, I intend to discuss the nature of his illness, how the illness affected him, the treatment he received and the impact it had on him and our lives together.

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.

Section 2. How Affected

5. My husband Ken and I got married on 19 August 1961 and in 1966 we had a daughter.
6. Up until his first heart bypass he was employed as a supervisor at Laporte Chemicals in Warrington. He returned to work shortly after the bypass, finishing his employment with the company when redundancy came up. He thought that his health should come first, so he opted for voluntary redundancy. Being the person he was, Ken did not stop working. He was self-employed for some time, before managing the local post office. He then managed another local shop up until his retirement in 2009.
7. Ken had a heart bypass on Easter Weekend 1986. He collapsed at home, after we had been out for the day visiting relatives in Worcestershire. The doctor came out and phoned an ambulance immediately. He was taken to Wythenshawe Hospital that evening and the doctors told him he had 6 weeks to live. A triple bypass was carried out a few days after. He was 45 at the time, and was a healthy man without any problems.
8. We discovered that Ken had previously had a heart attack, but he was not made aware of this until he had the bypass surgery. Prior to the heart bypass he had not receive any blood transfusions.
9. He was in intensive care for 24 hours before being transferred to a high dependency ward. After 3 days he was put on a normal ward, and within 2 weeks he was back at home.
10. In total, Ken was only off work for 8 weeks only. During this time, as he was very much into DIY and he wanted to keep fit, he built a patio; he recovered marvellously.

11. I could not fault the care he received. The surgeon, a Scottish gentleman, explained him the operation in detail to him and he even warned him that he could die on the operating table.
12. Ken had no problems after the surgery, and shortly after his return to work he started fundraising for the hospital. As a family we were so grateful for what the hospital did that we organised bike rides from Blackpool to Paris and dinner dances. Even Ken's surgeon Mr Campbell attended one of the dinner dances. We raised £10,000 over the period. To demonstrate their gratitude, the hospital opened a ward in Ken's name; Princess Margaret hosted the opening ceremony.
13. We thought the hospital staff had saved his life and that they were wonderful people: I am sure they were unaware of what the outcome was going to be. It was the blood transfusions he received in surgery that infected him with Hepatitis C (HCV). It makes you feel bitter to think that through no fault of his own he contracted an illness, which was going to kill him. The blood should have been screened.
14. Ken's first bypass changed his life, it was extremely good and he could live normally for 28 years before having to undergo another bypass. He was admitted on 4 January 2010 for the surgery, where he would receive blood transfusions again. Further blood tests were carried out before and after the surgery, but no problems were detected. He suffered from angina but after that he was fine again.
15. Around 2005/6 our GP told Ken that his liver levels were high and that he should stop drinking. Although Ken liked a drink every now and then, he definitely did not have an alcohol problem. This was discovered from a routine blood test. The GP's told him that the level in his liver instigated that he was drinking too much, but he was never sent to hospital for investigatory tests. As soon as he was told this, he never touched a drink again.

16. The doctors found out about HCV in 2011, only three years before his death (he died on 5 October 2014). A blood test had been carried out as part of a check up after his bypass, and Ken had no idea that anything was wrong. I don't know if the doctors either knew about HCV before and never told us about it or they actually didn't know anything. The only thing I know is that up to 2011 his liver levels were high but nobody ran any further tests or explained us why. Looking back at what happened in those years my daughter and I both believe the GP knew of the HCV at this point.
17. Dr GRO-D called him in for an appointment following the results. She explained that there was only two ways of contracting HCV, through drug use or unprotected sex with other men or women. He was not questioned about receiving blood transfusions, if he had tattoos or informed of any treatment. According to Ken, she remained rather aloof. Ken was mortified to come home and tell me what the doctor had said, especially after we had been married for 50 years.
18. My daughter told Ken that HCV could be contracted through a blood transfusion and she also told to a friend of hers at work, who also thought that HCV could be contracted via blood transfusions. This friend knew a nurse at Liverpool Hospital who was specialised in HCV, HIV and AIDS, so we made arrangements for Ken to be referred. It was from this point on that Ken's medical attention progressed, as all his care was directed from Liverpool. He did not go back to the GP again.
19. During the initial appointment at the Hospital in Liverpool, the doctors said that the HCV he had could only be transferred through blood. Ken was asked when he received his blood transfusions. It was determined that the infection was from the first bypass surgery, as that was blood imported from America and at that time it was not screened. The specialist was disgusted at GP's behaviour and words. He said that if she did not know how HCV was contracted, she was "*not much of a doctor*". We were told that the virus can lie dormant for a long period or may in fact never come

to light. For Ken something had triggered the virus, which then started to attack his liver.

