



SCANNED

Witness Name: Pamela Pennycook

Statement No.: WITN2242001

Exhibits: WITN2242002

Dated: 9th January 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF PAMELA PENNYCOOK

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 5th November 2018.

I, Pamela Pennycook, will say as follows: -

Section 1. Introduction

1. My name is Pamela Pennycook. My date of birth is the GRO-C 1969. My address is known to the Inquiry. I am living with my husband John Pennycook and my stepson Duncan who is 19 years old. I have another stepson who does not live at home with us. I intend to speak about my infection of hepatitis C, in particular the nature of my illness, how the illness affected me, the treatment received and the impact it had on my family and I and our lives together.

Infected Blood Inquiry

Fleetbank House, 1st Floor, 2-6 Salisbury Square, London EC4Y 8AE

contact@infectedbloodinquiry.org.uk

Freephone 08081691377

Section 2. How Infected

2. I received my blood transfusion on the 24th July 1980. I was 11 years old and admitted to the Princess Margaret Rose Hospital, Edinburgh as I was having spinal fusion surgery. During this operation I lost a lot of blood, so I was given 3 pints of blood during the operation and in the recovery room. **GRO-D** was the treating consultant. I don't know the infected batch number of the blood though. My parents, William Henry Kelly and Jill Kelly cannot recall ever being told that a blood transfusion had taken place and had no awareness of this for many years. They remember signing a consent form for the operation itself but they were not told that I'd had the transfusion. I remember seeing the blood when I woke up in the recovery ward though, I'd never had a blood transfusion before. They are clear that there was never any discussion, any explicit discussion about the possibility of having a blood transfusion or any risks associated with this.

3. Many years later in 2005, I was diagnosed with Osteoporosis and my GP based at Oxgangs Path surgery, Edinburgh decided to do some blood tests. This showed high liver markers, so the GP decided to do some further blood tests centred around my liver. I remember that on the 21st December 2005, I phoned my GP for the results and the GP receptionist gave me the results over the phone that I was hepatitis C positive. I was utterly shocked and started crying and I asked to see a GP straightaway. I was told no, there is no GP available and I got really upset; I told the receptionist that you gave me this information, I need to speak to someone about it now, so she put me on hold for ages and my GP, Dr Cameron, came on the phone apologising to me saying that the receptionist should not have said this and arranged to see me next day. I then spent the evening frightening myself with information.

4. The next day I saw Dr Cameron who apologised and gave me practical information about things to avoid like sexual contact and told me details

about the illness, that it was an infection that was spread via blood and to consider contacting previous sexual partners. I wasn't married to John at that point, I didn't meet him until June 2006. I was then referred to the Western General Infectious Diseases Unit in Edinburgh. The first time they saw me was February 2006. When I looked up information online, I found out that the infection was life shortening, that I would be put in a lead coffin and I would be put in a hazardous waste bag when I did die. It frightened the life out of me. I found out that I would have a toxic label stuck on my body when I did die. This caused me to completely go off the rails, I had to take time off work to come to terms with the diagnosis, my drinking got out of control and I lead a chaotic lifestyle, so much so, that I got pregnant in April 2006 and had to terminate the pregnancy as I was aware of the risk of passing the infection onto an unborn child. It was an awful time. I still remember going for my first appointment at the Western General, Edinburgh. There were set times that you would start treatments and I went on the first day, utterly shocked, there were prisoners and guards around me in the unit because that's when everybody else had their treatment as well. I remember thinking oh God, this is my life now it was a culture shock, being surrounded with prisoners with hepatitis C.

5. I was given contact details for C Plus, Edinburgh, a support network and I made contact with them quickly as they were a support group you could go to and visit for meetings for advice. This information was very helpful.
6. I think the information that I had this infection came at the right time and the investigations were fitting with my medical history.
7. It's disgusting that at the receptionist at the GP felt she had the right to give me that information on the phone and then deny me access to a doctor.
8. The GP gave me the information about the diagnosis and the practicalities of spreading infection. I was lucky, John is a policeman and he has an understanding of hepatitis C so when I started a relationship with him, he understood. I explained to him and he was very aware how the infection was transmitted, he had a good understanding that it was blood to blood contact.

I felt ashamed contacting previous sexual partners as I knew that some would not react well. To have to get in touch with them all when I have not spoken to them for many years, it was very emotional, but it had to be done.

