

Witness Name: Madeleine Blanchard

Statement No.: WITN0214001

Dated: 20 February 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF MADELEINE BLANCHARD

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 29 January 2019.

I, Madeleine Blanchard, will say as follows: -

Section 1. Introduction

1. My name is name is Madeleine Blanchard. My date of birth is GRO-C1943 and my address is known to the Inquiry. I am retired, having previously worked in accounts and I am divorced. I had four children and now have ten grandchildren and two great grandchildren. I intend to speak about my infection with Hepatitis C. In particular, the nature of if my illness, how the illness affected me, the treatment received and the impact it had on my family and our lives together.
2. I confirm that I am not legally represented and that I am not claiming anonymity.

Section 2. How Infected

3. I was infected by a blood transfusion in 1982. I have never had any tattoos or drug use and the source of my infection has been traced back to the blood I received. I underwent a hysterectomy and was advised before the operation that I would need a blood transfusion beforehand, as I was unlikely to recover well from the operation without it. I went to Edward VII Hospital in Windsor a week before my hysterectomy to receive my transfusion, which was, I believe, three units of blood. I was not advised of any risks from the transfusion at the time, though I remember seeing news stories about AIDS shortly afterward and worrying. I also remember the nurse, who was excellent, stating one of the blood bags was out of date so it could not be used and would have to be returned to Heatherwood Hospital in Ascot, which is where it had been sourced from and replaced with another bag. I received the blood and returned the following week for my hysterectomy in September 1982, which went well and I went home after eight days.
4. After the operation and transfusion I felt lethargic, but otherwise well. I did visit my GP a few times as everyone says after a hysterectomy you are meant to feel great, but I just felt tired. No one really does anything when you are just tired and I eventually put it down to my age, as I was 40 by this time.
5. After the required wait period of five years, I donated blood. I gave blood two or three times (with a gap of about 9 months to a year each time) and it was only on the last time that I was informed there was something not very satisfactory about my blood. This was in 1992. I was invited to attend the main transfusion clinic just off Regent Street and went along the following week. Everyone there was very good and it did not faze me having my blood taken, I just didn't think things would turn out how they did, though I did know something was not right. The nurses asked questions, but not intrusive ones, just asking whether I felt well, which I did. I sat in a waiting area with tea and coffee and magazines for about an

hour before I was called into the doctor's office. There was a doctor and a few nurses. I was asked first about the number of partners I had previously had. I explained I had only one who was my husband as he had been in the army for three years and on his return we got married when I was only 19. Next, they asked about drug use and whether I had ever shared needles. I explained that I had never had drugs, only aspirin when the kids gave me a headache and that I had never been bothered with drugs.

6. I was told that day that I had Hepatitis C. I had no idea what it was and to be fair I don't think they had any idea what it was at that time. I was told it affected the liver and I was warned not to allow other people to touch my blood, but not much more than this. I had heard of Hepatitis A and B and asked if it was the same and I was told it was similar.
7. The clinic could not make an appointment with a specialist for me. They advised me they would write to me and that I needed to show my GP the letter. I did this and my GP threw the letter back at me saying he had never heard of Hepatitis C and saying soon we would have D, E, F, G and H! And I think he was right. They did not know what to expect and did not warn me about cancer or cirrhosis.
8. In the early days, a lot of what I learned about Hepatitis C, I learned from the British Liver Trust. They were brilliant and like my best friend because they had the answers to all the questions I had. They did a newsletter, which got more infrequent with time, but was very good. They were always available to provide support. They had an event at the Royal free which I went to where they showed us the BBC Panorama and said they could provide a copy to us if we wanted. I bought Christmas cards and such from them, as I wanted to support them.
9. I also remember that in the news every day you would hear about Hepatitis C and that blood had been bought over from America but in those days no one would believe it. I think the news said that Scotland

had realised before England and that they had kept a lot of blood but didn't really know what Hepatitis C was either.