20. The hospital started to carry out tests. I remember that he always had appointments, regular ultrasound scans; he also had an endoscopy and even had a bone density test. He then went to Warrington Hospital for a full body scan. The level in his liver never changed for three years. Each time we received results, the hospital staff were pleased.

Section 3. Other Infections

21. Ken did not contract any other infections as a result of being given blood transfusions.
22. At Liverpool Hospital he was tested for HIV, but this was negative. This test was never offered by our doctors' practice in Lymm.

Section 4. Consent

23. When Ken went in for his first heart bypass, he knew he would receive a blood transfusion as part of the operation. He received 8 pints of blood to restart his body back up again, but he was never warned that there could be a risk of HCV infection or any other infection at all.
24. Ken was always informed when he was being treated and tested by doctors. Even when he was in hospital the nurses would come in and ask if they could take some blood.
25. To the best of my knowledge Ken was never the subject of any research.

Section 5. Impact

26. Ken was horrified to think that he was infected with HCV. There were times when the diagnosis would make Ken feel down, and he did suffer

from depression. Sometimes he would get annoyed because he did not contract HCV because of something he did.

27. A year before Ken was taken into hospital we started to notice a change in him. He woke up one morning and he could not move; his legs and feet were swollen. He couldn't even move a spoon to his mouth as his knuckles were swollen. He was screaming in agony. We were living in Wales at that time so I phoned our daughter. An ambulance was unable to come as we were out of the area; so we ended up driving Ken ourselves to Liverpool Hospital. He went straight to A&E and he was kept in for two weeks. At first he was placed in isolation as they thought it was an infection.
28. Nobody could explain to us what caused the swelling. I remember that at that time I thought that it could have been gout, because I have suffered with it from time to time, and the pain is indescribable. Yet the swelling was all over Ken's body. I asked the consultant whether it could be gout, but she did not even know what gout was; she explained that she would discuss it further with someone specialised in that field, but nothing ever came out from the tests. Ken was never referred back and basically the doctors never dealt with it, it's like they forgot about it. They did say it could be some form of arthritis but it was never confirmed, they were very vague about it and at a certain point they stopped discussing about it.
29. After leaving hospital Ken did get a little bit better, but he could not walk properly anymore. Even getting out of bed to go to the bathroom was too much for him and he required my assistance.
30. I took him to Liverpool Hospital for further tests and at this point he was on sticks. The consultant could not believe he was looking at the same man. He could not understand what had happened.
31. They gave Ken a bed and he was in hospital for 6 weeks. I lived virtually at the hospital. We even spent our 53rd wedding anniversary there. Our

daughter also spent a lot of time at the hospital. He was admitted at the beginning of August 2014 and left on the 5th September.

32. One day the liver specialist asked to have a word with me. A nurse was also present. He explained to me that Ken had acute liver failure and that there was absolutely nothing they could do. He told me that Ken only had a few weeks to live. He was very apologetic, and he said that he could not understand how the damage to the liver had advanced so much and so quickly. I asked about all the tests and scans that had been carried out before, to which he replied, "*they do not show much*".
33. I could not understand how he could say something like that after all the tests he underwent, I find it impossible that they showed nothing.
34. One evening I went to ask a nurse for something that Ken needed. This happened to be the same nurse that was in the meeting with the consultant. While answering to my request she told me "*I don' t know if you realise it but your husband is very poorly*". I was very angry with her; I remember that I reported the conversation to the other lady in charge of the ward. I found it rude and not nice at all.
35. Ken's deterioration was incredible. He couldn't recognise my daughter nor me. At this point Ken wanted to come home, he wanted to come back to our daughter's house. When he first came back he did not even want to eat.
36. The combination of the liver and the kidneys not working meant he had to have his stomach drained. 15 litres of liquid were drained from his body, and by the next day all that liquid would come straight back like nothing had been done. Ken was unable to stand up after the liquid was taken because of the total lack of balance. It was so painful to see him in that condition and suffering so much.

