

Witness Name: Linda Phyllis Newson
Statement No: WITN2972001
Exhibits: WITN2972002 – WITN2972005
Dated: June 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN WITNESS STATEMENT OF LINDA PHYLLIS NEWSON

I, Linda Phyllis Newson will say as follows:-

Section 1. Introduction

1. My name is Linda Phyllis Newson. My address is GRO-C
Birmingham, GRO-C. My date of birth is GRO-C 1949. I live with my
husband Peter and our two sons Paul and Douglas. We also have a daughter,
Natalie. I am a pensioner.
2. I am providing this statement in relation to my late mother, Phyllis Ellis, who was
born on GRO-C 1915 and who died on 9th September 1990 aged 74. My
mother died from Acquired Immunodeficiency Syndrome (AIDS). She contracted
HIV after receiving contaminated blood during a blood transfusion. I exhibit her
death certificate at WITN2972002.
3. This witness statement has been prepared without the benefit of access to my
mother's full medical records.

Section 2. How affected

4. In spring/summer 1982 my mother had an operation for ulcerative colitis at Charing Cross Hospital. She was very unwell after the operation, so her Consultant recommended that she have a blood transfusion to make her feel better. She took her Consultant's advice and had a blood transfusion.
5. I am not sure whether my mother had one or more transfusions after her operation. She certainly did not have any transfusions prior to the operation.
6. I was with my mother at Charing Cross Hospital at the time. Neither my mother nor I were told that there was a risk of her being exposed to infection from having a blood transfusion.
7. My mother and I talked a lot about what had happened to her. We did not feel that we could talk openly to other people about it. I am certain that my mother would have told me if she had ever been informed separately about the risk of being exposed to infection from blood transfusions.
8. My mother required a year of convalescence after her surgery.
9. She initially started to feel better. However, in 1984 she started to feel unwell again and she was diagnosed with liver cancer.
10. My father passed away in 1975 due to Chronic Obstructive Pulmonary Disease. He was only in his 60s. My mother was then left alone with my brother. However, after being diagnosed with cancer she asked if she could move in with me, so that my family and I could take care of her, as my brother had health issues. My mother therefore came to live with us. My mother also wanted to leave London to have some privacy.

11. The treatment for her liver cancer was arranged quickly. She had her first round of chemotherapy at Charing Cross Hospital.
12. We then arranged for her chemotherapy treatment to be transferred to Birmingham General Hospital (now Birmingham Children's Hospital), which was more convenient as she was living with my family and I.
13. My mother had intensive chemotherapy for 18 weeks. I attended my mother's treatment sessions and appointments with her.
14. I had to arrange childcare for my daughter when I went to the hospital with my mother.
15. The chemotherapy shrunk my mother's tumour considerably, which her Consultant told us prolonged her life.
16. Overall, my mother was well for a long time. Her doctors were amazed at how well she was during her chemotherapy, especially considering her age and the strength of her treatment. However, her health did eventually deteriorate.
16. My mother started having some strange symptoms. She developed recurring sores in her mouth, which wouldn't heal. She also had recurring candidiasis (oral thrush), which started in around December 1988. Because of this, she struggled to eat and she could hardly drink, which resulted in her losing a tremendous amount of weight.
17. She was given many different medications, but my mother was unable to clear the thrush. Eventually, the thrush spread from her mouth all the way through to her bladder.

18. My mother's treating doctors decided to investigate her symptoms. They carried out some tests which revealed that my mother had HIV.
19. As a result of receiving contaminated blood during the blood transfusion(s) my mother was infected with HIV, and I believe Hepatitis C or a combination of Hepatitis viruses.
20. I am not aware of my mother ever being tested for any variant of Hepatitis. However, I worked at a Marie Curie Hospice for a period of time and I understand that Hepatitis C (HCV) can cause liver cancer.
21. I therefore believe that my mother might have also had Hepatitis C. However, I am not aware of her ever being tested for it and she was not diagnosed with it.
22. My mother developed symptoms of liver cancer two years after her transfusion. I'm aware that Hepatitis C is an infection which has delayed onset.
23. My mother was told that she was HIV positive in early March 1990 at the Birmingham Heartlands Hospital. I believe that she was told by a Dr Ellis.
24. I was with my mother when she was told about her HIV infection. The doctor who told her said that the blood that she had been given during the transfusion at Charing Cross Hospital in 1982 had been contaminated and they were able to track the donor to Oxford. I was alarmed that the donor's blood hadn't been screened prior to it being given to patients.
25. I was shocked and upset, but I did not want it to show, in order to support her.
26. We weren't given any information to help us understand or manage my mother's infection during that meeting or at any time later. All they said in the meeting was

that the tests showed that she was HIV positive and they had referred her to the outpatient's clinic.

