

Witness Name: Dianne Rice
Statement No.: WITN2248001
Exhibits: N/A
Dated: 12th November 2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF DIANNE RICE

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 12th November 2018.

I, Dianne Rice, will say as follows: -

Section 1. Introduction

1. My name is Dianne Rice. My date of birth is [GRO-C] 1978 and my address is [GRO-C] [GRO-C] Glasgow [GRO-C] I am Helen Rice's daughter. I intend to speak about my mother's experience of becoming infected with hepatitis C. In particular, the nature of her illness, how the illness affected her, the treatment received and the impact it had on her and our family life.
2. My mum was infected with hepatitis C following a blood transfusion that she received after a gallbladder operation.

Section 2. How Affected

3. My mum received a gallbladder operation. Many years later she developed an abscess in her throat and went to hospital. Later on, she experienced a rapid weight loss. This weight loss was very extreme. My mum lost a significant amount of weight in a very short time. I gave birth to my daughter twenty-two years ago. There is a photo of my mum, dad, myself and my daughter after I gave birth to my daughter and in the photo my mum was quite plump, however, one year later she was literally skin and bone. My mum had her gallbladder operation and blood transfusion one year prior to my birth. When my mum was eventually diagnosed with hepatitis C she worried that I may have contracted Hep C also. My mother's symptoms started and developed approx 19 - 21 years ago. We didn't know what was wrong with her at the time.
4. I would say that her hepatitis C was severe. There were days when she could not even get out of bed, get dressed or have a shower.
5. The blood products which my mum received at the time of her blood transfusion came from American prisoners. The UK was buying blood at the time that came from prisoners and prostitutes in America.
6. My mum received the blood transfusion and was treated at Stobhill Hospital. When she started losing weight, she was treated by Dr Danesh who put her on steroids, which was the wrong treatment for her. She is now treated by Dr Mills and by her GP and the practice nurse. She also has regular screenings and injections in her eyes because she has started losing vision, but I don't know whether or not this is related to the infected blood products.
7. My mum was given the infected blood products following her gallbladder operation in 1977, the year before I was born.

8. No information at all was given beforehand about the risk of contracting an infection from blood products.
9. My mum was not infected with HIV, Hepatitis B or any virus other than hepatitis C.
10. My mum found out that she was infected with hepatitis C when she started to lose weight. She was in agony and it was persistence on her part by constantly attending her GP that allowed her to find out what was wrong when she did. If I am honest, my most powerful memory is about her Interferon experimental treatment. I have blocked out most of what happened at the time of the diagnosis because this is how I coped with it. I was too angry to think about it and it is too painful to remember. I remember that after my mum was diagnosed, we were just living day-to-day dealing with whatever happened that day.
11. I don't think there was much information available at the time and we had to find out a lot on our own about the infection itself, too. We were able to find out more through friends and by asking questions, and there was a stigma attached to the condition. I don't really think that any good information was given to us at the time. There were a lot of preconceptions and stigma even within the medical profession and many of them just assumed that my mum was like the "usual" hepatitis C patient and this made her feel very anxious and ashamed.
12. We were not given any information about how to understand and better manage the infection.
13. I think that information should have been provided earlier. In my opinion, healthcare professionals are meant to provide a safe environment instead of putting you in harm.
14. By administering these infected blood products, professors and healthcare professionals knowingly put people in danger and then they just failed to help and failed to apologise for having put people in danger in the first place. Only now there are posters advising about Hep C within GP Practices and Hospital environments, however, they are not

specific to infected bloods through transfusion. I feel this is all too little too late as it was the Government and healthcare professionals who have done this to people and are only putting up those posters because what happened has now been highlighted.

15. Information about the risks of others being infected as a result of my mother's infection was not forthcoming, and we only acquired some as a result of researching and asking questions. We were left to our own devices. I was only tested about ten years ago. Even then, the only reason why I was tested is because I had been feeling really lethargic and tired, and appeared to be showing some of the hepatitis C symptoms. My mum had read something or heard something on TV and urged me to get tested. We didn't know anything and I had already donated blood on several occasions by the time when I got tested. I know that the Blood Transfusion Service would have screened the blood, but even then there would have been a risk.

Section 3. Other Infections

16. I don't believe that my mum received any infection or infections other than hepatitis C as a result of being given infected blood products.

Section 4. Consent

17. My mum gave consent to her gallbladder operation. Everyone would have also given consent to receive blood products from a healthcare professional, but not one person would have given their consent if they knew that the products were contaminated. The healthcare professionals were aware of the risks posed by these blood products. I am aware of a news story of a man who had made many Freedom of Information requests through NHS and discovered that in fact the government and professionals were aware of what they were doing and the risks involved. This man had lost his father due to being infected through receiving contaminated blood products. Nothing was ever done about this. They just let it all carry on and no one was, as far as I'm aware, held responsible.

- 18 I think that my mum was treated or tested for the purposes of research. The healthcare professionals knew of the risks and were aware of what might come in years to come, and yet they chose to administer the products. There is no other explanation than that they wanted to conduct some form of research.

