

Witness Name: Victoria Burley

Statement No.: WITN2005001

Exhibits: WITN2005002-WITN2005010

Dated: 16 July 2020

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF VICTORIA BURLEY

Section 1. Introduction

1. I, Victoria Burley, will say as follows.
2. I live in GRO-C Buckinghamshire. My full address is known to the Inquiry. My date of birth is GRO-C 1956.
3. I have two children, a son and a daughter. My daughter lives close by and my son still lives at home with me.

Section 2. How Infected

4. On 5 August 1992, aged 36, I fell down the stairs at my aunt's house in GRO-C and sustained multiple fractures to my femur. I was taken to the Treliske Hospital in Truro by ambulance. I was taken straight to the trauma department

and my leg was put in traction overnight. I was in a great deal of pain. An operation was performed the next day to repair the fractures with a Richard's plate and screws. A letter dated 10 August 1992 confirming the operation is at Exhibit WITN2005002, the discharge summary dated 14 August 1992 is at Exhibit WITN2005003, and a follow up letter to Wycombe General dated 17 August 1992 is at Exhibit WITN2005004.

5. Just before the operation a nurse asked if I wanted a blood test for HIV and HCV. It was 1992 and they had started screening blood so I said yes, I would. When the nurse came back the same day she said I was HIV and HCV negative.
6. After the surgery, I was told I had been given a blood transfusion, though I cannot recall who told me. There is no record of the blood transfusion on either the letters of 10 and 17 August 1992 or the discharge summary. I have subsequently tried to obtain my medical records from Treliske Hospital and have been informed by the Royal Cornwall Hospital that my records have been destroyed in accordance with their Retention and Destruction Policy.
7. I was given no information or advice beforehand about the risk of being exposed to infection. I understand now that this sort of fracture to the femur, and the operation to insert a Richard's plate and screws, can cause a lot of bleeding and transfusions in theatre are common. However, I was not told in advance that I might receive a blood transfusion. I recall signing a consent form for the operation, but that was it.
8. As a result of being given contaminated blood I was infected with Hepatitis C (HCV).
9. I found out I had been infected with HCV much later, in 2007. I went to the GP at the time because I wasn't feeling well: I had very itchy skin and the GP ordered blood tests. The GP called me back in for the results. I thought I had cancer and was really wound up, so when he said I had HCV I said, 'oh thank

God for that, I thought I had cancer'. The GP told me that I would need a liver biopsy.

10. I do not feel I was given adequate information to help me understand and manage the infection. I have also felt that I have had to push for information. I believe clear and detailed information about the virus should have been given to me from the point of diagnosis.
11. I felt I was given very little information about the risks of others being infected as a result of my infection. I may have been warned about sharing toothbrushes, but little else. I do recall that the consultant I was referred to told me that my children should be tested.
12. My medical records contain a letter from the first appointment with the gastroenterologist dated 21 November 2007 confirming I had been suffering from itching for a year. The letter mentions my alcohol intake and previous intravenous drug use, but says, 'she says that she did not share needles and only used clean needles'. 'She also had hepatitis when she was 14 [...] I suspect this was probably either hepatitis A or EBV. She also had a blood transfusion fifteen years ago in Cornwall when she broke her femur'. The letter concludes by stating 'I discussed Mrs Burley with Dr Gorard, we feel that she has got chronic liver disease causing her low platelets and low albumin. This is likely secondary to her alcohol intake but she is at risk of viral hepatitis from her previous intravenous drug use.' The letters goes on to say that tests for Hepatitis B and C were repeated. Exhibit WITN2005005.
13. There is then a further letter dated 11 December 2007, also from gastroenterology, which says:

'Her results did show a positive hepatitis C antibody so I have explained to her that she has had hepatitis C at some point possibly relate to her previous drug abuse and she did have a blood transfusion in the past. However I have told her we need to do the hepatitis C RNA to make sure the virus is still there.

