

Witness Name: Susan Wilcock

Statement No.: WITN5801001

Exhibits: Nil

Dated: 25. Feb. 2022

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF SUSAN ELISABETH WILCOCK

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 4 October 2021.

I, Susan Elisabeth Wilcock, will say as follows: -

Section 1. Introduction

1. My name is Susan Elisabeth Wilcock. I was born on [GRO-C] 1977. I am married with two children, aged six and nine. I grew up in [GRO-C] [GRO-C] a village just outside [GRO-C] I lived there with my parents and sister Helen, who is three years younger. My mother's full name is Janet Luke; maiden name Walker. She was born on [GRO-C] 1943.
2. I intend to speak about my mother's infection with Hepatitis C (HCV), believed to have been contracted from a blood transfusion in the late 80s to treat pneumonia. In particular, I intend to discuss the nature of

illness, how the illness affected her, the treatment received and the impact it had on her and our lives together.

3. **This statement has been prepared without access to my mother's medical records.**

4. I also wish to acknowledge that as I was young when my mother was diagnosed with HCV, I have only been able to provide approximate time frames to matters based on life events. However, these time frames should be accepted as 'near to' rather than precise dates.

Section 2. How Affected

5. My mother grew up on a farm in the South lake district in Cumbria. She had a happy childhood, if materially modest by today's standards. It always sounded idyllic when she talked about it. She did well in the local school before boarding at a grammar school. She was a very kind, intelligent and unassuming person.

6. She enrolled a year early to study Pharmacy at Manchester University because she achieved so well at school. In those days it wasn't expected that women would go to university, so she was definitely ahead of her time. She got top marks in her year and was the only student to attain a first. She worked as a pharmacist in hospitals before working in a local pharmacist. When we were children, she worked part time in the local high street chemist.

7. In around 1987, when I was nine or ten, my mother went into Aylesbury Hospital for a routine appointment. She was in her forties. I have a feeling that it may have been something to do with her lungs but I cannot be sure. She had a minor operation. She said that when she woke up from the operation, she was alone in the recovery room. She was extremely cold which caused her to shake vigorously and uncontrollably.

8. She developed pneumonia. As a result, she had to have a blood transfusion. Having spoken to Helen, she can recall that our mum was very tired after the transfusion. Shortly afterwards, it was explained to us that she had undergone an operation from which she contracted Hepatitis C. No one said anything about the risks. I was aware that the virus carried risks, including the risk of death but I don't remember very much more.
9. Helen and I were told about our mother's illness at the time. However, it was a long time ago. I was young and information wasn't provided so openly, so it is difficult to remember exact dates. Moreover, I didn't actually know what HCV was at the time. My mum was a pharmacist, so she was very medical and would have known how to access that information.
10. My mum would have known that the principal mode of contracting HCV was through sharing drug needles. Obviously, she wasn't doing that. Her infection would have been quickly connected with the blood transfusion she received. There is no other way she could have been infected.
11. My mum was only provided with limited and vague precautions to take to prevent transmitting the virus to us. We were only advised not to share a toothbrush, which didn't seem that helpful as we wouldn't have shared toothbrushes in any case. GRO-C

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Section 3. Other Infections

12. I would assume that when my mother was tested for HCV, she was also tested for HIV. She took her health seriously and always attended her appointments. She wouldn't skip routine appointments or scans.

Section 4. Consent

13. I believe my mother consented to all her treatments for Hepatitis C and cancer. She was quite smart when it came to knowing about drugs and how they worked. However, she was not aware of the risks associated with the blood she was given in around 1987. As such, I do not think she provided her informed consent to this treatment.

Section 5. Impact

14. My mother's infection with Hepatitis C would have been very frightening for her. As I am now the age that she was when she was diagnosed, I can only imagine how terrified she must have felt. Nevertheless, she tried to hide her illness from us. Whilst I was aware she had HCV, it wasn't something we discussed openly as a family. The subject was always shut down.

15. The primary physical effect of my mother's infection with HCV was extreme tiredness. Even before she was diagnosed, Helen and I can remember her being in bed all day. My sister can recall curling up with her in bed for days on end. Although, on the whole we were happy, family life became somewhat dysfunctional.

16. Following my mother's diagnosis, I believe she suffered from OCD and depression. She had ups and downs. In many ways she was a very practical, down to earth person but she struggled to keep the house tidy. She wouldn't want Helen or I to help. She had to do everything herself and everything had to be done perfectly. However, the irony

was that this meant that things didn't get done at all. I think this was exacerbated by her tiredness from the infection.

17. We had a comfortable 4-bedroom house but as she refused to throw anything away, it was full of rubbish, boxes and newspapers. There was clutter everywhere so that there was never any space for anything useful. If we offered to help, she would always refuse. She was perpetually hoarding things such as yoghurt pot, old newspapers, old toys and clothes, but what she intended to use them for, I'm not even sure she knew.
18. My mother was subjected to various liver biopsies to monitor the damage of the virus to her liver. I believe these were followed by an overnight stay. My mother was then invited to a trial at the Oxford Radcliffe Hospital. This wasn't our local hospital but nor was it too far from us. I do not know how soon after her diagnosis that my mother was initiated onto the trial treatment. I am aware that it wasn't immediate. We just thought that she was lucky to take part.
19. My mother didn't know if she was on the placebo or trial drugs, but the medication seemed to help, particularly with the tiredness. I don't know whether she continued to take the drugs or whether she fully cleared the virus. However, it appeared to reverse some of the damage. She didn't mention any side effects from the drugs, but it wasn't in her nature to complain.
20. My mother only wanted to protect Helen and I from worrying. Having grown up on a farm, she was also very stoic and pragmatic. Nevertheless, her diagnosis must have frightened her. With two young kids of my own, if someone told me I had Hepatitis C and the future would look uncertain, I would feel terrified.
21. My dad was the main breadwinner. He worked full time. He died after my mum. He was more of the 'fast living' type so we expected mum to outlive him. My mum might have been able to work more if she wasn't

as tired. She worked as a locum in the local chemist which was sufficiently paid but wouldn't have entitled her to sick pay. She almost certainly would have had time off to attend her medical appointments.