Section 5. Impact

19. Being infected with hepatitis C had a terrible impact on my mother.
20. Due to hepatitis C, my mum became a completely different person. She was never particularly outspoken, but she was always well-dressed, hard-working and caring. She looked after my Gran during the last years of her life. My mum was a confident person. Now, she is always in pain and has become nervous and not confident. She is only starting not to become so scared of the stigma because we try and support her. She has lost something. She has definitely lost her quality of life.
21. The further medical complications or conditions that resulted from the infection is that my mum now has cirrhosis of the liver as well as pain and migraines and is always very tired and lethargic. She is not herself anymore.
22. The course of her illness was that the hepatitis C lay dormant for many years until she developed that abscess in her throat that I mentioned earlier on, and then everything went worse really rapidly. I don't remember any positive events, things just kept going downhill every single day. I thought that it would never stop.
23. My mum received Interferon and another treatment whose name I cannot remember to treat her hepatitis C. I cannot remember when she received these treatments, but I know that they were her last chance. I have blocked these events out in my memory as well because I knew at the time that if the treatment was not successful my mum would die.
24. I am unsure as to whether my mum faced any difficulties or obstacles in accessing her treatments.

25. I do not think that there were any other treatments available on the market that was not offered to my mum because the treatment that she received, in particular the Interferon, was a trial.
26. For my mother, injecting herself as part of the treatment was hard. She also didn't know if the treatment was going to work. My brother and I only recently found out about how dark times were for my mum. This was hard to hear and to know that by trying to shield us, she went through this herself. My mum wanted to give up and struggled a lot with not being independent. My mum was always on the go. She still struggles with not being able to do simple tasks like make her own cup of tea or cleaning up. Physically, the treatments caused my mum to be very pale and gaunt looking, and very weak. She lost a lot of hair. My mum always liked to look smart and this was a big issue for her. Her gums started to shrink and she was mortified because she had to wait one or two days until she was able to get to have teeth fitted. My mum just didn't feel like herself anymore.
27. There have been a few instances when dental practitioners have refused to treat my mum. In particular, there was one case when a receptionist made a very loud comment in a public area which embarrassed my mum very much. This is because of the stigma associated with hepatitis C. A couple of dental practitioners refused her treatment. No other medical practitioners have refused her treatment that I am aware of, but I am also aware that my mum and dad shield us from a lot of stuff. My mum wouldn't share anything that she found embarrassing.
28. My mother's hepatitis C had a massive effect on her private, family and social life. Initially, it was awful seeing her in so much pain and struggling with day-to-day stuff. My mum was always an early riser. She would be up, dressed, make breakfast and organise my brother and I for school and then would make her way to work. After my mum's health deteriorated there would be days when I would be on annual leave and visit where, I would often find my mum in her pyjamas.

29. When the kids were small and had the flu or a cold, they could not visit their Gran. My daughter and nieces are very much granny's girls, and they would love to go and see their Gran as often as possible, and most times on a daily basis, but my mum was not able to do gran stuff with them or go anywhere with them. I use to love picking my mum up to go to Braehead together. I cannot do that anymore when she is having a bad day, and even on a good day, she cannot stay as long as she would like to. Her illness has also limited her attendance to birthdays and other family functions. My parents will always make an effort to attend and event for an hour but this really affects my mum. She gets really tired really quickly and just ends up completely drained. My dad is my mum's carer and to allow my dad to have a break and maybe a drink I drove to the last family event. We left again shortly afterwards. My mum always feels guilty about leaving events early; however, it is just too much for her and just drains her for days after.
30. We are aware of the stigma associated with hepatitis C but we know that my mum has never been infected due to not being a drug user or a prostitute. This is something that does not apply to her and we know why she became infected. The stigma is not an issue with close friends and family.
31. My mum had to give up work due to hepatitis C and I must have been in my twenties when this happened. My mum worked until she could and then was forced to give up work. She attempted to go back, but she found that she couldn't. My dad was self-employed and had the luxury of making up his own hours, but he too had to give up work shortly after as he had to care for my mum and we all worked full-time. I had already moved out by then. When my brother and I were growing up my parents were not what you would describe as affluent, however, they did both work hard and always lived within their means. I am only aware now that there were financial struggles after they both were forced to stop working. This is something my parents would have sheltered my brother and I from.

Section 6. Treatment/Care/Support

32. We were never offered care, support or counselling as a result of my mum becoming infected with hepatitis C. Not even my mum was offered this. She might have attended one counselling session, but there was never any follow-up. This was something that I suggested because my mum was still very embarrassed about the stigma. Counselling was not something that the doctors ever offered or suggested, except for maybe that one session. I feel that counselling would and still be really helpful.

Section 7. Financial Assistance

33. I think that my parents might have received some payments from the Skipton Fund. I have no idea about what payments they might have received as I don't ask about these things.
34. My parents might have found out that financial assistance was available through the SIBF, but apart from that I have no idea. I know that the SIBF and Thompsons provided a lot of support.
35. I have never applied for or received any payment myself.
36. I think that people have been put through a lot. I am thankful that my mum is still alive, other families have not been so lucky, however, part of my mum's life has disappeared through no fault of her own. I believe that everyone infected and affected should have compensation. Money will never give them back what they lost, but they are owed something.

Section 8. Other Issues

37. My only involvement in the matter has been with the SIBF and Thompsons. I have never campaigned myself.

38. As mentioned previously A Freedom of Information request was submitted by someone whose dad had passed away. Minutes of a meeting were obtained as a result where it is indicated that government, professors and doctors were aware of the risks of infected blood. These minutes prove that they knew about the risks.
39. I know patients' medical records have gone missing, including my mums. I work for the NHS and feel really strongly that this was not accidental. NHS has policies and process in place for medical records and also retention policies for when medical records can be destroyed after death.

Statement of Truth

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

Signed

GRO-C

Dated May 6, 2020