

Witness Name: Wendy Stubbs

Statement No.: WITN00873002

Exhibit No: WITN00873003-07

Dated: 2019

INFECTED BLOOD INQUIRY

SUPPLEMENTARY WRITTEN STATEMENT OF WENDY STUBBS

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 11 March 2019.

I, Wendy Stubbs, will say as follows: -

Section 1. Introduction

1. My name is Wendy Stubbs, born GRO-C 1960. I live in Bradford, my full address is known to the Inquiry.
2. I wish to provide an additional statement to the Inquiry
3. I was interviewed by the Inquiry Investigator on 7 May 2019 about my husband Stephen Andrew Stubbs ("Steve") Hepatitis C Virus ("HCV") infection that he received from infected blood products while being treated for severe haemophilia as a child and throughout his adult life.

4. Since providing that statement additional changes to Steve's health and new information has come to light which mean I need to provide a supplementary statement to the Inquiry.
5. This statement should be read in conjunction with my first statement.

Medical Records

6. In paragraph five of my first statement to the Inquiry I did not have Steve's medical records. I have now obtained and reviewed records held by the Bradford Royal Infirmary. I do not know if they are all of his medical records.
7. I will speak about what I have read in his medical records in detail later in this statement.

Variant Creutzfeldt-Jakob Disease

8. In paragraph 21 of my first statement I said I do not believe Steve had been subject to any other infections. I no longer agree with that statement.
9. On 25 May 2019 Steve had a significant bleed in his knee which required him to be admitted to Bradford Royal Infirmary (BRI) for two weeks.
10. On 7 June 2019 he was discharged from the hospital as an inpatient but required daily treatment of Factor VIII (coginate) at the BRI as an outpatient.
11. On 9 June 2019, I was reviewing the discharge paperwork Steven was given. There was a letter dated 5 June 2019, 'Re S. Stubbs Discharge Summary' which addressed: care, procedures, investigations. On the fifth line down under the heading Safety Alert it said "18 April 2018 Hepatitis C (Confirmed)." On 6th line down it said, 14 September 2010 "at risk of variant Creutzfeldt-Jakob

disease (finding) (Confirmed) - Presented on 14 September 2010." I attached this document, marked **Exhibit Number WITN00873003**.

12. When I read this I went ice cold. I was horrified and totally shocked. I felt sick. All the conversations I have had with Stephen is that he didn't have CJD. I was blown away by what was on the paper. This was the first I had heard or seen about Stephen having vCJD or CJD.

13. I went to the lounge to see Stephen, and asked "When you were told about Hepatitis C, do you remember the results of the CJD test? I remember you were told about being tested for CJD." He said, "I haven't got it." I asked him how did he know? His answer was the same, "I was told I didn't have it."

14. I was very upset. I decided to write a letter to Dr Ackroyd, Stephen's Haemophilia Doctor. I needed to know what had happened, why this had happened and how this could happen.

15. That night I did my own research about CJD, during this I found a list of symptoms of someone who has CJD, Steve had all but one of the symptoms on the list. Steve's symptoms which were on the list: loss of physical coordination - slurred speech, muscle spasms and twitches, vision issues - he has an inability to distinguish shapes and lost shape recognition, fatigue and tired, shaking, ~~tremors~~ ^{tremors}, dementia, memory loss, impaired thinking, anxiety, personality changes, depression, sleeping patterns. This made me very worried.

16. On 10 of June 2019 Steve has his outpatient appointment at the BRI. Nurse Kirsty Mellor treated him and during the appointment I burst into tears. I asked her, "Can you see why I'm upset?" she said to me, "Yes, I can," her words then were "When I started here at the BRI, I was shocked how many gaps there were in patients notes and service in their care, it upsets me."

17. Ms Mellar then offered to speak to Sam (Dr Ackroyd), she indicated she knew he had a clinic the next day. Ms. Mellar then left the room. She came back and told us Dr Ackroyd was happy to speak to us tomorrow at noon.
18. Steve and I meet with Dr Ackroyd on Tuesday 11 June 2019. Dr Ackroyd started the conversation by saying he knew "This is quite an uncomfortable conversation we are going to have." He then said that he understood the concerns I had in regards to Stephen. He advised that "I have traced back to the batch where Stephen had received products" and that Stephen had been "administered with products where the donor had died of CJD." I attached marked **Exhibit Number WITN00873004** this list of batches Stephen has received. I can only assume those with the asterisk symbol (*) are infected batches.
19. I was very angry that we found out that Stephen had been exposed to CJD through a thoughtless print out. There had never been any mention of it, no discussion. I said I wanted more information. I said to Dr Ackroyd "If this was a member of your family, you would want to investigate."
20. I have done my own research and believe Stephen's symptoms are very, very similar to someone with CJD and it is causing myself and family great concern.
21. I found Dr Ackroyd's response to this flippant. It was nonchalant, blase about it all. I found him to be apologetic but unable to commit to anything. I asked him how many people had died from CJD, he said two, a haemophiliac and non haemophilia in 2014. I did not find this reassuring.
22. I asked him if Stephen had 14 months to live, because that is what I had read in articles. He said he would need to speak to Mark (Mr Busby, Stephen's Neuropsychological Consultant).

23. I demanded for this to be ruled out and Dr Ackroyd said "I accept your concerns and agree we should arrange for Stephen to have a lumbar puncture, a bone marrow and an EEG."

24. During the meeting I asked Dr Ackroyd, why is this "old news" from September 2010 and we haven't been informed. Dr Ackroyd said he had looked through notes and there was no reference to CJD or the discussion with us about it, but then said he would need to look through them with a fine tooth comb.

