Witness Name: Lesley Jane Alexander
Statement No.: WITN0075001
Exhibits: Nil
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25 FEB 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF LESLEY JANE ALEXANDER

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 14 November 2018.

I, Lesley Jane Alexander, will say as follows: -

Section 1. Introduction

1. My name is name is Lesley Jane Alexander and my date of the birth is GRO-C GRO-C 1947. My address is known to the Inquiry. I am retired and have a background in modern languages. I am divorced and live alone, although my two grown up sons and ex-husband live close by.

2. I intend to speak about my infection with the Hepatitis C virus (HCV), which I contracted from a blood transfusion. In particular, I intend to discuss the nature of my illness, how the illness affected me, the treatment received and the impact it had on my life.

3. I confirm that I have chosen not to be legally represented and that I am happy for the Inquiry team to assist me with drafting my statement.

Section 2. How Infected

4. In early 1989 I discovered that I was born with a hole in my heart. I recall going into Guy's Hospital on the Tuesday 15 August 1989, and being operated on Thursday 17 August - I had surgery to repair the atrial septal defect. Had it not been treated, it could have been fatal.

5. Five pints of transfused blood were set aside for the operation, and as far as I am aware I definitely had two of them. No possible risks of infection were communicated to me prior to the surgery.

6. I went back onto the ward and was deemed fit enough to go home the following Tuesday. A district nurse removed the long running stitching at home, and I was later signed off as a patient from Guy's Hospital. I recovered as normal and resumed my usual activities.

7. On 26 April 1996, I received a letter in the post from the South Thames Blood Transfusion Service stating that it was possible that I had been infected with HCV. An additional letter dated 24 May 1996 followed this. It informed me that the blood test came back positive for HCV only. I went into panic mode after the initial letter and I did not know what to do. I have since wondered why I was not informed for seven years - might it have something to do with the statute of limitations?

8. I had genotype 1B, which I later found out was the hardest to clear.

9. Initially I had an appointment with my GP but I do not recall what was said. Following this appointment, I was referred to King's College Hospital and had the first consultation with them on Tuesday 18 June 1996. At King's College Hospital, I met with Dr Paulo Ritzi and the main overarching liver consultant at the time was Dr J O'Grady.

10. No one at the time knew how to manage the virus, and the focus became on not infecting other people.

Section 3. Other Infections

11. I have not received any infection other than HCV as a result of being given infected blood.

12. I was tested for HIV during a course of treatment at the end of 2012, but this was negative.

Section 4. Consent

13. I consented to the blood test and treatments for HCV. I also knew all the possible pitfalls of the treatment, and was kept fully informed by Dr Agarwal at King's College Hospital.

Section 5. Impact

14. I had no physical effects prior to the treatment other than tiredness. There were days where I felt extremely tired, but did not know whether to put that down to the pace of life I had.

15. After the diagnosis, my brother who lives in Canada sent a lot of information about the virus. I recall being horrified and thoroughly depressed discovering how nasty it was. I found the lack of treatment available particularly worrying, along with it being referred to as the 'silent killer'.

16. I also recall speaking with a colleague at the time of the diagnosis. She was horrified to hear about the infection, because she knew the full implications of the virus.

17. Despite being low in spirits, I put my HCV status to the back of my mind. I did not want my life to be defined or limited by this diagnosis.

18. In spring 1997 I was put onto a 6-month course of self-injecting Interferon, which carried a 20% chance of success. It had no effect whatsoever but made day-to-day living extremely uncomfortable. I was nauseous, desperately tired and suffered with skin irritation.

19. Once the course of treatment finished, it was suggested I try again with Ribavirin. Combined with the Interferon this had a 25% chance of success. The small possibility of a positive outcome influenced my decision not to go through it all again.

20. From 2000 Dr Bomford directed my care at King's College Hospital. He was an extraordinarily nice man and very helpful. As I refused the dual course of treatment, nothing further could be offered.

21. For years I attended King's College Hospital twice a year to discuss my health situation.

22. Before Dr Bomford retired in 2012, he asked whether I would like to remain under King's College Hospital. He explained that a new doctor, Dr Kosh Agarwal was embarking on new treatments for all genotypes of HCV. From then onwards Dr Agarwal directed my care. He was a very nice able man, and I placed a lot of faith in him.