10. I was treated in London at the Middlesex Hospital from 1992 to 2005. I was monitored with ultrasound scans, biopsies and blood tests. I also went to a clinic on the Tottenham Court Road and sometimes I was the only one there in the early days, but eventually I would see hundreds at that clinic. I was always treated very well and looked after.

11. In 2005, I moved to GRO-C where I was under the care of Dr Alexander and Tracey Woodall at Addenbrooke's Hospital. They were always very good, particularly Tracey who was always available on the telephone if I needed to speak to her and even if it went to her pager she would call me back. It was there that I had my first MRI and I had further blood tests and biopsies and ultrasounds to monitor my liver. When I moved again, Tracey was good enough to help transfer me and she ensured I got an urgent appointment to follow up some recent test results that I will explain below.

12. In 2017, I moved to Broadgreen Hospital in Liverpool on the advice of Tracey Woodall at Addenbrooke's Hospital. There, I am under the care of Dr Cross. I got an appointment within a couple of weeks, thanks to Tracey's involvement. The results of my latest tests had shown changes that were a cause for concern. Between May and August of 2017 I had a number of tests including a CT, MRI, ultrasounds, blood tests and such.

13. In October 2017, I attended an appointment with Dr Cross, an oncologist, a specialist nurse and another trainee. Dr Cross asked if I knew why I had been called there and I explained I had a funny feeling about it. Dr Cross explained they had found a small tumour on my liver. He commented that I didn't look surprised at the news. I was upset when I heard it, but I had been living with Hepatitis C and I think I half expected it to happen.

14. Dr Cross explained the next steps were to organise another scan to see if they could attempt a treatment with lasers. The scan was only two weeks later, but by that time a blood clot had formed within the tumour making the laser treatment impossible.
15. In April 2018, I had TACE treatment, which is Transarterial Chemoembolization. I understood that this would fire some sort of treatment into the tumour and that it was important none of the tumour escaped and went where it was not supposed to go. It went well, but took approximately three hours and I was awake during the procedure. This treatment was not intended to cure the liver tumour, but to freeze it and stop it growing. It seems this has worked.
16. However, one scan revealed two nodules on my right lung. Fortunately, these have not grown. However, a later scan showed two more, larger nodules were found on my left lung and I am waiting to see what will happen with these.
17. From August 2018, I have been on SORafenib 200mg and I take two tablets in the evening. This is a chemotherapy tablet and it does make me very ill, especially with diarrhoea, but also with sickness and vomiting. However, the hospital staff are very good and treat me well. I have also been admitted a few times for mineral depletion as it causes a loss of calcium, magnesium and potassium, particularly magnesium. I now have a magnesium powder to make a drink twice a day to prevent me being admitted again and so far it seems to be working well.
18. I still attend regular monitoring appointments. I am always offered transport, but my daughter in law can usually move things around at work to take me. It is a lot of waiting time as you need to be there an hour early to have blood taken so that by the time you see the doctor they have the results and then you wait around again for your medication, but I am always treated well and the nurses all smile and say hello.

19. Two things stick in my mind. Firstly, about six years before my hysterectomy I decided to get sterilised as I had already had my four children and did not want anymore. The doctors were hesitant but one suggested doing a full hysterectomy because my womb was enlarged and would possibly cause me problems later. The other doctor decided against doing this unnecessarily. Part of me wonders whether I would have been infected with Hepatitis C if I had undergone a hysterectomy then. The other worry I have is that my infection was not picked up the first two times I donated blood. I do worry that I might have passed the infection on to someone else.

Section 3. Other Infections

20. To my knowledge I was only infected with Hepatitis C.

21. Some forms mentioned vCJD but I just specified I had not been diagnosed with it.

Section 4. Consent

22. To my knowledge, I was always treated with my full knowledge and consent.

23. I did take part in trials, especially as when I was diagnosed there was no treatment available. I always did these with full understanding and consent; everything was explained to me and provided on paper, too. I was happy to partake in the research as I thought it might help me in the end. I was told one of the drugs I trailed, Lamivudine, was not effective for treating Hepatitis C, but turned out to be good at treating Hepatitis B so at least it helped someone. I was a part of these trials before the interferon and ribavirin treatments became available.