Section 3. Other Infections

9. There have been no other infections other than hepatitis C and I've not been notified of anything else.

Section 4. Consent

10. No, I knew the GP was doing a blood test for my liver and I knew that there had been a blood transfusion, although my parents were not given any knowledge of this. Mum and Dad were devastated when they found out about the infection, when they read the leaflets they blamed themselves and they felt that they could have protected me, they carried along a lot of guilt for a long time.
11. For the blood transfusion, yes, I was 11 years old, so they never sought consent from my parents. After that no, I don't believe I've ever been treated or tested without my consent.
12. Initially yes, I do believe I was given adequate information ultimately, but at the beginning it was not very forthcoming. The information from the receptionist was unprofessional but after that people did tell me the practicalities of what was involved with hepatitis C.
13. No, I don't believe I have been tested or treated for the purposes of research.

Section 5. Impact

14. I've had practical problems with my lower right leg over the years and I keep experiencing recurring infections. When I was 18 years old, my lower right leg had to be amputated because of these infections. I was off Dumfries High School for long periods as a result and rather than going to university, I was rehabilitating from losing a limb. The GP couldn't get to the bottom of why I was feeling like this and experiencing all these infections and symptoms, I believe this was all related to the hepatitis C.
15. I lost my lower leg and I'm still having issues with the stump. I have to have surgery every couple years for this, it is always going to be a problem. The fact I've had to terminate a pregnancy, it made me feel worthless, it was the right decision at the time though, I couldn't risk passing infection onto the child.
16. The treatment I was on was the PEGylated Interferon and Ribavirin, I took this for six months and I was under the care of the Western General Hospital in Edinburgh. I was off work for 5 months while I underwent this treatment and there were periods of depression throughout, I couldn't concentrate, I had hair loss and was very sick. I am prone to having low moods and the depression kicked in about half way through the treatment. The GP gave me antidepressants for this but the side-effects were difficult to manage, so I also went to a counselling support group which helped. In February 2007, I was declared clear of hepatitis C. It felt like an anti-climax, you are told you are clear and from the amount of support that you have during this, you go to nothing. There was one 6-month follow-up appointment but after that, nothing ever again. I still have the side-effects in my body from the treatments, my inability to concentrate, the fogginess; I don't have the same clarity that I'd had previously. I lost about half a stone in weight. I'm still bothered with depression and problems with alcohol. With all the publicity of the hearings and things for this new Inquiry, it's bringing it all up again. The Penrose Inquiry was such a joke and then all these new proceedings and you think there is no ending to this, the first one was a whitewash, what will this one be? I hate Christmas now as this was the month I received my

diagnosis, 4 days before Christmas. It has always spoiled the festive time for my family as I shut down emotionally from the 1st to the 31st December and drink continually and become very depressed. After the 31st December, the whole family can breathe again and not feel as though they are walking on eggshells. As children, my stepsons could not understand why I could not enjoy Christmas and this partly caused my difficult relationship with them later on.

17. I also hate Mother's Day as I've never had a child of my own. The distress of this led to an emergency admission to the Royal Edinburgh Hospital, Morningside, in April 2016 for psychiatric evaluation as I was experiencing suicidal thoughts. Not for the first time, as I had overdosed on tablets years before. I struggle with the loss of my child due to the termination when I was newly diagnosed with HCV and the realisation as I'm in my late 40s, I will never have a child of my own. I constantly worry about how I will react when my stepsons become parents themselves. I've attended long periods of counselling over several months at a time and manage my feelings on alcohol to help me deal with these issues. It's still an ongoing battle with excessive drinking and depression.

18. I had to wait for a place to start treatment, which was probably the biggest obstacle, I couldn't get my head round this; I was ill, if I broke my leg, they wouldn't say come back in 8 weeks and start treatment but for HCV, you had to wait for your place. If you missed your place, you would have to wait for another period of time, many weeks, before you were given another opportunity. Also there was no privacy and you ended up being treated with prisoners during the treatment.

19. I can't think of any treatments which were not made available to me, nothing I can think of.

20. I met John 6 weeks before treatment started, so it was difficult to begin with. We made the decision for him to have a vasectomy 6 months into our relationship as I did not want the situation of another accidental pregnancy.