37. My daughter and I coped for two weeks with Ken at home but it was extremely difficult. During the night he would wake up every 10 minutes. He was slightly better during the day.
38. As a result of the HCV infection, Ken suffered with hepatic encephalopathy, a confusion caused by the damage to the liver from cirrhosis. Due to the liver not functioning properly, toxins were released into his brain and poisoned his body. He would say he could feel the confusion coming on. On one particular day, I went back to our home in Wales to collect some of our belongings. He said to our daughter and her husband that he was tired, so they took him upstairs to lie down. He kept asking for me and questioning if I was ever coming back. He was hallucinating at this point, but settled down when I arrived back.
39. Due to the confusion, Ken stopped driving. Despite being an experienced driver who was also confident driving abroad, he would tell me to drive. I ended up driving him to all of his hospital appointments.
40. We were told that the confusion could be treated by a medicine called Lactulose, a strong laxative that would remove toxins out of the body. It was horrendous; on each prescription Ken was prescribed to take 10 bottles at a time ^{on each prescription} and was becoming incontinent. He couldn't go on like that so I stopped giving him the medication. Despite he begged us not to, my daughter and I ended up taking Ken back to hospital on mid September. We had no choice, as we could not cope with caring for him at home. On 28th September we were told that Ken had only few days to live. He died 8 days later on the 5th October 2014.
41. My daughter and I came to the decision not to tell Ken that he was dying. That's why I got particularly annoyed at a young doctor at the hospital. He stopped me in a corridor of the hospital and said that they were going to have a word with Ken, to tell him the truth, that there was nothing more they could do. I warned him not to, and threatened to report him if he did. I immediately went to see the supervisor of the ward to explain what the

junior doctor said. She assured me that Ken would never find out, and actually he never did.

42. I cannot fault the care administered by the nurses, they were amazing and they could have not done more than what they did. I am annoyed at the consultant and his right hand assistant.
43. In relation to the obstacles we faced in accessing the treatment, a nurse consultant at Liverpool Hospital spoke about a treatment available shortly after Ken was diagnosed with HCV. She explained that it would make him extremely ill for at least 2 years, with severe flu like symptoms and that the treatment was very invasive. He did have cirrhosis of the liver at this stage and he was told that the side effects were severe and they said that he would die because of something else before than of HCV. She said the decision was up to Ken, but she strongly advised him not to have the treatment. As such, he refused the treatment.
44. Ken came to this decision also because of the test results he received after the diagnosis. The cirrhosis was not progressing and his liver levels were steady.
45. When I took Ken back to Liverpool Hospital in July 2014, the nursing specialist had good news for us. She explained that a new tablet brought out in Belgium was now available and that it would cure HCV. Only 500 people in the UK could receive the medication, and she phoned at a later date to say Ken's name had been put forward and accepted. We knew nothing of this tablet beforehand. This all happened before Ken's health deteriorated.
46. When they then found out that my husband had kidney failure he was too poorly to be given the tablet. I think that something should have been definitely done before Ken's health deteriorated.