24. I believe I have always been treated well and I couldn't have been treated fairer.

Section 5. Impact

25. Physically, I have mostly felt well and have not suffered too much so I cannot really complain. I do have to take 9 tablets a day and find this can be restrictive. I have suffered with sickness and diarrhoea. I have explained about the liver tumour already and the impact that has had on me physically, as well as the nodules on my lungs.
26. Mentally, I have been very strong, more often than not telling others, particularly my mum, not to worry because if I am not worried why should they worry. However, you do have your moments when you stop and think, but mostly you have to get on with it. I was a working mum and my eldest was eighteen and my youngest only twelve when I was diagnosed so I had plenty to keep me occupied. I am also lucky as my family have always been good to me. It has taken a lot of years to get to this point and has been a lot of worry on and off, but I always get up and fight another day because I am not the sort of person to just lay down. It has been a bit of a journey, but I tough it out. My son calls me Boadicea!
27. I have not suffered any further medical complaints as a result of the Hepatitis C infection. I did have a heart attack and had a stent placed, but these, I believe, were not related to my Hepatitis C infection.
28. It was only ten years after I was diagnosed that treatment became available. Before this time, I was advised that there was no treatment they could offer me and I took part in trials. In 2002, Ribovirin and Interferon became available. I had to sign paperwork to take this drug, as I was one of the first to try this treatment. I initially had a 32-week course of treatment.
29. The impact of the treatment was awful – it caused bad flu like symptoms, I lost a lot of weight and my hair began to fall out. My employer was very understanding at this time. After I completed the treatment it appeared I

was clear of the virus but at a check up three months later, I was told the virus had returned. I could not face another round of treatment immediately as it had made me feel so awful, but I later went on a 48-week course of treatment and this did clear my Hepatitis C, though the awful side effects returned during the treatment.

30. In addition to these side effects, I also developed Lichen Planus, which caused my hands, feet and mouth to blister. I was concerned whether I could get foot and mouth disease as that was around at that time, but my doctor diagnosed it from an old medical book. The blisters in my mouth made it very difficult to eat and hurt a lot. During this time I basically lived on Ambrosia rice because even porridge was too rough to eat and would cause me pain. I was treated for this at the John Radcliffe hospital as it was nearby. This does come back every now and then, but I have an ointment and know how to manage it.

31. I also suffered from terrible nosebleeds during the treatment. These were a regular occurrence. These would cause me to panic because I knew others should not touch my blood but these nosebleeds would just pour. We were provided with a 24-hour helpline for support, which was very good and I did have to call one night, as the nosebleed was not going to stop on its own. I had to have my nose cauterised in the end. I had to reduce my dose and in the end my treatment was dropped from eight tablets a day to four.

32. I did not have any difficulty in accessing treatment or medication. I am fortunate as my Hepatitis C did not affect other healthcare I was provided, such as dentistry. I have always been treated well. I do not think there were treatments available that I was not offered.

33. There was stigma surrounding Hepatitis C as it was assumed to be a drug related thing. Nobody outside of my family really knew at the time. There were some people who did not know and would make comments that would upset me, but I would not speak up about my infected status as I did

not want to draw attention to it. There was very much a stigma associated with it in the early days particularly.

34. My infection occurred after my education so the Hepatitis C did not have an impact on my education.

35. However, my Hepatitis C did affect my career. When I was diagnosed and going through treatment I worked for the ICI and they were very helpful and supportive. They always paid me my full hours and when I was unable to make it in for work as I was having a rough day they accepted this and paid me anyway. However, when family circumstances caused us to move, I could not manage the commute as it would exhaust me too much. I struggled to get another office job because the Hepatitis C would not allow me to pass the medical insurance requirements. When the medical insurance turned me down, so would the job. I eventually found a job at the MOD.

