

Witness Name: Stephen McArthur

Statement No.: WITN3757001

Exhibits: Nil

Dated: 7.2.20

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF STEPHEN MCARTHUR

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 10 September 2019.

I, Stephen McArthur, will say as follows: -

Section 1. Introduction

1. My name is Stephen McArthur. My date of birth is GRO-C 1963 and my address is known to the Inquiry. I live near Glasgow with my wife and we have two children. I intend to speak about my father, Alec McArthur, who contracted Hepatitis C following a kidney transplant. In particular, the nature of his illness, how the illness affected him, the treatment received and the impact it had on him and our lives together.

Section 2. How Affected

2. I am the youngest of three children of Alec and Mary McArthur. I have two older sisters, Sandra McKay and Janice Dickinson, both of whom

have also given statements to the Inquiry. (See WITN3707001 and WITN3626001 respectively)

3. My father died in August 2001 aged 69. His death certificate states that his cause of death was myelofibrosis, a form of bone marrow cancer, renal failure, gastro oesophageal haemorrhage and Hepatitis C.
4. Dad was diagnosed with Hepatitis C in 1992. He received a kidney transplant in 1984 and my family and I believe that either the transplant or a blood transfusion that he received during the operation was the source of the Hepatitis C infection.
5. Doctors told Dad in April 1984 that his kidneys had failed. Over the summer he had various testing done and no blood diseases were found. He was put on the transplant list in around August or September 1984 and a kidney became available in October. I recall that he was very excited about the transplant and then the reality of having an operation sunk in.
6. As far as I am aware, Dad was never informed of any risk of infection from either the kidney transplant or any blood transfusion that may be associated with it.
7. Following the operation, Dad was given immunosuppressant drugs and underwent Continuous Ambulatory Peritoneal Dialysis at home. He returned to work as an inspector for an insurance company, examining goods before they were exported, which required him to travel to different sites each day.
8. After a period of good health Dad began to feel and look unwell again. He was very tired and suffered from joint pain, and following further medical examination was told that he was being tested for leukaemia. He wasn't told that he was being tested for Hepatitis C before his diagnosis in 1992.

9. When Dad was diagnosed he was told that that it wasn't very serious and that he shouldn't worry about it. Mum was told that there was no danger of her catching it as it wasn't possible to pass it on. Our family weren't told we needed to take any precautions. In fact, very little information was provided on how to manage the condition to what to expect going forward.

10. My sister Sandra later saw Dad's medical records when they were obtained by Mum's solicitors. These apparently showed that the doctors knew that Dad had Hepatitis C in 1990, two years before he was told. This was never discussed with him prior to him being informed of the infection in 1992.

11. As far as I know, Dad was never informed of the source of the Hepatitis C infection. He never had any major operations prior to the kidney transplant. He didn't have any tattoos and he wasn't an intravenous drug user nor did he abuse alcohol. Dad was very happily married and he was a respected local church elder. The only possible answer was that he contracted it through the kidney transplant via the organ itself or, through a blood transfusion during the operation.

12. None of us children were ever tested for Hepatitis C. It was only after Dad died that Mum was tested and that was at her request. She had been looking after my daughter [GRO-C]
Mum was concerned that if she had Hepatitis C then it could be [GRO-C] although this was not the case [GRO-C]
[GRO-C]

Section 3. Other Infections

13. As far as I know Dad didn't receive any infection other than Hepatitis C. I don't know if he was tested for HIV.

Section 4. Consent

14. I believe that Dad was tested for Hepatitis C without his knowledge or consent, as I understand his medical records show that he tested positive two years before he was informed. Even if it was later, at that time he believed he was being tested in relation to leukaemia.

Section 5. Impact

15. Dad never really spoke to us about his illnesses and tended to keep things to himself. It was a generational thing and he just would not want to burden us with the worry.

16. As far as I am aware Dad was never offered any treatment for Hepatitis C, possibly because nothing was available. He was treated mainly at the Western Infirmary and also went to Southern General for treatment for the skin lesions he developed in the course of the illness.

17. From the early 1990s onwards, Dad became chronically fatigued. He was so frail, a shadow of the man he was. He lost the strength in his legs and feet and had peripheral neuropathy - the loss of sensation in the hands and feet. He was always cold and had repeated bouts of gout which was something he had never had previously. He began to develop skin lesions as mentioned, some of which had to be removed, including one from the top of his head. This required an operation involving a skin graft from his thigh.

18. Dad developed myelofibrosis in around 1995, possibly as a consequence of the immunosuppressant drugs he took following the kidney transplant. From that point he began to receive regular blood transfusions. At first this was a few times a month, then fortnightly, then weekly. He started out driving himself to the hospital for the transfusions and for his dialysis, but soon he became too weak, and the family took

over. I would often take Dad to and from his appointments, at times I felt like a taxi driver, I was back and forward so often.

19. Dad stopped working at about the same time he stopped driving, when he was 65. Dad used to take Mum everywhere as she couldn't drive. When he would take her to the shops, he would have to sleep in the car because he was so tired. One day he was asleep and a passer-by was so worried he had passed away that they called the police. They were just about to break the car window when Dad woke up. He really was that bad with the tiredness.