Whatever the case alcohol will be aggravating the situation and she has tried hard to cut down and is cutting down even more. She has an ultrasound this afternoon and we will see her in six weeks with the result and if it is positive proceed to liver biopsy.' Exhibit WITN2005006.

14. The liver biopsy was carried out in 2008 and showed cirrhosis of the liver. A letter dated 4 March 2008 describes the biopsy result as follows, 'Her liver biopsy showed appearances of hep C induced established cirrhosis with moderate inflammatory activity. No features of exacerbation due to alcohol or autoimmune hepatitis was seen.' Exhibit WITN2005007.
15. There is further information, or speculation, about how I may have acquired HCV in later correspondence also. A letter dated 7 March 2014 from King's College Hospital say, 'I note from your detailed letter she was diagnosed with hepatitis C infection in 2007. She tells me it is not very clear regarding the route of disease acquisition. However, on your letter I do note that she had used intravenous recreational drugs in the past during her teens. On further clarification, she tells me this only happened on a couple of occasions and she did not share needles. She also reports to have had a blood transfusion in the early 90s in UK following a fracture of her leg. She has had a tattoo done 10 years ago in the UK and reports that this is not the likely source of her having acquired hepatitis C. [...] She also has had a history of excess alcohol intake drinking up to 1-2 bottles of wine a day but has completely been abstinent over the last one year.' Exhibit WITN2005008.
16. I feel there has always been some suggestion that alcohol has worsened my condition and this letter, and previous letters cited above, demonstrate this. This letter from 2014 says I have not drunk for one year, when in fact it was approximately four years (which is now over 10 years). I would like my medical notes amended to correct these inaccuracies.
17. My medical records also contain suggestions like in this example from 2014, that I was an intravenous drug user. Again, this is not correct: I was studying

to be a nurse and I wanted to know how to take a blood sample from myself, so I did so. I have never used drugs intravenously and would like my notes corrected in this respect.

18. My GP records also contain a letter from 2013 from the Health Protection Agency, saying, 'We have received a laboratory report informing us that the above named patient has recently been tested positive for Hepatitis C. We would appreciate it if you could assist us in carrying out our recommendations: explore risk factors for exposure [...] We would be grateful if you could inform us if this patient's history indicates where the infection was probably acquired.' This is the first time I have seen this letter. I was not aware of this correspondence, or that my personal data was being shared in this way. The letter recommends testing for and vaccinating against Hepatitis B, but I was never offered this. I find it very upsetting that my personal information has been shared without my consent, and recommendations (such as a HBV vaccine) not followed up. It adds insult to injury. Exhibit WITN2005009.

Section 3. Other Infections

19. I do not believe I have received any infection or infections other than HCV as a result of being given infected blood.

Section 4. Consent

20. I do not believe I have been treated or tested without my knowledge, consent, or for the purposes of research.

Section 5. Impact

21. The mental impact of being infected with HCV before I was diagnosed were as follows. I had been on and off Prozac for many years. I used to get really

angry with my kids and shout at them a lot, which just wasn't me. After my divorce I went to a psychiatrist for [GRO-C] therapy [GRO-C]. The therapist told me I was doing a good job and to stop worrying about them. In retrospect, I think I was feeling depression and anger as a result of the HCV. I was also very forgetful and suffering with fatigue.

