

Witness Name: C.L. FORBES

Statement No: WITN2749001

Exhibits: 0

Dated: 16 FEBRUARY 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF CLIVE LLOYD FORBES

I, Clive Lloyd Forbes will say as follows: -

Section 1. Introduction

1. My name is Clive Lloyd Forbes. I was born on GRO-C 1957 and live at of GRO-C
GRO-C with my wife. I
am retired.
2. I make this statement as the son, of Duncan Stewart Forbes, deceased, who
was infected with Hepatitis C as a result of receiving contaminated blood
products and died on the 3 December 2003
3. **This witness statement has been prepared without the benefit of access
to my late father's full medical records.**

Section 2. How infected

4. My father had a heart attack in 1976, and from then on was conscious that it
could happen again. Consequently he made lifestyle changes and started
losing weight and stopped his occasional smoking.

5. In 1984 my father suffered another heart attack and was admitted to Killingbeck Hospital in Leeds where he underwent a quadruple heart bypass operation performed by Mr Uni Nair. During this operation he was given a blood transfusion. I believe that this is the blood transfusion that infected him with Hepatitis C. My father was told that if he did not have this operation, he only have at most another three months to live but with it, he could survive for a natural lifetime. There is a history of long life in my family as my aunts and uncles all lived into their eighties and my father wanted that life too.
6. My family was never informed exactly which blood or blood products were given to my father during the operation in 1984. Our family was aware that there was a risk involved in the major surgery taking place and understood that. We were not however given any advice or information which indicated there was a risk of infection from the blood or blood products he was to receive during the operation.
7. After his discharge from hospital he decided not to return to his former work as an engineer and got a job as a Security Officer at Leeds City Council's Social Security Government Buildings at Lawnswood in Leeds. He was very happy there.
8. My father was contacted in 1993, (I believe by the Leeds General Infirmary) and asked to attend the hospital and provide a sample of blood as there were concerns that the blood he received during his heart bypass operation in 1984 had been from a contaminated batch. He was subsequently contacted a couple of weeks later and attended the hospital where he was told that the blood he received was in fact contaminated and that he had been infected with Hepatitis C. The hospital told him that this had been an accidental contamination and that the disease was incurable. He was told that there was little that could be done for him and that his life expectancy would be no more than twenty years.
9. My mother has told me that the way in which the doctors informed my father of his infection was very cold and calculated, quite clearly designed to avoid

any admissions of guilt on their part. They kept saying it was accidental. There was a distinct lack of empathy or understanding and she remembers it was very much like, "This is how it is Mr Forbes, thank you and goodbye".

10. No further advice was communicated from the hospital or other medical practitioners to my father or to our family as to what, if any, risks we had been subject to, or what measures we should take to avoid infection in the future. For instance, no member of my family, including my mother who was potentially at most risk, was ever asked to undertake a blood test. It was left to us to find out for ourselves what we needed to do to ensure our safety from infection. I don't even remember my father having any further contact with the health authorities until he started to feel unwell due to infection after which he made regular visits to his doctor or to the hospital who would assess how the disease was progressing.
11. I consider that information sufficient for my father and mother to understand the risks of others being infected should have been provided.
12. In around May 2002 my father was diagnosed with early onset of Alzheimer's disease which was later diagnosed as Vascular Dementia and after my father had stays in Seacroft Hospital where his care could not be managed properly my mother was forced to have my dad placed in a high dependency care home in May 2003. In the home he was kept in relative isolation in view of the risks to staff and other residents from his Hepatitis C. He would not leave his room except for when a member of staff or we went to feed him. Someone would sit with him whilst he'd have his lunch or dinner.
13. In September 2003 we rushed my father to A&E at St James Hospital in Leeds as he had been vomiting blood. Whilst we were waiting for him to be seen by a doctor he vomited up what could only be described as a bucket full of solid brown smelly and horrible blood. He was in this hospital until his death on 3 December 2003.

Section 3. Other Infections

14. As far as my mother and I are aware, my father had only been infected with Hepatitis C.

Section 4. Consent

15. Following his diagnosis, I believe my father thought his ongoing appointments to the hospital were purely to monitor the speed and progression of the disease which he felt aided research into the disease for future use. When his hospital visits became more frequent, my father felt like a guinea pig that was constantly being tested.
16. I do not believe that he was tested without his knowledge or consent.
17. There was never really much offered to my father by way of treatment for Hepatitis C, so he could not have consented. I cannot say for sure whether treatment should have been available as I do not know what was out there.