47. Every time we went back for an appointment, they said they were still waiting to receive the tablet, but they would promise to have it by the end of the week. Looking back, I think they knew that he was too ill for it to work anyway.
48. Ken clung onto this as a cure, and would even keep asking if they had the tablet during the last 6 weeks leading up to his death.
49. In hindsight they were trying to make Ken and our family feel better, even though they knew how poorly he was. After Ken died we were bitter about the nurse specialist, why did she say he could have the tablet while he couldn't? She must have already known before that, that it would not have made a difference to Ken's situation.
50. They should have run tests beforehand to confirm he was eligible for the medication. He was constantly monitored and never missed appointments, so that could have been determined anyway.
51. I have been asked whether Ken ever experienced any issue with dental care. Ken did not visit the dentist in the period after his diagnosis, so the answer is no, he did not experience any problems with dental care. He might have done if he had gone to the dentist.
52. When Ken was first diagnosed with HCV, it did not affect our lives together. We continued to go out and go on holiday.
53. I have not suffered mentally as a result of Ken's infection with HCV. I always try to cope, although it can affect you in other ways. When Ken was poorly I did start to feel ill and I developed a terrible cough. At first I thought I might have caught from the hospital, but then I found out that it is asthma. My doctor explained to me that when you are older grief could bring on things like this. Initially I did not believe him, but as a matter of fact I still have a persistent cough.

54. I did have to think ahead in regard to personal items such as toothbrushes and razors. I had a consistent supply of gloves at home in case Ken cut himself or started to bleed. I was actually surprised that some of the nurses at the hospital did not use gloves at all. It must have been so risky for them.
55. As family we did not experience any stigma. We live in such a small place that we know everyone and they all know us. No one ever stepped back or acted differently towards us. Ken even told the ladies in the barbers and they were lovely with him.
56. Our daughter purposefully tells people about what happened to Ken, and no one has ever been horrible in response.
57. After Ken's death, the undertaker (who we knew well) particularly upset my daughter. He rang the house to say they would release his body, but he would be in a body bag. We had picked out clothes, but he refused to dress his body, offering only to lay the clothes on top of him. We were too distraught at the time to take this further, but they never said at the hospital that the infection is still contagious after death.
58. Our daughter suffered and still suffers from depression, so Ken's illness made her condition worse.
59. Ken's infection did have a financial effect on myself. He had a good pension, which he paid into over his working life. Part of this passed to me since his death, although the amount dropped significantly by around 35%.
60. Had he been younger when the HCV was discovered, I think it would have had a greater impact on his life.

Section 6. Treatment/Care/Support

- 61. I have been asked if we ever received any psychological support or counselling, Ken and I were never offered any support.
- 62. I am not sure if counselling would have helped us. It was not something I ever thought about, as no one ever mentioned it to me.
- 63. The Macmillan nurses did approach me at one point, but I did not want to engage with them. It was the right idea but at the wrong time. They were nice but I felt as though I did not need their assistance. This was the only occasion that anyone offered some help.

Section 7. Financial Assistance

- 64. Ken and I received financial assistance from the Skipton Fund from 2011 onwards. The nursing specialist at Liverpool Hospital told us about the fund straight away, and she filled out the forms on our behalf.
- 65. Within a couple of weeks we received the first stage payment of £25,000. This was followed by a second stage payment of £50,000 and a monthly payment of about £900.
- 66. In my opinion it does not matter how much money is awarded, it will not bring back my husband or compensate us for what he and I went through.
- 67. The application itself was fine, although the consultant did everything. This may also explain why we received the money quickly.
- 68. I do not qualify for EIBSS but I was only short by £100 per year which I do not find fair as it is only £8.33 per month and not thousands.

Section 8. Other Issues

69. I have been asked whether we have ever been involved in campaigning or in any previous litigation. I confirm that Ken and I have not been involved in any campaigning or litigation.
70. When Ken was receiving medical care at Liverpool Hospital I asked whether I should be tested for HCV. I was told this was not necessary.
71. I have a lot of expectations of this Inquiry. Answers must be given to questions like why infected blood was given and when people were aware of the risks. I would like to know what is going to happen to the individuals who allowed this to happen.
72. I would like to have justice for our family and others who have gone through the same experience, but I cannot see how this can be achieved when a lot of the people responsible could now be dead.
73. The use of infected blood has been a disgrace to the medical profession and it makes you distrust people working in that field. Recently my brother in law refused a blood transfusion on this basis, but they were able to prove the blood is now clean. Someone must have known that through all these years, the blood they were providing was infected.

Statement of Truth

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

Signed

GRO-C

Dated

18-2-19

