

Witness Name: Breda Pow

Statement No.: WITN0030-001

Exhibits: nil

Dated: 31 January 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF BREDA POW

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 8 January 2019.

I, Breda Pow, will say as follows: -

Section 1. Introduction

1. My name is Breda Pow, though my given name is Brigid. My date of birth is GRO-C 1948. I live at an address known to the Inquiry. I am recently retired, having previously owned and run a successful Bed & Breakfast business in GRO-C United Kingdom where myself and husband David have lived since 1980. We have two grown-up sons, Adam and Jordan and five grandchildren.
2. Adam was born in 1981 and Jordan was born in 1983. I stayed at home and looked after the boys until David was made redundant, when the boys were around seven and nine years old. I started up a local Bed & Breakfast business to supplement our income and have had a very good career running this business, while also catering, teaching and running food demonstrations.

3. I intend to speak about my experience of being infected with hepatitis C (HCV) through contaminated blood following a blood transfusion I received in 1981, immediately after the birth of Adam. In particular, the nature of my illness, how the illness affected me, the treatment received and the impact it has had on my life.

Section 2. How Infected

4. In 1981, David and I had recently moved to England from Northern Ireland, for work. We had made a happy transition to GRO-C I was pregnant with our first child, Adam, and gave birth to him in Countess of Chester Hospital. The birth experience was very traumatic and complications arose because Adam was born too late and was facing upwards. These days I would have received a caesarean section. Instead I was in labour for twenty-four hours and 2 doctors delivered Adam the only way they could, using forceps and then a ventouse.
5. After the birth, I had Adam with me for only a few hours and tried to feed him by pumping milk. He was soon transferred to the Special Care Baby Unit (SCBU) and we remained in hospital for 6 days. It was an absolute miracle that Adam did not suffer any brain damage and he had a strong heartbeat.
6. Following the birth, I experienced dizzy spells getting out of bed which I reported to the hospital. I then received a blood test and it was discovered my blood levels were very low, so the staff at the hospital gave me a blood transfusion. Many years later I found out that the blood was infected with the Hepatitis C Virus (HCV).
7. I had a very rough six months after the childbirth. In the years that followed, any other symptoms I experienced, that may well have been to do with the HCV, I continued to put down to the traumatic childbirth experience. I imagine that I was working through symptoms I would not have recognised as HCV and, being a strong person, I just got on with my life.
8. 1992 was when the bombshell happened and I was running the Bed & Breakfast at the time. One day, out of the blue, I was collecting mail in the hall and a brown envelope arrived which contained a letter from the blood

transfusion service to say they did not want blood I had donated a few weeks earlier as it contained the Hepatitis C virus. The letter said if I had any concerns to go to my GP. I felt as if the bottom had fallen out of my world. This was the first time I had given blood since childbirth. I had regularly been a blood donor in my twenties. The letter was stark, impersonal and devoid of any feeling of the affect that receiving this news could have on someone.

9. I went to my GP and he confirmed that I was infected with HCV. I asked how and why this had happened and what it meant to me but was not given any information. My GP said he did not know anything about my illness – it was as if he felt it was not part of his remit or territory. The advice I was given was there was nothing that could be done and I was lucky I was asymptomatic i.e. not exhibiting the normal symptoms, so I just had to get on with it. I was told that I should bring David and the children to get tested at the public health service. I discuss the trauma I felt after this experience in Section 4.

Section 3. Consent

10. I do not think I have ever received treatments or tests without my knowledge or consent. I do not remember much of the blood transfusion experience. I was in “cloud cuckoo land” at the time so it wasn’t really possible to ask me if I wanted the transfusion.
11. My only memory is my mother visiting and saying that she saw me go from a deathly colour before the transfusion, to having the pink come back into my skin afterwards. I didn’t sign anything to allow it, nor was David referred to. At the time it felt like a great solution to the light headedness I was experiencing.

