

Witness Name: L Walmsley
Statement No: WITN2811001
Exhibits: WITN2811002
Dated: February 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF LOUISE WALMSLEY

I, LOUISE WALMSLEY, will say as follows:-

Section 1. Introduction

1. My name is Louise Walmsley, DOB [GRO-C] 1970 and I live at [GRO-C]
[GRO-C] I work at the University of Manchester.
2. I make this statement as the widow of Raymond Frank Walmsley (date of birth [GRO-C]
[GRO-C] 1964) who died on 11 September 2018.
3. Ray died at Manchester Royal Infirmary (MRI). He was infected with Hepatitis C (genotype 1) as a result of a blood transfusion in 1991 and I believe that Hepatitis C caused his death. There is a Coroner's inquest pending and therefore, at this time, the cause of Ray's death has not been finalised. [GRO-D]
[GRO-D] the Consultant Hepatologist at MRI has proposed the following cause of death: 1a renal failure, 1b multifocal cholangiocarcinoma, 1c Hepatitis C; 2 Type 2 diabetes, cirrhosis of the liver.
4. This witness statement has been prepared without the benefit of access to my late husband's full medical records. If and in so far as I have been provided

with limited records the relevant entries are set out in the medical chronology at the end of this statement.

Section 2. How infected

5. Ray was born and grew up in Liverpool with his parents and his sister, GRO-C. He was a fit and healthy child.
6. He did well at school and after passing his exams went on to university. Whilst at university he developed nephritis after a severe cold. His kidneys failed and, as a consequence, in 1986 he required the first of three kidney transplants. The first procedure took place at the Liverpool Royal Hospital and his sister GRO-C was the kidney donor. Ray was very ill during this period but ultimately made a good recovery and was able to return to his university studies.
7. Ray moved to London to complete his BSc in Biochemistry and obtained a 2:1 Honours. His degree included a one year placement at Porton Down. He was a very able student and was successful in receiving funding to pursue a PhD. He completed his PhD in examining the effects of a cancer drug on DNA.
8. In 1990 his renal transplant began to fail and he underwent a second kidney transplant in 1992, this time from the national organ donation register. This took place at St Bart's Hospital in London. Ray's first renal transplant was removed in 1991 and he had a blood transfusion on 23 February 1991 as part of this procedure. The blood was contaminated blood and, as a result, Ray was subsequently diagnosed with Hepatitis C. The correspondence relating to the transfusion is now shown to me marked exhibit **WITN2811001**. I do not believe that Ray ever saw this correspondence.
9. I met Ray in 1994 when we were both working at the University of East London. He had finished his PhD in microbiology and was working in university administration to support academics in securing funding for research.

10. At that time he was taking immunosuppressant drugs. I remember that they were large tablets and that, as time went on, he seemed to have to take more and more medication just to combat the effects of the immunosuppressants.
11. A few years after this (in or about 1998) his second transplant started to fail. All the way through his ill health, and up until his death, Ray continued to work full time because he was a determined and resilient person who wanted to live as normal a life as possible.
12. Ray and I married in 2002 and moved to Manchester the following year where he was able to manage on haemodialysis at home three times a week. His care was transferred to the Manchester Royal Infirmary (MRI).
13. In 2007 another match was found and Ray underwent his third kidney transplant, this time at the MRI. This was again donated from the national register. Ray looked after each of his transplants as he was so grateful for the difference they made to his life and our life together.
14. Because of his scientific background Ray always sought to understand and maximise his knowledge of the various conditions he had during his life. Ray often discussed research papers he had read on his renal condition with his doctors. He had a positive attitude which saw him, and us, through the difficult times.
15. We lived very happily. As we had experienced times when our life was limited by Ray's dialysis, we made the most of the periods when Ray was well and we enjoyed wonderful holidays together (including a trip to the Maldives in December 2017), weekends away with friends, walks with our dog Stan and meals out.
16. Ray was diagnosed with diabetes a few years after his third transplant as a result of the number of years he had been on immunosuppressant medication. However, he did not let this get him down and managed his blood sugar and insulin injections meticulously; something his treating doctors commended him for.