23. The treatment I received was first tested in France. I was not part of the trial as such, but the follow up study. Being 68 at the time, I was quite old to be given the new treatment, but I may have been used as a wild card.

24. Dr Agarwal suggested that I take part in a combination treatment. This consisted of weekly Interferon injections, along with Ribavirin and a new drug Telaprevir daily, the latter for only 3 months of the course.

25. The whole course of treatment started in 2013 for a duration of 48 weeks. It was like chemotherapy. Telaprevir had a lot of side effects and I suffered from them all, including nausea, vomiting and total loss of

appetite. As well as having an effect on my immune system, the drug had a disastrous result on my red and white cell blood count. I had to inject myself once a week to boost the cell levels.

26. I did not want to admit I could not cope with the medication; I just wanted to keep going. Dr Agarwal was very impressed that I kept on with the programme, especially when others started to drop out.

27. I cannot put into words the hell I went through. I lost a couple of stone and would have to stop half a dozen of times to walk into the local town. Everything was exacerbated because I lived alone, people were about but I had no consistent support. Those close to me do not quite understand how awful it was.

28. Three months into the treatment I could stop taking Telaprevir, but continued with Interferon and Ribavirin. There were still side effects, I continued to be nauseous and lost my hair.

29. I was extremely low and depressed throughout the treatment, but refused to be brought down by the virus. My sleep was affected due to anxiety.

30. A full month after the treatment finished I was deemed to be free of the virus. This would have been in January 2014. It was an extremely hard road. I am not sure how I managed to get through it all, and I could not do it again.

31. I count Dr Agarwal as my saviour. I do not know where I would be without him, but definitely very ill. He has brought medical help to so many people, and is highly regarded internationally.

32. I still have lasting effects from the treatment, consisting of itches and twinges. I do get very tired but it is hard to determine whether this is a result of the cirrhosis, or a lasting side effect.

33. In 2006 I was diagnosed with cirrhosis of the liver. I was told by one of the HCV nurses that I had about 10 years left to live. I drove into my garden gate on the way home from this appointment, and later stressed that I should not have been told that. I am aware that cirrhosis is known as end stage liver disease and I feel it is so unfair I have the condition, through no fault of my own.

34. I am now under the care of Maidstone Hospital and have not had a check-up about the cirrhosis for over a year. It is supposed to be reviewed twice yearly. I have asked whether it is improving, but I was told 'Cirrhosis is cirrhosis' and it is bad regardless.

35. There was talk at King's College Hospital about the possibility of a liver transplant, as the cirrhosis was not self-induced. I do not know whether this would be able to happen now.

36. I do feel that the infection contributed to the breakdown of my marriage and divorce. After the diagnosis, my husband shared my anger, upset and worry, but he found it difficult to cope with, and never wanted to discuss it.

37. There was never any worry about spreading the infection, I became very careful and we never shared toothbrushes in the household.

38. During the same year as the heart operation, my husband was made redundant and set up his own business. It seemed as though his world was shrinking into the study. We also had my ill father living with us at the time. My husband's reaction was to stick his head in the sand, in the hope that everything would all go away.

39. Apart from the initial appointments he attended, I had no support from my husband. I felt very alone. Perhaps I was going to lose him anyway, but the HCV sadly put an end to our relationship.

40. We separated in 2000 and our divorce settled in 2003. Even though I now live on my own, I am very self-sufficient.

41. When I was diagnosed with HCV, my eldest son was at university and my youngest son at boarding school. They thought it was awful, but grew up with my HCV status being the norm. I do however feel that life would have taken a different course, had I not been given contaminated blood.

42. My children share my anger and upset, but have remained sympathetic and supportive. They admire that I have always kept going, even during the tough year in 2013. This is very comforting.

43. Circumstances including the divorce mean I go out less often. If I do it is during the day, as evening gatherings are few and far between for single individuals of my age.

44. I am very fortunate to have a network of long lasting supportive friends. Each of them have been very positive towards me.

45. One particular friend who lives nearby has been superb, and became my rock. She drove me to King's College Hospital for all the treatment under Dr Agarwal, as I could not manage on the train. The appointments started off weekly and reduced accordingly.

46. I had no social life whatsoever during the year of 2013.

47. Despite the condition of my health, I still try to keep active. I walk often and attend yoga classes. The focus on mindfulness and breathing helps me at lot. 'Carpe diem' is the motto I now follow.