27. We did not know much about HIV. The only information or knowledge that we did have about HIV came from the media.

28. I think we should have been given information about my mother's infection and how to manage it straightaway, as well as appropriate help and support.

29. I felt the way in which we were told about my mother's infection was appalling and callous. I also do not think that the context in which she was informed about her infection was appropriate. She was not aware that she had been tested for HIV, so she was completely unprepared to hear that she had such a serious infection.

30. My mother was also never informed about the potential risk of infection to others as a result of her infection. Again, the only information we got about this was from the media. At the time we learnt of my mother's infection, she was living with my husband and I and our 7 year old daughter and our two sons, who were 17 and 20.

31. My mother had a colostomy bag, which as she grew thinner would fall off of the belt it was attached to and cause a mess. I would clear this up for her and in doing so, be exposed to her bodily fluids and sometimes her blood. Once we learnt of her HIV infection, I was anxious that I may have been infected. I worried about who would care for my young daughter if anything happened to me.

Section 3. Other Infections

32. I am not aware of any other infections my mother received other than HIV and Hepatitis.

Section 4. Consent

33. I believe that my mother was tested without her knowledge and consent and without being given information, as she was tested for HIV without being told. My mother was anaemic, so she had regular blood tests and she was not always told what they were for. She would always assume that they were for her anaemia.

34. My mother and I were extremely close, so I am certain that she would have told me if she was being tested for infections. Also, if she had been aware that she was being tested for HIV, she wouldn't have been so shocked when she was told about her infection.

35. If we had been pre-warned that she was being tested for HIV, then at least we would have been able to prepare ourselves to receive the test result.

36. I suppose my mother could have been treated without her knowledge and consent and/ or used for research purposes, but I don't know anything about this.

Section 5. Impact

37. When my mother first found out that she was infected with HIV it was a massive shock to her. She described herself as having the "scourge of humanity". When we got home from the hospital, she put on rubber gloves which went up to her elbows and she wouldn't take them off. She wore them for a very long time, as she was paranoid about infecting others. Her infection caused her to create a physical barrier with the family that was never there before.

38. My mother was a very positive and strong lady, but her HIV infection really frightened her. She used to be a fun, happy and optimistic lady, but when she

found out about her infection, she developed anxiety and depression, which she talked to me about.

39. My mother was a short lady and she was always quite plump. However, as a result of her severe reoccurring candidiasis, she struggled to eat or drink, and lost a lot of weight. She used to have to drink through a straw. She went down to 6 stone and she didn't like how she looked. This affected her confidence. She used to say to me that she did not like how she looked anymore and she would not want to go out of the house as much.

40. My mother was a pretty lady and she used to have thick, strawberry blond hair and blue eyes. However, it all fell out when she had chemotherapy.

41. I recall washing her hair for her and whole clumps of it falling out. I was mortified, but all she said to me was that it was just hair. I think she only said that to comfort me, because she knew how upset I was about it.

42. I recall she once asked me to put curlers in the hair that she had left. When she woke up in the morning the curling rolls were on the bed with her remaining hair attached to them, as it had all fallen out.

43. I was friendly with the local hairdresser, who arranged a wig for my mother. However, my mother wouldn't go out of the house when she had no hair. She wouldn't be seen in public wearing the wig.

44. Thankfully, her hair grew back. However, losing her hair was very traumatic for her, as my mother was an elegant lady who took care of her appearance.

45. My mother's skin also got very thin in places, which made it very sore.

46. My mother was not treated very well at Birmingham Heartlands Hospital. I recall hearing patients call it "Heartless Hospital". She was always kept away from the other patients and was put in the isolation building, which was separate, until St Mary's hospice took her. I believe that this was due to the stigma associated with HIV and AIDS.
47. There was only a bed and a small cupboard in her room.
48. She fell out of her bed several times and was found on the floor. Her face was badly bruised after these incidents.
49. She was also meant to be on a soft food diet, but instead of the staff giving her a pudding or jelly to eat, she was given an apple, which she could not bite into. My mother's mouth was full of ulcers, so the food she was given in the isolation building was completely inappropriate. The member of staff leaving her the apple would run in, leave the apple on her side cupboard and run out.
50. She had no contact with other people when she was in isolation. She did not even see a nurse whilst she was in there.
51. My mother had to use a colostomy bag. As she had lost a lot of weight and at the time it was fixed to her by a belt, it would often fall down leaving a lot of mess. When she was in the hospital if the bag fell down, nobody would help her with it. She should really have had a stoma nurse.
52. I recall that whenever she had her chemotherapy treatment my mother was put in the kitchen with a drip, rather than in the ward on a bed.
53. My brother-in-law threatened the hospital with legal action if they didn't take proper care of her. Very soon after that my mother was transferred to St Mary's

Hospice, Birmingham. My mother was an inpatient at Birmingham Heartlands Hospital for about 2 weeks.

