Witness Name: Thomas Sexton
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# WITNESS STATEMENT OF THOMAS SEXTON

# INFECTED BLOOD INQUIRY

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## Introduction

1. My name is Thomas Paul Sexton. My date of birth and address are known to the Inquiry.

2. I am retired and usually live in GRO-C. At present, I am living nearby with my wife in GRO-C at my mother-in-law's home. GRO-C GRO-C My wife works full time. I have two daughters from my previous marriage, one who lives nearby and the other a little further away. I am close to both my daughters.

## How I became infected

3. In 1983 I was admitted to Hammersmith Hospital in London for a cholecystectomy. There had been two previous unsuccessful attempts to perform this operation so I was referred to London. I signed the consent form and had the operation.

4. After the operation I recall they said it was successful and they gave me the gallstones in a jar. But then I never got well again. Instead of being in hospital for a couple of weeks I was in there a long time, to the extent one of the doctors said I was becoming an embarrassment to them. I had had a blood transfusion or several blood transfusions during the operation. I had a drain under the wound and when they took that out the blood just spurted all over the place. I developed chest pains and they gave me another blood transfusion. The following day, the surgeon who operated on me, Professor Blumgart, commented that they should not have given me a blood transfusion. When I recollect that now, so many years later, I wonder whether he said it because he knew the blood was not good.

5. I also recall a doctor coming to my bedside with a large syringe with some yellow fluid in it which he said was a trial from America. I know I was asked to sign a consent form. I was so ill at the time I would have taken anything. There is no record of that consent form that I can see in my medical records. After seeing recent pictures of Factor VIII my suspicion is that I was given Factor VIII through the syringe.

6. After being discharged I was extremely tearful and, visiting my doctor, which is not the same doctor I have now, I was immediately sent the same evening to see a Dr Jilani, a psychiatrist at Nevill Hall Hospital in Abergavenny. The psychiatrist wanted to keep me in on a psychiatric ward, but I didn't want to stay there. I began treatment with anti-depressants, though I cannot recall which ones they were. I have tried several over the years. It took me some considerable time to become stable and I am still taking anti-depressants today, over thirty years later. Although I have tried to come off them two or three times, my mood swings, anxiety and depression have revisited me and my doctor now advises that I have to keep taking them for the rest of my life on a low dose.

7. When the three day hearing for the Inquiry started in September this year I watched it online. It brought it all back for me. My doctor had advised me to up

the dose of anti-depressants if I felt low, so I have done this for the last few months since the hearing because of the all the memories.

8. I was not given any information or advice before being given the blood transfusion or the syringe about the risk of being exposed to infection.

9. I was infected with Hepatitis C (HCV) as a result of being given blood or blood products.

10. I found out I had been infected with HCV when I received a letter from the National Blood Service on 12 June 1997 saying they wanted to test my blood. They came to my house and took blood. I then received a letter asking me to ring them, and they came to see me again and told me I had tested positive for HCV. This was on 8 September 1997.

11. I was not given adequate information to help me manage the infection. I was sent to Heath Hospital in Cardiff for appointments. I attended and asked about treatment. They said the money for the treatment would have to be provided by my local health authority. At the time, my local health authority said they were not prepared to put me on a course of treatment because they did not have the money. It took me many appointments, blood tests and correspondence with the health authority threatening I would take some legal action if treatment was not provided, before treatment was finally offered in 2000, approximately three years after finding out about my diagnosis.

12. I believe information should have been provided to me earlier. My address was the same, I had not moved, my circumstances were all the same. Unknowingly, I could have transmitted the disease during all that time.

13. When I was told the results of the tests and that I had tested positive for HCV I just felt devastated. There was no information given to me. No one told me if I could die of it. I went in for an operation in 1983 and came out and was

eventually told I had a disease. I had no idea if I would ever get better. The attitude of medical staff was nonchalant, I was told I had a disease and they would give me treatment and that was it. There was no support and no one to reassure me.

14. Very little information was given about the risks of others being infected as a result of the infection. My wife (now my ex-wife) asked whether it was sexually transmissible and they said they could not say because they did not know. There was no information about how not to affect your sexual partner. They just said that I would have to attend hospital appointments.