17. I was bemused when I saw the letters between the renal unit and his GP. One letter says that he was properly informed and counselled about his Hepatitis C. This is completely untrue.

18. Ray was told about his Hepatitis C diagnosis, almost as an aside comment, in an open dialysis unit. He was having dialysis and in the middle of the session a member of staff informed Ray that he had Hepatitis C but to be grateful that he didn't have HIV – Ray did not even know he had been tested. There were other people around when he was told and no support or advice – or frankly any compassion - was offered.

19. My recollection is that this happened around his birthday in November 1996.

20. I do not recall that Ray was given much information about the infection. I do not remember seeing any leaflets or being sat down and informed about it.

21. I remember Ray coming home in a distressed state and telling me what he had and that it would kill him. Ray was a microbiologist so undertook his own research into the infection as the doctors had told him so little.

22. No one ever suggested that I should be tested for Hepatitis C.

Section 3. Other Infections

23. There is reference in Ray's medical records to episodes of CMV – I believe he was exposed to this via contaminated blood.

Section 4. Consent

24. Ray did not know that he had been tested for Hepatitis C when he was nonchalantly told that he had the virus. He cannot therefore have consented to testing.

Section 5. Impact of the Infection

25. Ray was an exceptional person whose death leaves a massive void in my life and the lives of his family and many friends. I am immensely proud to describe myself as his wife and best friend.
26. Ray had regular liver scans with his most recent one being in May 2018 which came back clear. He also had a liver biopsy and colonoscopy in 2018 and everything came back okay. We were anxious ahead of each of these tests over the years as we well understood the possible outcomes. Up until July 2018 Ray was well and he had been for a long time. We had a good life together which made it all the more distressing when he went downhill so fast. In May everything seemed fine; by September he was dead. I and the rest of the family are still in shock.
27. Ray always worked full time and was proud of this. At the time of his death he was working in the Alliance Manchester Business School at the University of Manchester where he was a member of the School's senior administrative team and was recognised as a highly effective and respected colleague. As recently as July 2018 he was cycling to and from work. Ray was a very humble person who would have been amazed at the number of colleagues who attended his funeral.
28. In July he started complaining of pain in his side. He felt unwell, lost his appetite and became severely fatigued, both of which were highly unusual for him.
29. He was seen almost weekly by the MRI renal team during July-August 2018 and was admitted by Dr Greer after he attended the liver clinic on 13 August 2018. This was because fluid was building up around his stomach (now known to be ascetic fluid) which was affecting the function of his kidney transplant.
30. The fluid led to his transplant starting to fail and he had to go back on haemodialysis. That was distressing for Ray and for me.

31. While in hospital he had an MRI scan which indicated that he had some sort of mass on his liver. This was followed up by a liver biopsy on 6 September 2018. We knew that the mass was likely to indicate some form of cancer.
32. Ray's health deteriorated very quickly. He struggled with haemodialysis on 7 September because his blood pressure was so low. His blood pressure continued to be worryingly low on 8 and 9 September.
33. An Intensive Care Consultant told us on the evening of 9 September that the mass on Ray's liver was likely to be cancer, that the ascetic fluid had damaged Ray's lungs and had also caused his kidney transplant to fail. She explained the only way Ray could be dialysed was if he was placed in an induced coma in Intensive Care. She explained that Ray therefore had two options; he could either go into intensive care for dialysis but that this might not work and I would therefore be left with the decision of what to do or he could withdraw from treatment. Ray knew what this would mean; if he withdrew from treatment he knew he would die. He asked the Consultant how long he would have and she said "a matter of days." This Hobson's choice came as a huge shock to Ray, me and the rest of the family. We discussed the limited options with the Consultant and Ray made the decision not to go ahead with any further treatment. Distraught as I was, I understood and respected his decision.
34. Ray was physically very weak by that stage after not eating for a number of weeks and he was concerned about the quality of his life particularly as we both knew that a diagnosis of cancer was likely to be confirmed shortly.
35. Ray asked to be moved to a private room and I and his sister Karen stayed with him until he died on 11 September 2018.
36. Although I have been provided with Ray's medical records there is no documentation in relation to his last few days. I have repeatedly asked for this information but to no avail. I had to ask for information on the scan and biopsy from August-September as these were missing from the first batch of records sent to me. I simply do not understand this.

