

Witness Name: Margaret Madden

Statement No: WITN1364003

Exhibits: WITN1364004 - 006

Dated: April 2019

INFECTED BLOOD INQUIRY

SECOND WRITTEN STATEMENT OF MARGARET MADDEN

I, Margaret Madden, will say as follows:-

Section 1. Introduction

1. My name is Margaret Madden Jr. My date of birth is GRO-C 1950 and I live at GRO-C Cheshire, GRO-C with my wife.
2. I make this second witness statement on behalf of my mother, Margaret Alice Madden who was born on 10 August 1926 and died on 8 December 2005 as a result of Aspiration Pneumonia, Epistaxis Gross, Haemophilia A and Advanced Dementia.
3. I have also produced a 'First Witness Statement' on behalf my son, Daniel Leah 'WITN1364001' for the Inquiry.
4. I stated in my first witness statement (at paragraph 11) that it was in or about 1974 that I was offered the opportunity to learn how to give intravenous injections at Pendlebury Children's Hospital, Manchester. Unfortunately the date is incorrect, as I believe it was in the early/mid 1980s that I was taught how to administer FVIII.
5. This witness statement has been prepared without the benefit of access to my mother's full medical records. If and in so far I have been provided with

limited records the relevant entries are set out in the medical chronology at the end or exhibited to this statement.

Section 2. How Affected

6. My mother was a Haemophiliac with less than 1% clotting factor. It was most unusual that my mother was a Haemophiliac as it was usually a disease only associated with men. When I was born my mother severely haemorrhaged and was given 96 pints of blood and spent 9 months in hospital. In the early days the only treatment that was available to treat haemophilia was blood infusions.
7. Initially my mother received pints of blood and then she started to receive pints of plasma. I believe my mother started to receive Factor VIII (FVII) concentrate treatment in the late 1970s. However, there is a medical record to the Skipton Fund from Dr Hay, (undated) stating that my mother required FVIII replacement therapy throughout her life and contracted Hepatitis C (Hep C) from her treatment in the late 60s or early 70s. Unfortunately, I am unable to confirm if my mother received FVIII treatment prior to when I believe she received it. A copy of the above letter is exhibited at **'WITN1364004'**.
8. My mother and I lived separately and I travelled around 7 miles to see her. I visited about 4/5 times a week, during the day, but often at night. There were times that I struggled to visit my mother with 3 young children and therefore a nurse had to intervene and attend my mother's home to administer FVIII.
9. My mother was always treated at Manchester Royal Infirmary (MRI) and I believe she was treated either by Dr Israel, Dr Barrett and/or Dr Hay. In her last few weeks, she was taken to North Manchester General Hospital (NMGH), where she passed away.
10. I do not know when my mother was infected as it could have been anytime from when she started to take FVIII.
11. I do not believe that my mother was provided with any information or advice beforehand about the risk of being exposed to infections.

12. As a result of the contaminated FVIII concentrates, as stated above, my mother was infected with Hep C.
13. I believe that my mother received a letter from the doctors in the mid 1980s and she was told that she was infected with an infection. I recall this because I called her to tell her about Daniel's infected status, she told me that she was also told that she was infected with something but it was not AIDS. She said that the doctors told her not to worry about it and that it would not kill her and nothing would happen, it is just something found in the blood now and again. I believe that the doctors told her at the time that she had Non A Non B (NANB) Hepatitis. I believe that no one knew what NANB was then. I do recall my mother telling me that the doctors did say that if she had a needle prick to go straight to the hospital.
14. In the early 1990s after my son, Daniel passed away my mother came to live me. I started to attend hospital appointments with her. I saw in her medical records that she tested positive for Hep C and negative for HIV. I questioned the doctor about the results, but he said that there is nothing to worry about. We were not told that she would be tested for Hep C or HIV, it was a routine appointment that we attended and I found out. The doctors did inform me that my mother was told and if I was not told then it was nothing to do with them. The doctor said is that there is nothing to worry about. At this time, no information or leaflets were provided.
15. Approximately 6 months after I attended the appointment with my mother, she found out further information about Hep C through her friend because she also had it. She told me that she was worried about infecting other people and wanted to lock the flat up. Her friend passed away and my mother never really got over it. She was never told by the doctors that there was a risk of transmitting Hep C she was only told by a friend.