15. GRO-C GRO-C There were no instructions on what to do and what not to do. There was just no information on how to manage the risks.

## Other infections

16. I do not know of any other infection I have received as a result of the infected blood other than the HCV. I continue to have blood tests with my doctor.

## Consent

17. I believe I have been treated without my knowledge. I am very concerned about the syringe of yellow liquid I was given in 1983. I signed a consent form but I have no knowledge of what was in the syringe and no one told me. My suspicion is heightened because there is nothing in my notes relating to this particular incident.

18. Although I recall signing something at the time the syringe was given to me I was very ill and would have signed anything.

19. I believe I was not given adequate or full information about what I was given.

20. I also believe I may possibly have been used for the purposes of research. During my time as an inpatient at Hammersmith Hospital they took my up to a room. I was suffering terribly with anxiety. There was a very, very large screen, like a television screen, in front of me with lots of dots. I didn't know what it was doing and I wondered if it was counting my blood cells. I couldn't say whether this was before or after I was given the syringe. I was frightened. I thought I was dying.

## Impact

21. The main mental effect of being infected with HCV is depressive illness. In the beginning I was tearful and anxious, I was unsociable and I slept a lot. I still suffer mood swings. I get good days and bad days. My concentration is not that good at times.

22. The main physical effect is the fatigue, which has been constant and which is the worst effect for me. I used to be able to do a task for a long time, but now it is stop, start, stop, start. I was a fit person before this virus; I played football and could run.

23. The conditions HCV has contributed to for me has been arthritis in my hands and knees. I have had a Blue Badge for six years because walking is difficult, and cold weather worsens the arthritis. Sometimes I cannot unscrew a bottle with my hands because I cannot grip well. I tend to pick up colds, coughs and stomach upsets easily. I take Omeprazole daily and did receive medical investigation for a burst ulcer in my stomach approximately 10 years ago.

24. The treatment I was offered for HCV was interferon and ribavirin. This treatment was very debilitating. It affected my whole life. I only wanted to be alone. It was easier to be alone. I didn't want to be around people. I could understand then why people want to end it all. It took a long while to get back to any social life. Even now I wouldn't want to be in a too crowded environment. I wondered what the infection had done to my body between 1983 and the time they contacted me in 1997.

25. Prior to starting treatment I had to have a liver biopsy. I attended hospital with my ex-wife and had to attend the disease clinic. This was daunting for me and frightening for my ex-wife. During my course of treatment with interferon and ribavirin I was given the contact details for a nurse 24 hours a day.

26. At the time of my treatment, I was employed as a full time trade union officer and during my treatment my employer was ok. I could not manage any meetings in the morning however, and I went down to one meeting a day by the end of the treatment. I would return home from work, get something to eat, and put a flask of tea and a jug of juice next to the bed. I would go to bed and inject myself and take my tablets and just shake and shiver. My daughters were nearby and came every day to change my bedclothes. I believe, from what I have been told, that a lot of people could not withstand the treatment. I wondered at the time whether the treatment was killing me.

27. This treatment lasted from August 2000 until 6 February 2001. At the end of my treatment I was told I was cured and discharged.

28. I could not access the treatment with interferon and ribavirin for three years, between 1997 when I was told of the infection, and 2000, when treatment was started. I was told this was due to a lack of funding as it was my local health board who had to fund the treatment and they said they could not afford to do so.

29. I believe counselling ought to have been made available to me but was not. I understand counselling is now being offered but I don't know if I want it after 30 years. Why wasn't I offered counselling at the time? I needed it then and would have taken up the offer of counselling at the time, but nothing was offered. I was just discharged. I felt I should have been signposted to help. I was not signposted to anything.

30. In terms of how my infected status as impacted on other care, when trying to access dental care a long time ago the dentist I went to said he would not treat me because of my HCV.

