

Witness Name: Louise Tansley

Statement No: WITN1554001

Exhibits: 0

Dated: 28 March 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF LOUISE TANSLEY

I, Louise Tansley will say as follows:-

Section 1. Introduction

1. My name is Louise Tansley. My date of birth is the GRO-C 1967 and I live at GRO-C
GRO-C with my husband, Craig Tansley. We have two adult children, Lewis and Elisabeth. I am currently employed as a part-time cleaner at our local church.
2. This witness statement is made in relation to my late younger brother, Simon John Campion (Simon) who was born on the GRO-C 1969, and who sadly passed away on the 27th July 1996 at the age of 27. He was had Haemophilia and was treated with contaminated blood products, as a result he contracted Human Immunodeficiency Virus (HIV), Hepatitis B (HBV) and Hepatitis C (HCV). He died of Acquired Immune Deficiency Syndrome (AIDS) with complications relating to Pneumonia.
3. This impact statement has been made with the benefit of partial access to Simon's medical records.

Section 2. How affected

4. Simon had severe Haemophilia A and was diagnosed at the age of three months old by Dr Arthur at the Derbyshire Children's Hospital.
5. Haemophilia runs in my family GRO-C
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6. Simon was treated with blood products from the time he was diagnosed until his death. I recall that one of them was Factor VIII.
3. Simon was treated at the Derbyshire Royal Infirmary by Dr Winfield when he was very young then Dr Mitchell and later by Dr A McKernan.
7. As far as I am aware my parents or Simon were never informed about the risk of being exposed to infection from blood products.
8. My mother was, at some point, aware from press reports that blood products from America were contaminated, but I do not believe that she ever expressed her concerns to Simon's doctor.
9. Simon was diagnosed with HIV in 1985, he was about 15 years old. I recall that I went with my parents and Simon to a group meeting at the hospital with other haemophiliacs, their families, doctors, academics and dentists. Prior to this meeting Simon had been told that he had contracted HIV and the meeting was apparently to discuss the effects of living with HIV however it descended into a farce with doctors saying that they would refuse to treat patients with HIV. The families were made to feel stupid and were talked over. We were told to go away get on with our lives and not to tell any one.

10. I do not recall whether there was much practical information provided at that meeting about the infection or how to manage, it was very vague and we were all in shock as much as anything. Also at that time questioning doctors was viewed as inappropriate.

11. The effect of the advice was to go forward with our lives and not to tell anybody about the infection due to the stigma associated with it. I think information was gained from the media rather than any medical staff.

12. I believe that we should have been provided with information about HIV at the initial meeting with the doctors or at least soon thereafter.

13. Just before Simon died we found out that he had also been infected with HCV, and in 2018 when Simon's medical records were received they showed he also had HBV.

Section 3. Other Infections

14. I am not aware of any other infections that Simon might have contracted as a result of being treated with contaminated blood products. However, in his medical records, there is a letter from Dr Hoffman, referring to a Cytomegalovirus (CMV).

Section 4. Consent

15. I believe that there was never any adequate information provided to Simon or our parents about the treatment or tests that were performed on him.

16. Also, I believe that if we knew then what we know now, we would have asked more questions to better understand what was happening.

Section 5. Impact

17. Simon's illness and his death have affected me and my family enormously.

18. I was about 17 when Simon was diagnosed with HIV. I admit that I was selfishly grateful that I had not been infected. I did not really understand the consequences of the infection and I just continued my life as before. It was not until Simon became seriously ill that it dawned on me how concerning it was.

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I believe that my

father might be blaming himself for Simon's infections and death as he was the one who injected him with the treatment.

21. My mother is socially withdrawn, she is not able to communicate what has happened to her son as it was kept a secret due to the stigma associated with HIV.

22. I moved away from home to work and carved out my own life. I met Craig in 1988/89 and shortly afterwards Simon started to go downhill. It was just not right that someone of his age was suffering.

23. I suffered from anxiety and depression during the last couple of years of Simon's life but I had to be strong for our parents and my own children. I recall someone at Simon's funeral saying to me that I needed to be strong for our parents. I also had a young family at the time so I had no choice but to get on with it. As a result I do not feel I grieved properly for Simon.

24. I felt I could not be sociable with people, I was constantly hiding my feelings, I had negative feelings and I suppressed those feelings. I also have very low self esteem.

25. I often feel guilty that Simon passed away and I am still alive. I often feel alone but I am happily married.

26. I have only started opening up to friends about what had happened to Simon in the last 5 or 6 years. I now have a great network of friends who support me.

27. Taking part in this Inquiry is difficult but it is helpful in dealing with what has happened. I feel I have to re-live it all over again. I hope that this will help in the end.

28. In 2015 I received 15 sessions of cognitive behavioural therapy through my GP which I found helpful. I also took antidepressants for a year and I take tablets for anxiety when they are needed.

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30. Dealing with the stigma attached to Simon's infection was very difficult, we kept Simon's condition a secret and when we were asked how Simon died, we would say that he died of cancer as it is an honourable disease. Also I worked in the care industry and I was worried that if my employers knew of Simon's condition I would lose my job.

31. I know that Simon loved children and he really wanted to have a family of his own, which he was deprived of through no fault of his own. I have also been

deprived of the opportunity to be an aunt. He also did not get the chance to see his niece and nephew grow up, which is very upsetting to me. As a result of this we were never able to do fun activities together as a family.

32. Craig and I now have aging parents to look after and my father cannot cope with what has happened. My mother is becoming stronger as she is talking about what has happened more.

Section 6. Treatment/Care/Support

33. I do not believe that Simon was treated fairly at hospitals due to the prejudice associated with HIV. At Leicester Royal Infirmary he was always treated in isolation, he felt like a leper, he was always placed in a private room, medical staff always wore gowns and masks, and nobody would want to pick up his bed pans so as not to be responsible for them or even to touch them.
34. There was also an occasion when a dentist refused to treat him because of Simon's HIV status. He had to go to hospital to receive dental treatment.
35. Overall, I believe that care was not really an issue. The issue was the lack of information and support. I feel the Haemophilia Society was not supportive in providing on-going advice and guidance or financial information.
36. A letter was found in Simon's medical records stating that he was offered counselling; however, in fact counselling was never offered to any of us. I only received counselling in 2015 through my own GP.
38. The only time support was received was when the Terence Higgins Trust put us in touch with Jenny Deakin (Jenny), a personal case worker from the Leicester AIDS Support Service. She took a lot of time to explain things to us and supported us.

Section 7. Financial Assistance

38. We were not made aware of any trusts or funds available until we were put in touch with Jenny.

39. In about December 1992, Simon started to receive a payment from the McFarlane Trust of £40 per week. A disability care allowance of about £40 per week from the DHSS and dad's carers' allowance of a similar amount were also claimed.

40. Our dad was Simon's main carer and as a result he did not work. Also after Simon died we did not know of the support available as this left his dad with no income at all.

41. Further we did not apply to Skipton Fund for financial assistance as we did not know that Simon had HCV until after he died and were never told that these funds were potentially available.

42. Simon also received ex gratia payment of about £23,000 on condition he signed an indemnity form.

43. After Simon died, we received £1,000 towards his funeral expenses. None of us had to apply for it. We also received a small sum from the MacFarlane Trust after Simon died representing back payments that were due to him.

Anonymity, disclosure and redaction

50. 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.

61. I do not wish to be called 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

Louise Tansley

Dated: 28 March, 2019