

Witness Name: Caroline Carmichael

Statement No.: WITN2102001

Exhibits: **NONE**

Dated: 29/11/2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF CAROLINE CARMICHAEL

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 29th November 2018.

I, Caroline Carmichael, will say as follows: -

Section 1. Introduction

1. My name is Caroline Carmichael. My date of birth is GRO-C 1955. My address is known to the Inquiry. I am married and retired, although I am now self employed as a safeguarder by the Scottish Government. I intend to speak about my late sister Deborah "Debbie" McKay nee McSweeney. In particular, the nature of her illness, how the illness affected her, the treatment received and the impact it had on her and our lives together.

Section 2. How Affected

2. My late sister was infected because of a blood transfusion; she was born on GRO-C 1962 and she was divorced at the time of her death,

and had no children. My sister passed away on GRO-C 2014. I do not have any of my sister's medical records at the date of this statement being taken. I was the executor of my sister's will when she passed away and intend to act as her representative as she is no longer here to speak for herself.

3. At the end of 1981 or the beginning of 1982, my sister was at the Apollo Theatre in Glasgow, which is no longer there, and she had an accident. My sister entered a door believing it to be a ladies toilet and it turned out to be a disused lift shaft, and she fell and injured herself. I believe she broke her arm and collarbone, and was very seriously injured. Her injuries were only slightly lessened because she landed in water. My sister was taken to Glasgow Royal Infirmary, and required a blood transfusion as part of the lifesaving treatment being done to her. I do not know the name of any of her treating doctors. My sister would only have been 19 or 20 years old at the time of this accident.
4. It is my understanding that my sister's GP sent her to be tested for Hepatitis C. I am unsure why this was. I do not know the name of my sister's GP, but he or she would have been at Woodside Health Centre in Glasgow. I believe it may have been the Western Infirmary where my sister went to be tested. I recall that there was a professor there who was involved in her testing and later treatment, but I do not recall his or her name. This test came back as positive. This was roughly around two years following Debbie's accident. I do not recall my sister ever having to receive a blood transfusion at any time prior to this or after. I have some memory of my sister having a liver function test at some point very shortly before her diagnosis, and I believe this showed a bad amount of damage to her liver. My sister was convinced for much of her life that she would die of liver damage.
5. I believe it was the Western Infirmary where my sister received treatment until she moved to Hastings around 1992. I believe that my sister was on treatments for her Hepatitis C throughout her life. The

only treatment I remember the name of was Interferon, and this was the first treatment that my sister received. It was my understanding from speaking with Debbie at the time that this was still quite experimental at the time, as were other treatments she had. She was at the vanguard of new treatments for Hepatitis C being trialled. I believe this treatment was first done at the Western Infirmary and was thereafter done at home by injection. Debbie was a nurse who lived with my sister Eileen at that time, so she was quite capable of giving injections.

6. I am not aware of what information was given to my sister at the time of her diagnosis. I do not think there would have been much information as this was in the mid-1980s. I am not aware if this information would have been given by her GP or the professor I have mentioned being at the Western Infirmary.
7. I do not have any knowledge of what Debbie was given about her infection, as I was not with her when the doctor told her, and she did not tell me what she was told. Debbie had a medical background as a nurse, so I believe that she would have looked into this herself.
8. I do think perhaps they could have told her sooner, if they knew about the blood being infected prior to her diagnosis.
9. I do not have any knowledge of how the Hepatitis C test results were communicated to Debbie. I believe that it may have been when Debbie was given her results that she was told of the link between her Hepatitis C and her earlier blood transfusion. It may have been that they were starting to make the link then between these blood transfusions and the spread of Hepatitis C. They may have been more open with Debbie as she was a nurse and in some sense was a colleague to those who communicated the results to her.
10. I believe with Debbie's knowledge as a nurse, she had an awareness about cross contamination already. I am unaware what was

communicated to Debbie by the doctor. I do not know the name of the doctor who would have told her. I believe that Debbie wore gloves at work a lot, as she told me this, and this may have been connected to the risk of cross-contamination.

Section 3. Other Infections

11. I am not aware of my sister having contracted any other infections.

Section 4. Consent

12. I do not believe that there has ever been any inference that my sister was treated or tested without her consent. She was subject to treatments that I believe were experimental for the time, but these were with her consent and the advice of her doctors as far as I am aware. I believe that these treatments were experimental as they were new at the time. I am not aware of the names of the treatments that my sister has.

