

Witness Name: Elaine Huxley

Statement No: WITN2354001

Dated: 11 December 2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF MS ELAINE HUXLEY

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 11 December 2018. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

I, Elaine Huxley, will say as follows:-

1. **Introduction**

1. My name is Elaine Huxley. My date of birth and address are known to the Inquiry. I am divorced with three grown-up children, four grown-up grandchildren and I am a retired NHS support worker. I still work part-time as a support worker caring for the elderly.

2. As a result of contaminated blood I was infected with hepatitis C.

2. **How Infected**

1. When I was 29 years old in 1976 I was admitted to hospital to undergo a total abdominal hysterectomy. The hospital was then called Bridgend General Hospital and is now the Princess of Wales Hospital at Coity Rd, Bridgend CF31 1RQ. I recall my doctor's name was Dr Obaid.
2. After my operation I remember clearly that I had woken up at around 5 am and I was bleeding heavily. I and the other ladies on the ward, who were very concerned, pressed our buzzers to attempt to get the nurses' attention.
3. I was waiting for a least an hour before a doctor came in to see me. By then I had haemorrhaged and lost a significant amount of blood. It was clear that I was bleeding internally. All of my bedding and clothing were soaked in blood. When the doctor came in I remember agreeing to go back to surgery. However, instead of performing surgery they performed a blood transfusion.
4. First of all I understand they gave me five units of blood. I remember the blood bag hanging up next to me. Then I understand they gave me a further three units of blood as the initial five was not sufficient.
5. Following the transfusion I was really unwell and I had to stay in hospital for around six weeks. I was extremely upset about this as I had been told by the doctor that the hysterectomy was a routine procedure requiring around 10 days stay in hospital. This was a very difficult time because I had three children under six years old at that time who needed to be looked after in my absence.

6. I believe that the hospital did not follow the correct procedure following my operation as nobody carried out hourly observations or monitored my blood pressure. I believe that the failure to follow correct procedure led to me needing the blood transfusion. I believe it unlikely that I would have been so unwell had any nurses or doctors responded to my calling for help in a timely manner.
7. After I had recovered from my hysterectomy surgery I wanted to give something back to my community so I became a blood donor. I had initially been donating blood at mobile units; firstly at Ogmere Vale and secondly at Bridgend. I was a blood donor for around six years until I received an unexpected letter from the National Blood Service in 1992. The letter told me to contact my GP to discuss my blood donation.
8. My GP was at surgery at
 I made an appointment to see my GP. I can't remember the name of my GP at that time. I was told by the GP that my bloods had been tested after I had donated it and the test had showed a positive result for hepatitis C.
9. I was shocked and surprised to receive this information. I had understood hepatitis C to be an illness contracted by people who were promiscuous or users of drugs and I was neither. My GP told me that I would need to attend a clinic at the hospital every six months to check on the affect of hepatitis C on my health and in particular on my liver.
10. When I left the GP that day I didn't know what to think. I do not feel like I was provided with adequate support or information at all. I remember being given some advice to pass on to my family to do with not sharing toothbrushes or razors but I do not feel that this advice was adequate. I was extremely worried about the risk of passing on the infection. I thought it would be extremely serious and would affect me for the rest of my life.

11. I feel like there should have been someone other than my GP to support me when I was told I was infected. It seemed like my GP did not know much about the condition and referred me to the clinic which meant that a significant period of time went by when I knew nothing about the condition and was extremely worried about what it would mean for me and my family. For example, my husband was told to get tested. We had been divorced since I was 40. I do not feel like I was provided with adequate support or information at all.

12. Even at the hospital clinic, all that the doctor would do is take a sample of my blood and ask how I was. I never felt that I was in control. I didn't know what was going on with my own body.

13. I never understood how serious hepatitis C can be. I wasn't informed about the damage it can do to your liver. It was only much later on, through the Public Inquiry that I found out that the infection can be fatal.

3. **Other infections**

1. There have been some lasting impacts on my body and in particular my immune system. I am not sure if these are attributable to the hepatitis C or the hepatitis C treatment I had in 2007. Either way I do not believe they would have occurred had I not been infected by contaminated blood.

2. I have a condition called actinic purpura which causes sore itchy patches on my arms and legs. I am told by my doctor that I will have this for the rest of my life and that it affects patients with poor or compromised immune systems. Because of this condition, I have an extremely high risk of skin cancer and I cannot spend any time outside

in the sun. This is extremely upsetting and difficult for me because I love the outdoors and used to be a sun worshipper.

3. Due to my compromised immune system I also contracted MRSA in 2007.

4. **Consent**

1. I was not advised prior to having my blood transfusion that there was any risk of infection whatsoever associated with blood or blood products.

2. I do not believe that I was ever tested behind my back or without my knowledge and consent but I wouldn't know if I had been. The records of my entire time in Bridgend General Hospital in 1976 have been removed or destroyed and are missing.

5. **Impact**

1. The hepatitis C didn't really make me feel unwell until I underwent treatment for it in 2007. It did, however, affect me in other ways. It was really stressful when I had to tell my family that I had been infected with hepatitis C as I had no idea how to protect them or what this meant for them. As time went by, there were difficult situations where I had to tell people that I have been infected and had to suffer the judgements arising from the stigma surrounding the condition at the time.