That took away my choice about having future children, but it was the right decision for [GRO-C] at the time because [GRO-C] had already had two children. The priority was to get me through the treatment to get better. One thing that I've never got over though, the day I had the termination, is the same day my sister gave birth to her son. That was awful. We were in the same hospital and I went from termination to visiting her in the maternity ward. None of my family know about the termination, that is extremely difficult. I have issues bonding with my nephew as a result. While he was a baby I was on the treatments, I would have mood swings and I wasn't allowed to be on my own with him, that was my sister's decision. My sister will look at me now and she doesn't understand why I have trouble bonding with my nephew when other aunts do not. John was never able to come with me for the treatment because he is a policeman. He couldn't come as prisoners would come as well and he didn't want to make a stressful situation worse as he felt he might be recognised. He feels guilty about this but it was fitting at the time.

21. There was a lot of stigma around keeping things secret, it felt like a dirty secret. I did tell my immediate boss because I had to take time off work and when I came back 5 months later my colleagues thought I'd gone to rehab because they had heard that I had a liver problem. I used to work for a drug and alcohol team in Dundee and I have an insight about hepatitis C which I gained before diagnosis myself. When I was diagnosed originally, I remember been very frightened and thinking, how have I got this? What does it mean for me? Can it kill me? I know the virus can come back even after your clear though because it is an infection and that is something to bear in mind. My sister knows about the infection but she has no awareness of the termination.
22. When I was in high school, I had to get home tutors once a week because I was off school so much. I thought I would have to repeat a year but the decision was made to concentrate on strong subjects only and I was able to get some O grades and Highers but then after losing my leg I couldn't go on to university. I would have probably done Business Studies or some sort of

broad degree to gain more of a career rather than just a job which is what I have now had this not happened. I am a mortgage processor now, it's a job not a career. I see opportunities for the graduates in the company, but they have bypassed me. I work for a major high street bank. Originally when I was in school I wanted to go down the nursing route but my GP wrote to the head of nursing and said to her that I should be given advice not pursue this as a career path as it would be boring, I am very confused that he went to the trouble to really discourage me from going into the medical profession myself. I discovered this letter, years later in my medical records.

23. I have had a long periods of absence from work due to the problem with my leg. I have depression and have recently had to cut my hours to cope with everything that is going on. 30 hours per week is more manageable than full-time, which is what I was doing previously. I have been warned though, that if I have any more periods of absence, it will proceed to a disciplinary group and that in itself is a stressor. I have worked there for in 19 years now.

24. I couldn't go to university so I just got a job. I have recently reduced my hours so that's a reduction in salary. Life insurance is astronomical; therefore, I have no life insurance. Everything falls into John's name, I don't declare hepatitis C with travel insurance.

25. It was difficult on John and still is, it's difficult on his boys, they were 6 and 9 years old when I started treatment and that has caused a strain in our relationship. I have a fractured relationship with the eldest but now I do feel closer to the younger one, Duncan. John takes on the role as a carer for me, when I get problems with my artificial leg as well as work, he is a big support.

Section 6. Treatment/Care/Support

26. No support was offered at the time I went through treatment, but looking back I think there could have been more support, particularly after treatment.

There was never any psychological support, it was an anti-climax, you were just left to continue on, so I don't know if there is anything going on today, with my liver or if the infection has ever returned. C Plus were all the support I received, they were very good.

Section 7. Financial Assistance

27. C Plus told me about the Skipton fund, that would have been in June 2006.

28. I received £20,000 from the Skipton fund then £30,000 2 years ago from the Scottish Infected Blood Support Scheme. Then from January this year I will be receiving £6300 per year in financial assistance.

29. I found it straightforward to use the forms. I'm used to forms though because of my job so I can imagine if you're not used to forms it would be a bit daunting.

30. I faced no obstacles in applying for financial assistance that I'm aware of.

31. No, I can't remember any preconditions that were imposed.

32. I don't understand why the level of support varies everywhere, it should be the same across the board, you were infected or you were not infected it's as simple as that.

Section 8. Other Issues

33. There is only one document that I have kept a copy of myself, that proves I have had a blood transfusion. I am providing a copy of this to Thompsons Solicitors to provide to the Inquiry. I wish reference to be made to a letter dated 13/12/2006 from my consultant at Western General Hospital, Dr [GRO-D] [GRO-D] to my GP Dr J Cameron, which states: "It would appear though the records of her transfusion no longer exist and so no further action can be taken." Yet Dr [GRO-D] gave me a copy of the blood transfusion report and told me: "Keep this safe. You'll need it one day."

34. Thompsons Solicitors are recovering my medical records and I will be given an opportunity to review these.

Statement of Truth

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

Signed: GRO-C

Dated 23/2/19.