Section 4. Impact

12. The impact, mental and physical, this experience has had on my life has been ongoing over the past 38 years and is incalculable. I do not know where to start with balancing raising children, running a business, going to hospitals to ask for help, receiving blank looks and shrugged shoulders. The

worst part has been the stigma associated with HCV and cirrhosis. It is assumed that this condition is a result of being an alcoholic, sharing dirty needles and is generally associated with people who do not have a healthy lifestyle. It's 'dirty'. As a result, I have kept my HCV quiet. I only told my siblings a few years ago and never told my mother and father. I was worried about the impact me having HCV would have on my business, so I told nobody unless I had to for medical or insurance purposes. I didn't tell my sons until around the time I received the first payment from the Skipton Fund.

13. The initial experience after I found out about my diagnosis was horrific. I was traumatised, as was David and I suffered from panic attacks for a number of years after receiving the letter from the blood transfusion service. I feel like the person who wrote that letter must have thought nothing about it. Particularly when I went to get the post for the three months after getting the original letter, I had panic attacks about what news might come next.

14. I was also petrified at the time GRO-C
GRO-C the public health service also did our hygiene checks for the Bed & Breakfast. I was worried they would see my HCV as a health risk if I cut myself and left blood anywhere which would lead to the business being shut down. I had many sleepless nights and nightmares worrying about this.

15. As time passed, I think my self-preservation instincts kicked in and I learnt how to compartmentalise everything so that I could get on with life and continue to raise my children and run my business. The major impact has been psychological and I have always felt like I was carrying a burden at the back of my mind.

16. I do not think the experience impacted the upbringing of my family, it was something I worked through myself and with David who has been my rock this whole time.

17. As I mentioned previously, my GP sent us to the public health service GRO-C

GRO-C which made me feel like he did not want us in the hospital, in case we somehow contaminated it. GRO-C

GRO-C

GRO-C It then

became a matter of how to have a comfortable sexual relationship with David. [GRO-C] Life went on as normal [GRO-C]
[GRO-C]

18. In terms of business, the main impact has been living in fear that I would not be well enough to work and the prospect of insurance cover if this should happen. Our Bed & Breakfast eventually grew into a hotel which meant we were working 24/7 and taking phone calls in the middle of the night to let people in or if anything happened at the hotel. There were times when I was unable to do everything for the B&B and David was able to take up the slack. I could not have done it without him.
19. I had to address life insurance and pension policies when I learnt of my HCV diagnosis. I wanted to make sure that, as self-employed people, David and I would be covered with enough of a pension. I was advised by my insurance company that I should disclose my HCV. I had to provide further information to the insurance company, such as GP reports which was another traumatic experience that formalised my diagnosis to me. I have also had to go without travel insurance on holidays, I couldn't get any. The alternative was not to travel.
20. I have not felt like I was treated any differently by hospital staff because of my diagnosis, other than the obligation to disclose my HCV when completing medical or dental forms. This always made me feel dreadful and vulnerable because of the associated stigma, especially because I was unable to explain how I became infected with the virus.

Section 5. Treatment/Care/Support

21. Following my diagnosis, I visited my GP regularly and went for liver blood tests every six months at Countess of Chester Hospital. The conversation and information never changed – I was told my liver was fine and I never questioned it. This went on for some years (I cannot recall exactly how many) until I asked a younger GP who was seeing me at the time to be referred to a specialist. He was surprised no one had ever referred me before.