37. Ray was still so lovely to all of the nursing staff. When he died, one of the nurses told me that Ray was the most composed and dignified patient she had ever come across.

38. The difficult thing for me to understand is that up until July Ray's health was fine. We had actually been due to be on holiday in Majorca when Ray died. Ray well understood the effect that Hepatitis C was having on his liver and therefore, before he went into hospital and knew how desperately ill he was, we had a discussion about him giving up work to improve his work:life balance. The Hepatitis C caused him fatigue and made him acutely aware of the shortness of life. We had talked about getting another dog and Ray was considering undertaking voluntary work after he left paid employment. This was a big decision for Ray and one that I am heartbroken he was not able to see through.

39. We both knew that Ray was unlikely to live to his 70's or 80's, but to die at 53 is just too young.

40. Ironically Ray did not want to be a part of the Infected Blood Inquiry – he just wanted to forget about it and move on. However Ray's death means I have felt the need to get involved and I have the full support of our family in doing so.

41. Ray was too young to die and I am too young to be a widow. I am an articulate person but I find it difficult to put into words how I feel having lost him. We were blissfully happy together. He died too early and I am clear in my mind that he would still be here if he had not contracted Hepatitis C as a result of his blood transfusion.

Section 6. Treatment/care/support

42. After Ray was diagnosed neither he nor I were offered any counselling.

43. Ray told very few people about his Hepatitis C because of the stigma and lack of understanding – even within the NHS. I recall attending a hospital appointment with Ray in which he was asked by the doctor when he had stopped taking intravenous drugs because they assumed that was how he had become infected. I remember on another occasion when Ray calmly told the doctor how he had actually been infected, the doctor replied ‘oh and has that been proven?’.
44. Ray received treatment for his Hepatitis C in 2015. The treatment hospitalised him.
45. This was a gruelling treatment but was deemed to have been successful although we fully understood that the Hepatitis C had already caused cirrhosis of the liver which was irreparable and was likely to lead to cancer at some point.
46. When Ray was on this treatment I thought he was dying. He had extreme diarrhoea multiple times a day, terrible nightmares and night sweats. He was struggling to eat and this caused weight loss to Ray who was already a slim man.
47. Ray was very stubborn and very determined and wanted to see it out. Around New Years Day I told him that he needed to get some help as he was in such a bad way. He stayed in hospital for about a week and needed a blood transfusion whilst he was there.
48. He was so brave and I have no idea how he agreed to carry on, but he managed to complete the full course of treatment.
49. We subsequently received confirmation that he had cleared the virus but the damage to the liver was already done.

Section 7. Financial Assistance

50. Ray was registered with the Skipton Fund and received the Stage One and Stage Two payments.

51. I received a grant to help pay for his funeral and have also received a discretionary payment of £10,000 as Ray's widow.

52. Ray received payments from EIBSS on a monthly basis.

53. I have found EIBSS appalling to deal with. When Ray died I emailed them to inform them of his death because I did not want to be accused of receiving money that I was no longer due. When I hadn't received a response after five days I telephoned them. I explained very clearly why I was calling and was then told that they needed to speak to my husband to confirm his security details. I broke down on the phone. I simply could not believe how crass they were being. To make things even worse, the woman then went on to say "the good news is that you'll still receive September's payment." I made a formal complaint. The response I received said that EIBSS apologised for any distress it "may" have caused and that the individual I had spoken to would be receiving "coaching".

Section 8. Other Issues

54. I need someone to step forward and say categorically that Ray was infected with Hepatitis C via a blood transfusion, to admit that this should not have happened, and to acknowledge that Ray died an untimely death as a result of an infected blood transfusion.

55. I feel like Ray was, and continues to be, just a reference number to people. He is my husband and was an amazing son, brother, uncle and friend.

56. It is my understanding that Scotland had already stopped these blood transfusions in 1991 so why were they still being given to people in England?

Anonymity

57. I do not want to remain anonymous

58. 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

28/2/19