22. It is very difficult to look back on my childhood and objectively assess the effect of my mother's diagnosis on our lives. In many ways we had quite a happy childhood; we went on lovely family holidays and felt content. However, at the same time, my mother's diagnosis inevitably put a lot of strain on the family. My mum and dad were happily married but they were quite different characters. I do not think they had a perfect, easy marriage and spent a lot of time fighting. The extent to which this was caused by hepatitis as compared with other factors, I do not know.

23. I am grateful that Helen and I have grown up into functioning adults. We were lucky that our parents loved us but it wasn't always easy at home due to the conflict. As children we were both very shy GRO-C GRO-C which didn't help. My mother's illness continued to hang over us.

24. I do not think my mother was subjected to any stigma in the medical community. If she did, she didn't say. As a pharmacist, she was well known and respected in the doctor's surgery and village as a whole. I suppose any stigma would have derived from suspicions that she was a drug user, but I think people knew this not to be the case. When she went to the dentist, she was obliged to declare her HCV status. I don't recall this being a problem.

25. She was in quite good health apart from the Hepatitis C. She played tennis into her fifties and enjoyed yoga. She also maintained a reasonably healthy diet. In 2016, when she was around 73, she was diagnosed with ovarian cancer. She was working at the pharmacy on a Wednesday afternoon together with an hour or two at the weekend.

She was initially misdiagnosed with an extremely rare, aggressive form of cancer, for which she was given aggressive chemotherapy.

26. By Christmas 2016, after six months of chemo, she was barely alive. She was admitted into hospital for six weeks. When she had recovered, she was discharged. However, she was told that she probably only had six months to live and that there was nothing more they could do. On the advice of a neighbour, we sought a second opinion. We consulted a cancer hospital in London, The Royal Marsden. They told us that ovarian cancer is almost always serious, but that she had a less aggressive strain than initially suspected and further treatment was possible, which she went on to have
27. When she had cancer, she wasn't eligible for any of the cancer trials because her Hepatitis C would have complicated the results. At the time there were discussions about possible immunotherapy. When someone in the family has cancer, one becomes fixated with tracking new developments and avenues. However, there are so many different types of cancer that it gets very complicated for the layperson. Sometimes it is best not to delve too deeply; it can become very upsetting.
28. The cancer caused problems with her bladder and kidneys so that urine had to exit from a hole in her back. By the summer of 2017, she recovered enough to have a hysterectomy and debulking operation which went quite well. She recovered for a year or two.
29. In her final years, my mother often visited me, tidying the garden and spending time with the grandchildren. She did another round of chemo. When her health deteriorated, she spent a few months in a care home and then she passed away. Three years had passed since her diagnosis with cancer.

Section 6. Treatment/Care/Support

30. No support or counselling was offered to my mother nor our family as a result of the circumstances surrounding her diagnosis with Hepatitis C.

Section 7. Financial Assistance

31. I don't know how my mum came to find out about the Skipton Fund. I can remember that the prospect of financial assistance for those infected through contaminated blood was in the news at one point. My mother was also involved with the medical world so she probably would have heard that way too. It wouldn't have been difficult for her to find out.

32. I believe she received a lump sum of around £20,000, in addition to an ongoing payment of around two hundred a month. However, no amount will ever be enough to pay for one's health. I think we had to cancel the payments when she died. No payments were received by the wider family.

Section 8. Other Issues

33. In some ways I think we were lucky that in spite of her infection with Hepatitis C, my mother continued to live a reasonably fulfilling life. However, her life and the lives of her family were undeniably affected by her receipt of contaminated blood. I wish this never happened and hope it never happens again.

Statement of Truth

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

Signed

GRO-C

Dated

25. FEB. 2022

Use of my statement

I, Jusan Wilcock, confirm that by submitting my signed written statement to the Infected Blood Inquiry, I understand it may be used in the following ways:

- publication on the Inquiry website;
- reference and/or inclusion in any interim and/or final report;
- disclosure to core participants and where instructed, their legal representatives via the Inquiry's database or by any other means as directed by the Chair of the Inquiry;
- disclosure to any person or organisation, including any instructed legal representatives, who is the subject of criticism in my written statement, as set out in the Inquiry's Statement of Approach - Anonymity and Redaction.

I also confirm that I have been advised of the option to seek anonymity and that if granted my identity may nevertheless be disclosed to a person or organisation, including any instructed legal representatives, who is the subject of criticism in my written statement in order that they are afforded a fair opportunity to respond to the criticism.

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Please tick this box if you are seeking anonymity, in which case consent is considered to be provided subject to the determination of any application for anonymity.

Signed

GRO-C

Date

25. FEB. 2022

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