22. I was referred to Dr Sturgeon at Fazackerly Hospital in Liverpool, who carried out a liver biopsy and informed me I had medium to severe liver damage. He did not use the word cirrhosis. I do not recall precisely when this was but it would have been between 1996 and 2000. Dr Sturgeon said he could offer me some treatment.
23. The first course of treatment Dr Sturgeon tried with me was Interferon. I was self-injecting once a day for about a year, which was a horrific experience while trying to run the Bed & Breakfast and bring up two children. I found the whole process awful and was never able to get used to it. The physical side effects were wretched and I felt as if I had the flu. I also had depression at this time and was put on medication, however I cannot recall the name of the medication.
24. The Interferon treatment did not work. I was told this is because the HCV I had was rare and made of a mix of two genomes – I am not entirely sure what this means. I was put on Ribavirin a couple of months later and experienced similar symptoms while on this treatment as with Interferon. I continued to remain on antidepressants and through all of this was trying to get on with living my life. This treatment did not work either.
25. When my treatment referred to in paragraphs 23 and 24 did not work, Dr Sturgeon told me the best thing I can do is go away and live my life as best I can and hope that I remain healthy, with the chances being that I would be fine until I reached my early seventies and that this was as much as I could expect. Again, I was not told about cirrhosis. I have no negative feelings about this, I know that he was doing his best and did not have the answer. He also said that down the line something else might come along.
26. Around four years ago I went to Countess of Chester Hospital and Dr Karmo looked at my case. I was given the option of trying another round of Interferon or Ribavirin again, or waiting for new treatment to come through in around two years. I decided to wait for the new treatment.
27. Over the course of the next two years I visited Dr Karmo a couple of times. During this period as with previous treatment, I was never told I had cirrhosis. It was never mentioned and doctors always spoke euphemistically. I in turn never wanted to ask the question – did I have cirrhosis? It frightened me. I did ask the clinician nurses but they always

told me to ask the doctors. One day when I had a female doctor for an endoscopy I plucked up the courage to ask if I had cirrhosis and her response was "oh yes did nobody tell you?". I had also not been told I had varicosis.

28. After a period of about two years since I had first seen Dr Karmo, the new treatment came out (I cannot remember the drug name) and I went to the top of the list to receive it as a part of a research programme. I took tablets over the course of about three months, until about eighteen months ago Dr Karmo informed me the virus had cleared.
29. I continue to have my six-monthly check-ups which no longer affect me. Each visit I have been informed the virus is non-traceable. I feel very lucky and consider it a miracle to have survived and to have finally responded to some treatment.
30. Throughout the course of my treatment and interaction with doctors and the health authority, the fact that I had been infected with contaminated blood never came up. I only realised I had received contaminated blood as information started to come out publicly in the late 1990s to early 2000s. I only found through my own research and general knowledge from reading the paper every day and using computers. Doctors never asked if I had discussions with people for compensation or asked about the effects of receiving contaminated blood. This is where I have felt let down.

Section 6. Financial Assistance

31. I made an application to the Skipton Fund sometime between 2010 to 2014, after I learnt that I had cirrhosis. I was amazed when the Skipton Fund accepted my application for funding. It was the first time I felt like my experience had been acknowledged and that the state had taken some responsibility.
32. I have received a first stage payment of £20,000 and a second stage payment of £50,000 because of my cirrhosis. All of this money has gone to my boys, as it felt to me like the money was contaminated. I did not feel bad about taking the money but it does not make me feel good because of the stigma that I feel is attached to the money. I do also receive £18,000 per

year in 12 monthly instalments, I think this includes a winter heating allowance. I keep this and accept it in a way that I cannot with the lump compensation sums.

Section 7. Other Issues

33. A while ago, just before I retired I asked for my medical records and was informed my maternity notes could not be found. I found this odd and do not know why this happened.
34. What I have really struggled with throughout this experience is that no one in the health service who I have come into contact with has given any acknowledgement of what has happened to me, and that the circumstances I have been facing are a result of receiving contaminated blood. At the end of the day for victims, one of the main things is the feeling that something has been done wrong to you and that your life may have been different if that wrong had not happened to you.
35. I know the government has acknowledged the infected blood scandal has happened but I still feel that many people do not know what happened. I cannot understand why such a tragedy was allowed to happen and would like to see the incident acknowledged as a disaster. I feel like no one has taken responsibility and I still find myself having to explain that I have been a victim.

Statement of Truth

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

Signed

GRO-C

Dated 31/1/19