20. Dad was always cold and would wear a big sheepskin jacket and hat whenever he went. I remember on one occasion he asked me to take him for a drive along the coast. He was wearing the jacket and hat, he had about three blankets covering him and we had the heating in the car all the way up, and he was still freezing!

21. My parents would go on holiday every year and would often travel to France to visit Mum's sister. After he contracted Hepatitis C, Dad couldn't get travel insurance to go to France so this had to stop which was hard on Mum, He became too unwell to spend much time away from home.

22. Dad had been involved in a lot of community and church activities: he was a football referee, he played golf and tennis, he sat on community counsel and he was a church elder. He lost the energy to participate in those activities and eventually couldn't even attend church services.

23. In the year before he died, Dad was pretty much confined to his bed. My parents' bedroom was upstairs, so the bed was moved downstairs into the living room for Dad and Mum would sleep on the sofa to be near him.

24. Mum nursed Dad herself without help from a nurse or any other community service. When Mum had to go into hospital to have varicose veins removed so my sister Janis moved in to look after Dad.

25. Mum would only leave the house if someone was there to look after Dad. Often my sister Sandra's father-in-law would come and sit with Dad so Mum could go shopping. I know that on occasions Dad would be in such a bad mood that he would pretend to be asleep so he wouldn't have to talk to him.
26. The last time Dad was admitted to hospital, he was in a ward of four people at first and the standard of care was very poor. He was lying down constantly on his back. He would be given his medication but no help to take it. He couldn't drink it lying flat and on his own and so needed a straw, but the nurses wouldn't give him one. He also had a bad fall onto the concrete floor when a nurse tried to operate a hoist on her own but they didn't tell us about that at first.
27. Later, Dad was put into single room. He had sores all over this body that were leaking blood and he needed continual blood transfusions and the bed linen was saturated with blood. Not all of the nurses used gowns and gloves and Mum was horrified at their approach and later put in a complaint to the hospital. They replied and apologised, and said the staff would be reminded about proper processes.
28. There was also one occasion when we could hear a group of nurses outside the room celebrating one of their 21st birthdays. Apparently, it was a tradition that when a nurse turned 21 she would be thrown into a bath of cold water. It was hard for us to hear these celebrations while we were with Dad. Especially, in the condition he was in at that time, it just seemed so thoughtless on their part.
29. On the evening that Dad died, Mum had stayed on in the hospital after my sisters and I had gone home. A minister came to visit and shortly afterwards Dad passed away. The staff told Mum that if she didn't call us to come back that night, we wouldn't be able to see the body, it would need to be put in a bag because of the risk of infection. Mum decided against calling us back so we didn't see Dad again.

30. Dad couldn't get life insurance so he had saved up money for his funeral which was covered. However, he also couldn't get mortgage insurance, which meant that Mum had to sell their house when she couldn't continue the repayments.
31. Mum became very unwell after Dad died, she was sleeping all day and staying awake all night. There were two things that helped her carry on. One was she started babysitting my elder daughter during the day. The other was that a family friend, who had just moved to Glasgow for work, moved in with her, and this meant someone was home with Mum every night. Some purpose and a bit of company kept her going, otherwise.....I'm not sure what she would have done.
32. Mum took anti-depressants for almost 20 years, from before Dad died until around month she passed away. When we were cleaning her house, we found she had kept books on depression in paper covers so we wouldn't know she had them. I don't believe that my mum would have needed anti-depressants if it were not for the illnesses that afflicted my Dad, some of which the HCV contributed to I'm sure.
33. My children are the youngest grandchildren and my second child was born after Dad died, so he never met her.

Section 6. Treatment/Care/Support

34. When Dad had his skin lesions treated or went to the dental hospital he was always the last patient of the day. He was told this was because of the risk of infection and that the equipment needed to be cleaned. For the skin lesions, he was sometimes scheduled for a morning appointment and then told he had to wait once the staff looked through his notes and saw he had Hepatitis C, which was frustrating for him. He asked to have the information on the front of this file so it wouldn't keep happening, but was told this couldn't be done for privacy reasons.

35. Removal of the lesions was always painful because Dad could only be given a limited amount of anaesthetic, I'm not sure what the medical reason was, if it was related to Hepatitis C or something else.

36. No one in my family was offered counselling or psychological support during Dad's illness or after his death. As far as I am aware he was never offered any counselling in relation to the infection. Mum had to seek her own psychological treatment in later years.

Section 7. Financial Assistance

37. I don't know if Mum applied to the Skipton Fund. If she did, she didn't receive any payments. I don't believe that she ever received any type of financial assistance.

Section 8. Other Issues

38. Sometime in the 1990s I can recall my parents attending a meeting in Edinburgh involving other people who had received infected blood, including haemophiliacs. I'm not sure what they were looking to do but I know that they met with the same group a few times.

39. In around 2003, Mum was represented by Thompsons Solicitors as part of a judicial review. Dad's death was one that interested them but it came to nothing. It was during this period that my sister Sandra was able to view Dad's records. It all came to nothing as I think that they eventually decided to go ahead with another family who had a better chance of success.

Statement of Truth

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

Signed

GRO-C

Dated

7.2.20