2. The worst way that my condition affected me was at work. As an NHS support worker, we used to do CPR training which involved pretending to give mouth to mouth resuscitation to a dummy. Due to the risk of infection, I was not able to participate in this training. We also did mask training and I was similarly unable to participate in this. I would feel ashamed to tell my supervisors at work the reason why I could not

participate. I felt that if I told them I would be singled out in front of everyone and I would not have the opportunity to explain the way that I contracted hepatitis C. I couldn't tell everybody who I met that I had contracted the infection through NHS blood. The situation used to make me feel really upset and defensive.

3. Another way that the condition has affected me at work is that during my treatment in 2007 I could not treat certain patients at work due to the high risk of infection at a time when my immune system was compromised by the treatment.
4. I was constantly worried about infecting my family. However, times were different back then. It was more a case of just getting on with it and hoping that the condition never became serious. If I had known then what I know now about how serious the condition can be I would have been even more concerned.
5. Finally, there are some unexpected financial issues associated with having a hepatitis C diagnosis. It is impossible to obtain travel insurance at a reasonable cost.
6. **Treatment/Care Support**
 1. In 2006 I remember watching a television programme; it may have been The News, when I saw that there was a potential cure for hepatitis C coming onto the market. My specialist doctor at the hepatitis clinic at Bridgend Hospital was called Doctor Yap. Initially when I mentioned the treatment I had seen on the news to Dr Yap he was unwilling to prescribe it saying that it was really expensive and because it was in the early trial stages it was only being offered to some patients.

2. Around six months to a year later I asked Dr Yap at the clinic again if I could have that treatment and this time I was told that I could have it if I wanted to.
3. I started my treatment for hepatitis C in 2007. It was a seven week course of Pegylated Interferon Alpha (180mgs) and Ribavirin (800mgs). The treatment is a six month course of injections. I do not feel that I should have been sent home to administer treatment to myself. I felt frightened, unsure and unsupported.
4. I was not told about the side-effects of the treatment or their severity. This period of treatment was the most unwell I had ever felt in my life. I was extremely tired and I was plagued with aches and pains and felt miserable.
5. I feel that I should have been better advised about the treatment. Firstly, if I hadn't seen the treatment on the news I would never have known about. I do not believe Dr Yap would have told me. Secondly I don't believe patients should be sent away to inject themselves without clinical assistance. Thirdly I should have been properly warned about the side effects.
6. The treatment was successful and I was free of hepatitis C in September 2009.
7. I have experienced some recent health problems which I believe are related to the treatment I had and my compromised immune system. I travelled to London to attend the opening hearings of the Public Inquiry in October 2018. When I came back from London I felt terribly unwell and had to see my GP. I had a blood test which showed that my potassium level was too high. I was extremely concerned by this and I have asked for a liver biopsy.

8. Many of the people I spoke to at the hearings in London told me to ask for a liver biopsy if I had never had one. In fact my medical records refer to a biopsy in 2003 but I do not remember this taking place. I do not recall ever having a biopsy. 9 out of 10 people I met who had been infected had liver biopsies. I feel like I am having to fight for treatment still after all these years.

7. **Financial Assistance**

1. In terms of financial support, I remember applying to a support scheme through the hospital in Cardiff. I think it was the Skipton Fund although it may have had a different name back then. I can't remember the application process but I think it was straightforward. I received around £300 per month and I also got a one off payment of around £20,000 from the Skipton Fund.

2. I do remember that around the time that I was applying for financial help which I believe was around 1999 Theresa May rang me up. I understand that she was an MP at the time and Shadow Spokesman for Schools, Disabled People and Women in 1998–1999. She told me not to worry and that she would make sure that there will be financial help for me.

3. I am glad that I was able to get some financial support, I am aware having spoken to other victims; the victims in both Scotland and Ireland have received more compensation than victims in England and Wales. I can't understand why this is the case or how it could possibly be fair.

4. After my treatment concluded successfully in 2007 I wrote to the Skipton Fund to let them know that I no longer had hepatitis C. I was worried that I would have to pay the money back if I no longer had hepatitis C. They told me that my payments would continue.

8. Other Issues

1. It is very concerning that the medical records of the time when I was in hospital for my hysterectomy and the blood transfusion have disappeared when the rest of my medical records remain intact. The only explanation I have received for this from Bridgend Hospital is that the records were only kept for a period of time and then destroyed. It seems a convenient coincidence that the only records missing relate to the time I was given infected blood by the NHS.
2. All of the records relating to the hospital visit have gone. The hospital used to be called Bridgend General Hospital and now it is now the Princess of Wales Hospital managed by Abertawe Bro Morgannwy University Health Board Trust.
3. The hearings in London were a real eye-opener for me. I couldn't believe how many people had been affected by contaminated blood, how serious it was and how many people had lost loved ones. One of the things that annoys me the most about what happened is finding out that the NHS, who I trusted and have worked for most of my life, went ahead and bought cheap infected blood from drug users, prostitutes and prisoners with absolutely no regard for the consequences to normal people like me.
4. In some ways I am very lucky that my infection did not spread in my family and did not kill me. This happened to lots of other people whose families I met in London. In another way I am not lucky because I have lived my life under the cloud of a secret that has gone on to affect my health and my happiness.

Statement of Truth

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

Signed... **GRO-C**

Dated... 11-12-18