Section 5. Impact

13. a. In terms of how Debbie's diagnosis affected her, I think that because she was a young girl at the time of her diagnosis, being in her early 20s, it affected her greatly over time. She was fairly happy-go-lucky sort of girl, and I do not think it immediately sunk in what sort of impact this would have on her. I believe Debbie learned more about the impact that this would have on her through her job as a nurse and over time. Debbie would say things like how she was never going to get old. I feel this was her way of saying she wouldn't live long, but she would often say this in a humorous tone, which may have been her way of coping with her infection.
14. I believe that the physical effects of Debbie's Hepatitis C were only apparent once she had started to receive treatment.

15. When Debbie passed away her death certificate listed her cause of death as having been firstly metastatic malignancy of unknown origin and secondly hepatitis C. I believe this may mean that these are linked. The first reason was cancer which had spread through her stomach, ovaries, liver and other internal organs. She was not aware of the cancer until the last two weeks of her life.
16. Debbie had been on holiday with colleagues in Tenerife, I believe. Her colleagues said to me afterwards that she had been tired on holiday and often went to bed early. When Debbie came back she was supposed to start back at work on the Monday but admitted herself to Conquest Hospital at St Leonards-on-Sea. While there, whatever investigations took place revealed that she had the cancer and that it was untreatable. Debbie called me herself on the Friday following her admittance to hospital and said that she had cancer and that I should come down to Hastings to see her in hospital. I went down on that Friday, and Debbie was lucid until they started increasing what they were giving her for pain, and she passed away on the following Tuesday with me and our sister Eileen by her bedside.
17. I believe that Debbie may have written off her symptoms that may have been the cancer as being the symptoms she had been feeling for a long time after having had treatment for her hepatitis. If Debbie had not had hepatitis C and the treatment thereafter, she would have been healthy normally and may have noticed the symptoms of her cancer.
18. I am unaware of what made Debbie go for the test on her liver that resulted in her doctor recommending that she go to be tested for Hepatitis C. As far as I am aware, Debbie was asymptomatic until the symptoms that followed her Interferon treatment and any following treatments.
19. While I am aware that Debbie had more treatments beyond the interferon she had initially, I am not aware of what these treatments

were called nor what they consisted of. I believe that the Interferon was very difficult for Debbie. I am not able to give an estimate of how long she was on this treatment. I recall that this treatment caused her to be pale, shaky, tired, lethargic and she had to take pain relief. I would describe some of the symptoms Debbie experienced as being flu-like. I recall seeing her shivering and she told me that she had difficulty sleeping at night. I do not believe that the interferon worked, as Debbie had other treatments after.

20. I am not aware of how many treatments Debbie had, but I do believe that she remained on treatments for the remainder of her life. Debbie may not have told me details as this was not something that she discussed all of the time.
21. I do not believe that Debbie had any difficulties in accessing treatment. If she did, she did not tell me.
22. As Debbie was having treatments that I understood to be experimental, I would not say that she had any difficulties accessing treatment. As I have said, she was at the vanguard of treatments being offered at the time. I do not recall Debbie ever saying that she had found a treatment and gone to her doctors and had been told she could not have it.
23. I believe that while Debbie suffered a number of symptoms, as I have described, as a result of her treatment. As I recall, Debbie did have periods where she was tired and quite debilitated by her treatments. She would not show any signs of weakness at work but would be flat out once she got home and would have to go to bed to rest. I believe it was difficult for her that she did not have the energy levels she would have expected. Debbie was not the type of person to dwell on things and I would describe her as quite flighty. This may have been something to do with what I would describe as brain fog, where she did have some issues with concentration. She went from one thing to another, in the sense of not always focussing on any one thing. I

remember she told me that she fell asleep on the bus on the way home from work and that frightened her, as she was worried about her energy levels. She had woken up after the bus had passed her stop. I think she told me that this happened a few times.