22. My GP records note the fatigue I suffered with. In the 1990s the notes mention 'low mood', 'always tired. Crying all the time. Depression', and there is also mention of flu symptoms. There is an entry in January 2002 recording, 'T.A.T.T.' (tired all the time). This is alongside elevated levels for Gamma GT (184 U/L (therapeutic range 7-64 U/L); AST 70 U/L (therapeutic range 10-42 U/L)). The same levels were also raised in February 2001. In the handwritten GP notes from February 2002 it says, 'LFT's ↑ Discussed alcohol'. I do not know whether things should have been checked out more thoroughly as a result of these findings, but am concerned that my alcohol intake was seen as the primary concern and for this reason no further investigations were carried out. (Medical notes available on request).
23. After diagnosis the mental impact of the infection worsened and I felt broken hearted and disbelieving. I feel I am not coping. I feel my whole life has been shot to pieces. I feel sorry for myself and am very bitter: how many people are wandering around with this disease? I feel it just goes on and on and gets worse and worse.
24. Physically, before diagnosis, I felt extreme itchiness. Since the diagnosis I have suffered with the following physical symptoms and complications of HCV: decompensated cirrhosis, chronic liver disease, diuretic-controlled ascites, recurrent hepatic encephalopathy, oesophageal varices, hepatomegaly, mild splenomegaly, portal hypertension gastropathy, portosystemic shunts (not amenable to radiological embolization) and hiatus hernia.
25. The hepatic encephalopathy has been the worst complication of HCV for me. This affects the way I walk and my daughter tells me that sometimes I look

drunk because the encephalopathy causes me to stumble and sway when walking: I found it difficult to stand up straight. I have subsequently been prescribed Rifaximin for this. I find this the most difficult part of the condition to deal with: I stop in the middle of a sentence and cannot recall what I was talking about. I have tried to discuss this condition with my GP but am constantly told that they do not have enough time to discuss it with me.

26. I have also now been refused a liver transplant as a result of the tongue cancer (see below). When I was diagnosed with tongue cancer the doctors told me that they would not be able to perform any surgery, including a liver transplant, because the type of cancer I had was rare and any subsequent surgery may compromise my immune system and cause the cancer to return. A letter from the liver team at Kings College Hospital dated 6 April 2018 confirms this, 'we have discussed that given she has had cancer therefore she would no longer be a candidate for a liver transplant in the future as she would require immunosuppressant post transplant. Immunosuppressants would be contraindicated with her past medical history of cancer.' Exhibit WITN2005010.
27. I have suffered with tongue cancer in 2017/2018 (malignant neoplasm of tongue) for which I was treated in ITU for nine weeks, intubated and given platelet transfusions. I also have Vitamin D deficiency. I do not know whether either are related to HCV or its treatment.
28. I began 48 weeks of Pegylated Interferon and Ribavirin treatment for HCV in 2008. The treatment was stopped because it was not working and I was told I was a non responder. I didn't find this first round of treatment too bad.
29. I then received further HCV treatment in 2013, this time with Interferon, Ribavirin, and Telaprevir. This time round the treatment almost killed me: I suffered with total fatigue, so much so that on one occasion I fell asleep whilst standing up chopping potatoes. I suffered from nausea and dizziness, I could not see straight and I felt wobbly on waking. I was unable to walk up the stairs and had to crawl up, and come down on my bottom. I also suffered from

'hypos' but have been tested for diabetes numerous times. I had sweats and shakes and these have continued post treatment. This round of treatment was stopped due to 'virological breakthrough' and thrombocytopenia. I felt very disappointed that treatment had to be stopped, and was told there was no other treatment option available at the time.

30. A year after this treatment, in 2014, I was referred to Kings for possible clinical trials and assessment for liver transplant (though this is now no longer an option due to the tongue cancer, see above).
31. I received a third round of treatment with Sofosbuvir, Ledipasvir and Ribavirin in 2015 for 12 weeks, which finally succeeded in clearing the virus. During this round of treatment I lost a lot of my teeth and suffered with joint pain, but it was still better than the second round of treatment.
32. I now receive regular three monthly follow-up appointments at the hepatitis clinic at Kings College London which includes liver ultrasound scans as I have been told I am at risk of hepatoma. Despite treatment concluding and being told I have cleared the virus I continue to suffer with fatigue and feeling down.
33. I do not think I faced any difficulties or obstacles in accessing treatment. I think I was one of the first people to get Sofosbuvir. My medical records confirm I was chosen as eligible for access to anti viral agents via the NHSE Early Access Scheme, which allows a specific number of UK patients who fall within strict criteria to obtain access to treatment which have yet to be licensed and/or NICE approved.
34. I do not think there were treatments which ought to have been made available to me but were not, save that I would have liked to have been referred to a mental health specialist as that would no doubt have helped me greatly.
35. I do not believe my infected status has impacted on my treatment, whether medical or dental.