54. We originally tried to get my mother admitted to the Marie Curie Hospice in Solihull, which was only around 15 minutes away from where we lived. However, she was rejected.

55. My mother had great care at St Mary's Hospice, however it was two hours away from us and I had young children at the time. We had to travel that distance to visit my mother every night for 4 months. The only day off we had were Wednesdays, when my sister would visit her. We were all exhausted.

56. My mother was unwell with HIV, later AIDS, and possibly Hepatitis C for around eight years before she passed away.

57. In terms of the impact of her HIV infection on her private life, my mother wanted to keep it secret. She did not want anybody other than her closest family to know about her status. The only people, other than the medical staff, who knew about it, were me, my sister, my brother and our partners.

58. We both felt like we were living a lie, as we were not able to tell people the truth about her health. We were open about her having cancer, as that was the kind of illness that people would be sympathetic about, whereas there was a lot of stigma in relation to HIV, so we kept it very private.

59. My mother always lived a very healthy and clean life. The way HIV was portrayed by the media at the time was as something to be ashamed of and as something that only people such as prostitutes and drug addicts would get.

60. My mother's health impacted her social life significantly. She became very withdrawn. The only people she would socialise with outside of our family were

our friends and neighbours. Because she had moved to Birmingham from London, she had left behind her own friends, neighbours and her sister and she was not well enough to move back.

61. My mother's HIV infection affected me greatly. I constantly felt like I was carrying a heavy weight on my shoulders, not being able to open up to people fully. My mother was unwell for 8 years before she died.

62. I felt like I was running on autopilot. I was looking after a family of five and I was physically and mentally exhausted. It felt like I was constantly changing bedding, washing and cleaning, which was also very expensive. We had no help or respite.

63. On top of that, I was emotionally exhausted. I went to all of my mother's appointments with her and I could not show her that I was upset, as I didn't want to upset her further.

64. My mother was my best friend. Before she became unwell, we used to have a lot of fun together and would go on holidays together. I saw her suffer greatly over the years and I lost her to an awful illness.

65. I did not tell my children about their grandmother's HIV infection until a while after her death. They were aware that she was unwell before she died and they thought that she died of cancer. I only got as far as telling them that she contracted a virus from infected blood, but they didn't ask what the virus was. I believe that they might have guessed the rest.

66. I recall an instance when my daughter was five years old and she had had her ears pierced. She was sat on my mother's lap. She took my mother's earrings out and wanted to insert them into her own freshly pierced ears. I jumped up in panic to take my mother's earrings out of my daughter's hands. I was terrified that my

mother's blood could have been on them and that my daughter could have been infected with HIV.

67. There was another time when our cat bit my mother and I wiped the blood off of her. I was anxious that this could have led me to me being infected.

68. This and other situations made me very anxious and played on my mind. I have never been tested for any infections.

69. Looking back, I'm glad that I didn't tell my children about my mother's infection earlier, as children talk and if they knew their friends could have gone home and told their parents about it. I can imagine that they would have lost a lot of friends as their friend's parents would not have wanted their children over at our house anymore.

70. The only person who I told the truth about the nature of my mother's illness was my best friend, who was very supportive.

71. The period before my mother's death and her death was an awful time for my family. My late brother, Michael, passed away before my mother; on 31st July 1990, aged 49. He had a heart attack and was found dead in his house. He was in poor health himself and he was paranoid about his health. Living with our mother, who was also unwell, put a lot of strain on him. After his death, the doctor said that Michael's heart attack was a direct result of the stress of his and our mother's health over the years.

72. My aunt, my mother's sister, Rose, was unwell at Michael's funeral, and she passed away from a stroke 10 days later.

73. My uncle, my mother's younger brother, Jim, passed away a week after Aunt Rose. Then my mother passed away on 9th September 1990.

74. We lost four family members in a very short period of time, which was extremely traumatic and it all resulted from stress.

75. It is upsetting to think that my children, particularly my daughter, Natalie, spent their childhood living with someone with a serious illness. It was difficult for my sons when my mother was very unwell.

76. My mother was a kind and loving person. She was loved by many people, because of her positive energy and always having nice things to say. She didn't have any bad in her. She loved spending time with her grandchildren and we were all heartbroken when she died.

77. My mother's infection also put a massive financial strain on my family. At the time when she moved in with us, we had only two bedrooms, so we had to re-mortgage our house in order to add another bedroom.

78. I had to go back to work to help out financially. My husband was and still is a self-employed painter/decorator, so there were times when he had a lot of work and there were also times when he did not have much work, which affected our finances. This meant that we did not have a stable source of income, whilst we needed to provide for a rather large household.