36. Financially, I was not impacted too greatly as I always lived in good areas and had support. However, after I left my husband I could not get insurance for a mortgage and so I moved in with my daughter and her four children. My daughter contacted the council and fortunately I was rehoused quickly because of the combination of young children and my needles from my treatment. I was rehoused in sheltered housing so this worked out well for me.

37. The infection did impact my family. My marriage broke down, not materially because of the infection, but it did play a part as my husband was an attention seeker and my illness distracted from that. I remember in 1992 just after I was diagnosed we attended my eldest son's wedding. I had only been diagnosed the week before. I told my mum that evening and told my husband, but did not want anyone else to know at that time. However, at the wedding my husband told my brothers and eventually it got round to the whole family. I was gutted as I didn't want it to detract from the wedding and wasn't ready to tell everyone. Family members

approached my mum saying they had heard it was like AIDS and she had to explain it wasn't the same. My husband's actions did somewhat force my hand to tell people sooner than I would have liked. My husband never attended appointments with me, except for one time where he said he would not have been able to give me my injection for treatment. Usually, I went with my mother or my daughter, as I felt far more supported.

38. My daughter more or less ran the house and my infection did put a bit more onto her, really, though I did manage mostly. However, she liked cooking and so she would get home from school and have dinner almost ready by the time I got home and she loved hoovering and being in charge whilst I was in hospital.

39. I think the person it impacted the most was my mother. My mother would attend appointments with me when they were in London and we would use it as a day out to mooch around the shops and have a coffee and I missed that when I moved. However, I think my mum worried the most, especially in the early days.

Section 6. Treatment/Care/Support

40. I do not believe I have faced any obstacles to obtaining treatment.

41. I do not believe psychological support or counselling was ever offered to me, but I do not feel I have needed it.

Section 7. Financial Assistance

42. I heard about the Skipton fund by coincidence as my son's neighbour heard about it on the radio and printed out details from the internet for me. I later saw it mentioned on the news, but no one officially told me about it.

43. I applied and found the process easy enough. I had to call Skipton and get a form to take to my doctor to get it signed. The doctor did not know

anything about the compensation and was surprised to see the form. He had only seen one form before earlier in the week, but no one had informed them about the compensation process. I received the first stage payment for Hepatitis C.

44. Later, I received the second stage payment for Hepatitis C, but only found out I was eligible by coincidence. Tracey at Addenbrooke's asked me if I had applied for it and got my money and I had not. She said I could because of cirrhosis and asked if the doctors in London had told me I had cirrhosis and I don't believe they had. This was the first time I was given any indication that I had liver damage.
45. Skipton changed over to EIBSS and I receive £1500 a month from them and the changeover went okay. They have always been very helpful and the money given was reasonable, especially as I had not been expecting it. They wrote to me recently to advise me I may be eligible for top up payments as well.
46. I do not remember signing any waiver or that there were any preconditions to receiving the money from the fund.
47. However, the compensation payments did affect my benefits even though they should not. The government pension people have been the bane of my life. They stopped all my benefits, my rent, council tax and such despite having all the paperwork. They rang me in July on my birthday to ask about my savings and I was honest and included the compensation thinking I was entitled to it all. I was never advised to keep the compensation in a separate account to avoid any confusion. They only advised me they had stopped everything after three weeks by letter.
48. I had to call them to sort things and send all my private information and original documentation to them so I sent it via insured post. However, they sent it back just normal post. It was not a good experience to have to share everything with them. It was only in January the following year that

they called very early in the morning to say they had made a terrible mistake, but they did not offer an apology at all. It took until May to finally get reimbursed all the money.

49. During this time I was living on the compensation and, had I not had that money, I would probably have been evicted. To ensure more security in the future and avoid the same mistake happening again, I used the money to put a lump sum down on my house. This experience caused a lot of stress and strain, as there is no arguing with them. I was considering going to my MP as a last resort. The Skipton Trust (and the Caxton Trust who the Skipton Trust put me in contact with) were supportive during this time, but only offered financial assistance, which I did not really need.

Statement of Truth

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

Signed

GRO-C

Dated

20-02-2018