36. The impact of the HCV infection has caused me to become very bitter. I have continued to feel depressed and still take Prozac. My family has been greatly affected: I expect far too much from them, at a time when they are starting their own lives. I don't want them to be burdened with looking after me. I want them to just say, 'call me if you need me, I am off to lead my own life'.
37. Socially, I have lost a few friends, as some have pulled away. I no longer go out and stay in my house. I have a few very good friends and they make an effort to get me out of the house now and again. I am now an introvert, though I didn't used to be: I now prefer not to socialise.
38. The virus may have impacted on my education and career. After the fractured femur and my divorce, I returned to college age 40 to get my Associated Accounting Technician qualification. I did manage to get the qualification, though it took me three years and I found it very difficult: I thought I was a bit stupid. I now wonder whether this may have instead been the effects of the virus as I had never felt like that about myself before.
39. My career has been badly affected. When I was awaiting the results of the blood tests which would tell me I had HCV, my employer asked for a doctor's note. I gave them a note from the doctor which said 'blood disorder'. At the time I was within the three month probation period. Within a couple of weeks I was told I had not passed probation due to 'non-performance', however I suspect it may have been because of the sick note revealing the blood disorder.
40. When I worked in the United States I was a nurse. When I moved to the UK there were no nursing jobs so I started working for Ladbroke's and worked my way up to management level. I then stopped work to have my children and was a stay at home mum for a few years, eventually returning to work at weekends. I then took an accountancy course and became self employed. As a result of the HCV virus and the time off work caused by illness from the virus I lost clients and have now had to retire. I no longer feel able to work, either mentally or physically.

41. The impact of my infection on my children has caused me to depend on them. They have not been able to lead independent lives, and branch out as I would have liked them to. My daughter has recently had a baby but spends as much time as she can helping me. This virus has ruined everything. My son experienced difficulties in getting tested for HCV, as the consultant advised. He has also not left home, and I believe this is partly because he worries about my health too much.

Section 6. Treatment/Care/Support

42. Counselling or psychological support has never been made available to me in consequence of being infected. I feel very strongly about this and wish that I could have received therapy of some sort as I would certainly have taken up any offer of it.
43. I asked my GP about what support might be available and was told that the only option I had was Healthy Minds, to which I had to refer myself. I have done so, and have just started to receive support, which is all online, but I would prefer to sit and talk to someone face to face. I have asked my GP for counselling, and have even asked my consultant: three different times they have said they would get someone in for me at Kings, but I have received nothing.

Section 7. Financial Assistance

44. I have not been offered any financial assistance from any of the Trusts or Funds set up to distribute payments. I found out about the existence of financial support through Kings College Hospital. The Skipton Fund refused my application for financial assistance because my blood transfusion took place in 1992 when, they say, all blood was screened for the Hepatitis C virus.

45. I understand that there are many people in the same situation, who were infected post 1991, yet have received no financial assistance. The more I find out about this, the more people I have come across. I feel the cut-off date of 1991 is arbitrary and does not reflect that people have continued to become infected through contaminated blood past this point, with no financial help at all. I simply cannot believe that the screening that was introduced could possibly have eliminated the Hepatitis C virus from all blood and blood products in circulation at the time.
46. I have just applied to EIBSS and am awaiting their response.
47. As noted above, I have been unable to obtain copies of my medical records from Treliske Hospital, Truro, and this gives me great cause for concern.

Section 8. Other Issues

48. I hope the Inquiry will consider, in particular, the mental health impacts caused by the infections from contaminated blood. In my experience, hepatic encephalopathy is particularly difficult to live with.

Statement of Truth

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

Signed GRO-C

Dated 16/07/2020