Section 3. Other Infections

16. I believe my mother received a letter in 2001 about vCJD. Although the letter states that none of the implicated batches had been used by the Manchester Haemophilia Centre, I strongly believe my mother had vCJD and as a result she passed away in addition to what was stated in her death certificate at paragraph 2. There are medical records that mention that there was a possibility that my mother had vCJD. Copies of the medical records are exhibited at **'WITN1364005'**.

17. I also believe that there is a chance that my mother developed cirrhosis as a result of the infection. It was only in the last few weeks of her life when she was taken to NMGH that the nurse said that she had cirrhosis. There is a medical record (Clinical Notes), undated, which is exhibited at **'WITN1364006'**, which states 'anaemia/epistaxis: ? due to progression Hep C/cirrhosis'. We were not provided with any information about this by the doctor.

Section 4. Consent

18. I believe that my mother was treated and tested without her knowledge, consent, without being given adequate or full information and for the purposes of research.

Section 5. Impact of the Infection

19. My mother used to live in a sheltered home before she came to live with me. She wouldn't let anyone in the flat when she found out what Hep C was and she started going crazy. She started to lose a lot of weight and she was yellow, but she had been yellow for a very long time. I did question doctors about her being yellow and the doctors confirmed that it was one of the symptoms of Hep C. She also lost her appetite. I asked the doctors if this was normal and I was told that sometimes they could lose their appetite but it will come back. Her appetite unfortunately did not come back. I also noticed her having mood swings and she started a swearing lot when she never used

to. She was brought up well mannered so I found her swearing very out of character.

20. My mother eventually started to let people into her home. However, her way of life around other people changed drastically. She was very cautious about people using her stuff in the flat especially when someone would have a cup of tea. She would make sure that the cup is washed properly and rinsed under the tap a few time before anyone could drink out of it. She started to become obsessive about not infecting others, which really affected her day-to-day living.

21. When my son, Daniel died, my mother did come and live with me and I cared for her. She became wheelchair bound. I was able to carry her that's how much weight she had lost. When I became poorly I was unable to care for her and she went into a nursing home.

22. My mother got dementia and I believe it was as a result of the vCJD. My disappeared into a different person when she fell sick.

23. Whilst my mother was in the nursing home, I believe it was the last year of her life when she deteriorated quickly and passed away. Whilst she was at the nursing home I was told by the doctors at MRI that she only had 6 weeks to live. She was then transferred to North Manchester General Hospital and from there she passed away.

24. My mother was not given any treatment for the Hep C. At the time, I had no knowledge that there was treatment and I do not know if any treatment could have helped her.

25. I was really mad as to what happened. My son and my cousin passed away as a result of the infections and then I found out that my mother was also infected. It was very upsetting to see what my mother was going through as a result of the infection. When she started to live with me, she did not want to leave the house as she was too frightened of infecting other people. I did eventually get her out of the house for her to get some fresh air. My mother

was a strong, independent person and being infected really changed her mentally and physically.

26. The stigma did affect my mother. It was one of the reasons why initially she locked herself in her home wouldn't let anybody in. As previously stated, she did not want to infect anyone and she was also worried about what people's reaction would be because there was a stigma attached to it.
27. My mother's sister was affected in a very bad way as they were very close. My mother confided in her sister and was able to speak to her openly about anything. My mother's sister also had a son that was infected, so she found everything that was going on very difficult.

Section 6. Treatment/care/support

28. I do not believe my mother received any counselling or psychological support as a result of the infection.

Section 7. Financial Assistance

29. I was told by a social worker that my mother was given money in relation to the Hep C. The social worker dealt with everything for my mother in relation to the finances.
30. I did apply for the Stage 2 payment from the Skipton Fund and did not receive anything. I received a letter stating that there was no proof that my mother had severe liver disease, even though there is a medical record, as stated at paragraph 17, which suggests that her 'anaemia could be due to progression of Hep C/cirrhosis'.
31. The application process was difficult to fill in and I had lots of problems filling it in. I found it difficult to get the information that was needed from the hospital and doctors for the application form.

Anonymity, disclosure and redaction

32. I confirm that I do not wish to apply for anonymity and that I understand this statement will be published and disclosed as part of the Inquiry.

33. I want to give oral evidence to the Inquiry.

Statement of Truth

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

Signed...

GRO-C

Dated

25/4/19