25. We left awaiting the arrangement of a lumbar puncture, bone marrow and EEG tests.

26. On the 3rd of July 2019 Stephen was supposed to have a bone marrow test, that morning the Nursing Sister called and said the bone marrow wasn't going to take place, but to come in the next day for a Lumbar puncture. I was furious, it felt like more mucking about. It transpired that there is no reason for a bone marrow sample.

27. On 4 July 2019 Stephen had a Lumbar Puncture. I understand they normally remove 10 ml of fluid but they took 25 ml from Stephen because of all the different proteins they will test for at the Edinburgh CJD Laboratories. *He was very ill following this procedure*

28. We are awaiting the outcome of these tests.

29. In the meantime our life continues to be turned upside down. Stephen is no longer able to drive, the DVLA has revoked his licence. Stephen has not been able to return to work, I am hopeful he will be able to. An Occupational Health

Nurse is scheduled to visit and assess things for Stephen soon.

NOT RELEVANT

NOT RELEVANT

30. I have now begun counselling through Carers Resource which has come about through the Alzheimer's and Dementia support network. I am finding it helpful.

31. On 18 June 2019 I requested Stephen's medical records from the BRI in writing. I was not advised, nor did I know a SAR form was required. When I chased the Hospital, I was advised my letter had been misplaced. When I told them the Investigator from the Infected Blood Inquiry was coming to visit me, my request seemed to progress quickly.
32. On the morning of 22 July 2019, we received a printer paper box of Stephens medical records. I do wonder if this is all of them. There do not seem very many given he has had a lifetime of treatment and medical matters.
33. I have briefly reviewed the medical records we have received. The first mention I have read about CJD is 10 August 2009 when there was a hand written comment on the page: "? re CJD". My interpretation of this is it is neither ruled in nor ruled out.
34. The next I have read where CJD mentioned, is on 17 September 2010 in a 'Surgical management Plan for Patient with a Bleeding Disorder' - under the heading 'Special Instructions' it says "follow infection control guidance for patients 'at risk' for vCJD, infection control made aware on 8 September 2010 and they will prepare a risk assessment report for both infection risks."
35. Included in the medical notes was a biopsy report from 17 September 2010 which noted damage to the liver and noted "The etiology of it may be Non-alcoholic metabolic syndrome or alcohol related disease." I do find it offensive that there is some suggestion Stephen 'chosen lifestyle' inflicted the damage to his liver. It is careless, when it is actually from being infected with HCV from blood products. I have attached a copy of the medical records, marked **Exhibit Number WITN00873005**.

Financial Impact and Assistance

36. I wish to update my first statement about the financial impact the infection has on our lives. I also wish to update my first statement about the financial assistance we have received.
37. I have applied for further assistance from the EBISS through the 'discretionary support scheme'. I have been told that we do not qualify for this support because we are seeking to be compensated for work at our home and Steve's new bed which we purchased last year. We did not realise we were entitled to this support last year despite seeking support from the EIBSS during this time under a different category.
38. The EIBSS have declined making a retrospective payment to us. I believe if we had applied last year we would have qualified for the payments. I am reapplying as I do not accept their decision.
39. This service does not help or assist me. I have attached a copy of the email correspondence and marked it **Exhibit Number WITN00873006**.
40. Steve has now failed his occupational assessment due to dementia and can no longer work. We are hoping his company can apply for insurance to cover loss of earnings due to not being well enough to work.
41. With Steve not working we are desperate financially. I have called the Department for Work and Pensions, Steve is to urgently be assessed for a Personal Independence Payment (PIPS). I cannot apply for a caregivers allowance, disability or any other benefit until we are approved for PIPS.
42. I have applied again to the EIBSS for the Special Category Mechanism, the organisation which is supposed to be helping those infected. I have also

applied for Stage Two payments. Stephen is only getting sicker and we are desperate.

43. The EIBSS is a difficult system and organisation for lay people to understand and engage with. I think they need to have more flexibility and compassion. They don't appear to understand the complexity of it all. The system feels arbitrary.

44. Collectively Steve's consultants are of the opinion the HCV or vCJD is the cause of his dementia. It would be impossible to disprove. Yet, I am having to plead to what feels like deaf ears.

45. From what I understand, the Stage Two payments are reserved for advanced liver conditions. I don't understand why it doesn't accept advance mental health conditions ie: early onset Dementia and Alzheimers when it was caused by my husband receiving infected blood products. I have attached the letter I sent to the EIBSS dated 13 August 2019 marked **Exhibit Number WITN00873007**, which outlines my plea for support.

46. I am angry, upset and exhausted. I feel like he was done wrong by when he was given infected products; he was done wrong by when he wasn't told about the query over vCJD/CJD, he was done wrong by when we had to fight for his Dementia and Alzheimer's diagnosis and he continues to be done wrong by the service which is supposed to provide financial assistance. At every stage Steve has been done wrong by. It is completely unacceptable.

47. I want to be able to care for Steve and provide the best for him in the small time we may have together. I wish to be able to respectfully pay for his care when he is in such a way, that I cannot care for him.

48. The service that is supposed to be helping him doesn't seem to be.

49. Going forward I would like to see the service be empathic and provide adequate financial support for those they have infected.

50. I hope the EIBSS will change, and move to assist others and alleviate the distress this organisation has caused my family should others find them in a similar situation.

Statement of Truth

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

Signed GRO-C

Dated 11th September 2019.