Section 5. Impact of the Infection

18. I recall speaking with my father just after the diagnosis had been given to him. He appeared to be in a state of shock and could not understand how he had been allowed to infected with Hepatitis C. He seemed to be upset that yet again he would have to change and restrict his lifestyle at a time of his life when he wanted to enjoy himself and his family. My father would only ever have a couple of pints on Saturday evenings with my mother or with me on Sunday lunchtimes so he was never a heavy drinker. He was told he would have to give up alcohol completely.
19. As a family we were devastated. My mother was deeply shocked and concerned that for nine years she and the rest of us had been unaware that my father had a transmittable and deadly disease that could have potentially

infected any one of us and others elsewhere. She still carries that burden to this day and hopes that nobody else has been affected.

20. The last ten years of my father's life were extremely unpleasant and difficult for everyone as the disease took hold of his body and restricted his life. He was forced to give up work and the disease made normal daily life a constant struggle. In his final year, my father became very jaundiced. His quality of life decreased. He used to be very active. He would walk the dog twice a day, go every Tuesday to organ recitals at Leeds Town Hall. He was, despite being a manual worker, an articulate and self-educated man who had a wonderful sense of humour. He was also extremely well read. He was the archetypal family man who worked hard to ensure his family were looked after. In fact until his final 18 months of his life, he was still driving a car, but thereafter things changed and gradually the number of activities my father engaged in decreased.

21. Prior to his final year, my father wrote a book about his life and experiences including his time in the army fighting in Burma and Borneo during the Malayan Emergency in 1948-50. He also wrote poetry, but my father never projected his worries to us as he didn't want us to be affected. He kept his emotions to himself and always tried to protect his family from any problems.

22. I don't know what medications he was supplied with or if any treatments were considered for him by the doctors. He was told that Hepatitis C was an incurable disease. I know that going back and forth to the hospital became a real physical and mental chore to my parents and took a big toll on their well-being which was worsened by the fact that the hospital appointments did not improve my father's condition in any way.

23. The initial impact on the family as I've said above was devastating; knowing that one's father had been given a notification of his impending death, which was in fact 9 years late in its announcement.

24. Once the diagnosis had sunk in, we all did our best to normalise life for my father whilst being acutely aware that were he to cut himself and bleed we would need to ensure that we did not leave ourselves open to infection in any way. Since my father was taking Warfarin, blood thinning medications, he bled very easily whenever he was cut. It would take a very long time for the bleeding to stop. We had to be particularly cautious around him when he bled like this. It was a fear of the unknown and because we suspected the risk of transmission to pass more easily than it actually did, it was very difficult, especially for my father as he was stripped of his right to play with his grandchildren freely.
25. Whenever he was with the grandchildren there would be an obvious "wall" between him and them and it had a profound effect on us all. The fact that no medical professional had ever educated us or had ever given us any information as to how best to manage the disease made us very ignorant in deciphering how far the risk could be assessed. For us, it was best to be safe rather than sorry.
26. As a son, I watched my father's health deteriorate in a slow and difficult way which was very tough. Being unable to do anything to alleviate his condition meant that I felt helpless. I watched my mother become emotionally drained which in turn impacted on me and my sister and I'm sure it adversely affected our relationships with our spouses, children, friends and work colleagues. Friends and other family members had to be warned of his condition when they were around him which was unpleasant for him and us.
27. In some ways it is fortunate that my father was diagnosed with Vascular Dementia. It meant that during the final and critical stages of his life when the Hepatitis C really kicked in, he was not really aware of what was happening to him or where he was. When he vomited, he just seemed to go back to sleep again until the next time. It was truly heart breaking for us as a family to witness his slow death but when it came it was a relief for us all.

28. In terms of stigma, thankfully his friends were always supportive but if he went to hospital the staff would need to be warned that he had Hepatitis C. It was like having big letters on his forehead which was embarrassing for him. There was no way to avoid it.

Section 6. Treatment/care/support

29. To the best of mine and my mother's knowledge, no drugs or treatment was ever offered to my father. He was only told that he would not be able to have alcohol anymore. Any treatment for Hepatitis would have been long term and I cannot recall my father ever having visited hospital that frequently.

30. I believe no counselling or psychological support was offered to my father, mother, or any of our family members. If it had been offered my parents certainly would have accepted and it may even have helped.

Section 7. Financial Assistance

31. No member of our family, including my father has ever received any assistance financially or otherwise from any trust, agency or authority prior to or following my father's death.

Section 8. Other Issues

32. I have not been involved in any Litigation.

Anonymity

33. I do not wish to remain anonymous and I want to give oral evidence to the Inquiry.

Statement of Truth

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

GRO-C

Signed

Clive Lloyd Forbes

Dated

16/02/2019