48. I have never faced any stigma as a result of being infected with HCV. I was conscious of the stigma internally, but informed people when it was necessary, and so as not to endanger others. I made it clear to both dentists and other medical professions.

49. Although I did not suffer, I did feel there was a need to explain myself, and state that it was the consequence of a blood transfusion - something out of my control.

50. No one has ever looked down on me, and any reaction I had was kind and sympathetic.

51. I have not lost a huge amount in earnings because of the infection, but I could no longer work full time.

52. I had no money of my own until the divorce settled, where I was given half the equity of the house and half of my husband's investments. The investments suffered with the depression of interest rates, so I ended up using savings for living costs. I receive no maintenance from my husband or any part of his pensions.

53. I did not feel up to trying a new profession after the divorce. This was partly due to my age, and the tiredness I experienced. Hypothetically I would have had more get up and go without HCV.

54. As a part time worker I never built up a pension scheme.

Section 6. Treatment/Care/Support

55. I have received no counselling in consequence of being infected with HCV.

56. I was given the details of a support group at Maidstone Hospital, which I attended once. I found it unhelpful and negative as everyone just discussed the awful consequences of the virus.

Section 7. Financial Assistance

57. I am so thankful for the Skipton Fund. In the early 2000s, I was granted an initial lump sum of £20,000 because I contracted HCV as a result of a blood transfusion.

58. It was my eldest son who found out about the scheme, which was set up to compensate those who have suffered as a consequence of contaminated blood. He had a Blackberry at the time and it came up on his news feed. After he told me, I noticed a small item in the newspaper the next day.

59. No one from King's College Hospital notified me of the Skipton Fund, so I brought it up in the next appointment with Dr Bomford. He filled out the form with me and then submitted the application on my behalf.

60. I received the payment in a matter of months after the application was submitted, definitely no longer than 6 months.

61. After being told I had liver cirrhosis in 2006, I received another pay out of £25,000.

62. I now receive an annuity from the EIBSS, which is in the region of £14,500 - £15,000 a year. I was not aware of the other funds until they amalgamated under the new scheme.

63. I do not receive any payments other than the annuity.

64. No preconditions were imposed on the payments, only that I had received contaminated transfused blood. As Dr Bomford assisted with the application form, he could verify this.

65. I have ambivalent feelings about receiving the money. I am sitting in a comfortable home and can feel guilty, but then I did not contract HCV through my own doing.

66. Without financial assistance I would have no savings by now, nor could I live in a complex designed for those of retirement age.

Section 8. Other Issues

67. I do not let being infected with HCV determine who I am. It is in the filing cabinet at the back of my mind and I will not let it define me.

68. I feel very angry and cheated that so much information has been held for so long. I resent being kept in the dark for so long and that information was deliberately withheld. I should have been notified I had HCV as soon as it was discovered.

69. There has definitely been some kind of cover up, and a lack of readiness to admit that the NHS was at fault. Something should have been done sooner to address the scandal, rather than it all being brushed under the carpet.

70. I found the 70th anniversary celebrations of the NHS particularly difficult. Sadly it is the nature that with big organisations there are dark little corners. I would like a line to be drawn and nothing of the like to happen again, yet other issues have been exposed including actions such as those at the Staffordshire Maternity Ward.

71. I never have been involved with campaigning.

72. However I did look into a class action that was brought up by solicitors in Newcastle. I was married at the time and dropped the idea because I did not have the funds to be able to be involved. It actually worked out to my

advantage; individuals were given a small pay out, but were excluded from financial assistance provided by the Skipton Fund.

73. Further, after hearing that a woman in the USA had been awarded a sum of money by a tobacco company, in compensation for the illness and suffering caused by smoking their brand of cigarettes, I decided to write to the Telegraph in February 1999. I highlighted that no one had then ever been offered any kind of compensation for the mental anguish and physical suffering brought on by the contaminated blood. Unsurprisingly, I received no reply.

74. I do sympathise hugely with haemophiliacs, but the reporting so far (especially from the BBC) has very much focused on them. It must be made aware that an awful lot of people were infected by blood transfusions. Like myself, these individuals were perfectly healthy but came out with a ticking time bomb.

75. Before the Inquiry not much was known about the contaminated blood scandal, but for me it has brought back the emotions of anger and despair.

Statement of Truth

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

Signed GRO-C

Dated 20th February 2019