24. I do not believe that Debbie's condition had any impact on her receiving any medical care. I do not recall Debbie mentioning having any issues accessing any dental care.
25. In terms of the impact on Debbie's social life, I would not say that her condition had any impact on this, other than her perhaps not being able to have as much of a social life at times. I believe when she was working she was not able to have much of a social life because of how tired she was, but if she had days off, it would have no impact. She was a social animal and made the most of the life she had. She just withdrew whenever she felt unwell.
26. Debbie never had any children. She treated my daughter, Emma Carmichael, as if she was her own daughter and they were very close. Emma would describe her Auntie Debbie as her surrogate mum at times. Emma was like the daughter she never had. Debbie always said to Emma that when she passed she would leave everything to her. Emma was devastated when Debbie passed. I do not recall Debbie saying anything about why she never had children, but knowing her, I believe that this may have been because she was worried about passing on hepatitis C to any baby she would have had.
27. I do not believe that Debbie's condition was the cause of her divorce. Her husband was called James Collin McKay. They were married in 1991 and divorced in 2001. If her condition played any part in this I was not aware. I am not aware if her ex-husband ever got tested for hepatitis C.
28. I do not believe that Debbie's condition affected our relationship as sisters. We were very close. I noticed that often Debbie would have a bit of a dark sense of humour about her condition and this may have been

a coping mechanism. As a nurse she was used to dealing with death and was no stranger to the idea of how to cope with loss. Every time I saw her I worried it could be the last time I saw her. The things in the media at the time about hepatitis scared us as a family, but as a reasonable person I would like to think I had a balanced view. Even in 1992, Debbie moved down to Hastings, where our sister Eileen lived, and this did not affect our closeness. Our mum was still living in Glasgow through much of that time, so she came up 4 or 5 times a year, and I would see her. I would also go and visit Debbie once or twice a year. We spoke every week on the phone still.

29. In terms of how it affected me, myself, I lived with the thought of knowing that my sister had a life-threatening illness. I often think now of all the things that Debbie is missing out on now. She was a young woman of 53 when she passed and it was so very sudden. The decline was within the space of two weeks before she passed.
30. I am thankful that my mum passed away before Debbie as I do not think she could have survived the loss. They were very close. I think while our mum was still alive Debbie was always downplaying her condition, and almost brushed it off. I think she wanted to make sure that our mum did not worry about her.
31. I do not believe that Debbie's condition affected her working life, and it certainly had no impact on mine. I am not sure that Debbie's workmates or superiors were aware of her condition, but I cannot say for certain that she did or did not tell them. Debbie still managed to work her way up to being a ward sister. Debbie was not the academic type, but this was a huge achievement for her to work up to that position. I think she pushed through the symptoms of her condition to not allow this to affect her work. Debbie even did a conversion course in England to become a registered nurse at one stage. I do not recall when exactly this happened. She worked very hard and did not allow her condition to stifle her ambitions.

32. There was a period a couple of years before Debbie passed that I believe her declining health did have an impact on her work. She took a year where she worked part time, as she was not feeling well and was feeling exhausted by her work. Unfortunately she needed to go back to full time work to support herself financially and worked up until nearly two weeks before she passed away.

Section 6. Treatment/Care/Support

33. I am not aware if Debbie was offered any counselling at any time through her diagnosis and treatment. No counselling was ever offered to the extended family. I do believe that this would have been beneficial for us. We would have felt better informed. I would describe this lack of support was inadequate on the part of health staff who dealt with Debbie. If we understood better the pain and discomfort that Debbie was experiencing then we could have been more supportive and I think I would have pushed more to help, even if Debbie might not always have been open to accepting help.

Section 7. Financial Assistance

34. I am not aware of Debbie getting any funds through any of the various funds who offer monetary assistance to those infected with contaminated blood. This may just not have been something she felt like she could or should discuss with us. As I was executor of my sister's estate, I was privy to her bank statements and I do not recall seeing anything that looked like it came from a fund or grant.

Section 8. Other Issues

35. I do not believe that Debbie had any involvement with the Penrose Inquiry. I think this may have been because she was living in London at the time. I did not follow it closely but I was aware of it. There was a hope that this would provide answers but it did not seem to, as far as I am aware. I am hopeful that this current inquiry will provide the answers that Penrose did not.
36. My giving this statement is about getting a resolution and an answer about why this happened to my sister. This is not about money. The

system has been grossly unfair for those who were infected. This devastated my sister's life and our family's lives. I feel that I have been best placed to give a voice to my sister's story since she is no longer here to do this for herself.

Statement of Truth

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

Signed

GRO-C

Dated

13/1/19