79. I lost my administrative job at the Department of Health and Social Security after my mother died. I went to the doctors after she died and he suggested I took some time off work whilst I was grieving. I had also developed Crohn's disease before my mother died, which I was told by my doctor was likely to have been exacerbated by stress over the years. In total I had a round 90 days off work in the period before my mother died, when I was caring for her and visiting her in hospital/the hospice and after she died. I was on a temporary contract and I was meant to go on a permanent one. However, I was not offered it after all. I later

discovered that the my high level of absence, both due to visiting my mother in the hospice and the time I took off work after she died, had gone against me.

80. When my mother was still alive, I was told that I could apply to become my mother's full-time carer and claim carer's allowance.

81. An assessment was arranged in relation to my application for carer's allowance; however, my application was rejected, as my mother was mobile. The fact she was not able to care for herself was not taken into account.

82. My mother only received a state pension of £20 a week, so she was not able to contribute to our household. Whenever she received her money I encouraged her to buy something for herself.

83. My husband also lost a lot of time off work. When my mother had her chemotherapy treatment he would drive her to the hospital and back. As he was self-employed, his job was very flexible, but he lost many opportunities to gain new clients. Having my mother living with us and caring for her put a massive strain on our finances.

84. It was extremely difficult for me to get a job after losing my administrative job. I feel like I was blacklisted. I went through an entire job application process, which included tests and an interview before a panel, at the Solihull Police Station, which I thought went very well. They seemed very impressed with me. I was sure that I had got the job, but I was unsuccessful. I also applied to an immigration office at Birmingham airport. Once again, I felt like that my application went very well, but within two weeks of doing my tests I had received a letter stating that my application had not been successful.

85. Every time I applied for a job, I got rejected. Eventually, I applied for a job as a cleaning supervisor. I had an interview with the matron and I later became good

friends with her. In the interview I was honest with her and I told her that I had taken time off to look after my mother who had been unwell, and how much time I had taken off. I was offered and took the job. When it came through, the matron showed me my reference from the Department of Health and Social Security. My reference stated that I had taken 90 days off work, but it added that I was capable of permanent employment. It became apparent to me that that had been the reason why I was struggling to get a job.

86. My mother's infection had an impact on my financial circumstances. Not only did I lose a well-paid job, I was denied further job opportunities for a long time. When I got the as a domestic supervisor, it was not as well-paid as the original job I had at the Department of Health and Social Security. The drop in my earnings and pension contributions was a hard blow to take.

87. I also feel like I was not able to reach my full potential, because I had devoted many years to caring for my mother.

88. As a result of what happened to my mother, I developed depression and anxiety, which I still live with today.

Section 6. Treatment/Care/Support

89. My mother did not have any treatment for HIV. I don't believe there was any treatment available at the time.

90. If there were any treatments available at the time, I believe that they should have been made available to her. However, I am not aware of any such treatments.

91. No support or counselling has ever been offered to my mother or our family in consequence of her HIV infection which she received from contaminated blood.

This made my mother feel unimportant, especially as she was suffering from anxiety and depression.

Section 7. Financial Assistance

92. My mother was not aware of any financial assistance being available before she died, so she didn't apply for any.

93. My sister became aware of financial assistance being available from the Department of Health after our mother died. Not long after our mother died we had applied for financial assistance, and my two sisters, [GRO-B], Rita and I received £13,000 each. This was a one off payment and we had never received any further payments after that. I exhibit the paperwork I have in relation to this at WITN2972003.

94. I believe that [GRO-B] found out about the financial assistance through a letter from the Department of Health, as she had written letters to MPs.

95. It would have been nice for our mother to have been able to use the money herself. She could have gone on a nice holiday or spent it on herself. She really liked shoes and she loved to dress well, so if she had received some money, she could have at least enjoyed the time that she had left.

Section 8. Other Issues

96. My sister [GRO-B] has been involved in campaigning on behalf of our family and has written to MPs and Margaret Thatcher in the past. She also participated in the Sunday Times campaign. I exhibit at WITN2972004 documentation relating to her campaigning.

97. My mother was said to be the oldest person infected with HIV in England. A Sunday Times correspondent, Michael Durham, came to our house to interview my mother and made this claim in his article. I exhibit the article written by him at WITN2972005.

98. I was shocked by a letter I came across in relation to my mother's treatment. It was a letter from a doctor saying that he had treated my mother for a long running illness, lung cancer. However, she did not have lung cancer; she had liver cancer. I have questioned whether this was a deliberate cover up. This letter is enclosed in the documentation exhibited at WITN2972003.

Anonymity, disclosure and redaction

99. I would like to give oral evidence to the Inquiry. If I am selected, I would prefer to give evidence in Leeds.

Statement of Truth

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

Signed....

GRO-C

Linda Phyllis Newson /

Date...

5/6/19