31. The impact on my private, family and social life has been devastating. My first marriage ended because of the virus and the depression. I suffered extremely low moods, and was snappy and anxious. I was not pleasant to live with,

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32. My social life was non-existent. I would get invitations to things but made excuses as I didn't want to go. I became more anti-social during the treatment. I lived alone in a rented, furnished room in shared accommodation. As a child I was brought up in an orphanage: when I came out of the orphanage I moved to a furnished room and lived on my own, and then progressed from there, I bought a house, started a family. All of a sudden, it was all gone and I was back right where I started, living alone in a furnished room.

33. After a time I moved out of the furnished accommodation and went to the housing association and moved into a small cottage. My daughters helped me furnish it and I gradually became more sociable. I think my daughter was my motivation: she told me I was not being me.

34. HCV was a stigma because it was a disease. I never told anyone outside of my immediate family about the disease. When I had the treatment at work I told my personnel manager but no one else: colleagues might think they could catch it. Now I am cured and there is the public inquiry I have told a few very close friends of my wife and I. I don't feel there is any difference between what virus you have: everyone infected with contaminated blood went for treatment for something and came away with a disease. There is no difference with regards to the stigma.

35. In terms of work-related effects, my employer was tolerant of the infection although I was off work for 12 or so months after the operation in 1983. I went back to work and managed to continue working until I retired with only short amounts of time off. I went to work because I had the feeling I had to do something: I lived alone and was depressed. Going to work I found difficult but it was something to get out and do. Once my depression had settled down I felt more that I wanted to do things but I did not have a social life. I would work and then come home, I was exhausted. That was enough for me.

36. The financial effects of being infected with HCV included the loss of earnings following the 12 months off after the operation in 1983. Although I was paid for some of this I was not paid for all of it. I had further small amounts of time off during the rest of my career. I was fortunate to have an understanding employer. I think my ex-wife's mother helped her out financially. Money was not abundant but we managed to stay out of debt.

37. The infection impacted on my family. My ex-wife never coped with it and our marriage ended. My daughters have been very concerned about me, particularly with my depression and have done everything to support me in the times when they could.

## Treatment/Care/Support

38. I have outlined the difficulties I faced in obtaining treatment above. It was only my insistence and the threat of legal action that got it.

39. Care was non-existent. There was no one you could talk to about your treatment. Although I had a contact number for a nurse for 24 hours a day during my treatment this was just for the doses I was administering, it was not care or support. It would have been good to have someone who would check on you. My marriage had broken up and I was living alone. I was quite isolated.

40. Counselling or psychological support has never been made available to me. It was never offered or talked about. And I had no knowledge of any support services. No one from hospital or anyone like that signposted me to help. There was nothing. Just the treatment and the cure and that was it. There were no follow-up checks. I find that very surprising. I still suffer with fatigue. No one can tell you anything, you have to ask yourself. Just like the treatment, if I had not written to the health authority I wouldn't have had that treatment then.

## Financial Assistance

41. My first indication that there was any ex-gratia payments available for people infected with HCV was through a newspaper, the Daily Mail. I acquired the phone number and, on speaking to the Skipton Fund, had to furnish them with proof of the infection, treatment, etc. I was awarded £20,000 approximately 15 or 16 years ago. From that date I received no more support until 2016 when they awarded £3,500 per annum. That then went up to £4,500 per annum and last October 2017 I was upgraded on the new scheme from Hepatitis C Stage 1 to Stage 2 and will now receive £18,000 per annum through the EIBSS scheme.

42. I had to gather all the information myself from hospitals (Hammersmith, Cardiff) and my GP, and I had to give all that information to the Skipton Fund so that they could check my claim was genuine.

43. There are difficulties in applying for financial assistance. For example, going up to HCV Stage 2 is very subjective. I know that my depression is definitely caused as a result of HCV, and that this has lasted since 1983. However, when my doctor filled in the application form, she said my mental health problems were 'highly likely' (rather than definitely) to be attributable to HCV and had only existed from 1994. The doctor also said I had osteoarthritis and not rheumatoid arthritis, if she had said the latter (which was thankfully confirmed in later correspondence from my GP in support of my application) this would have meant I would have been given the award. My old GP surgery from several years ago would have known me better and would have filled in the form more accurately. Being reliant on a doctor to complete the form means it is subjective, especially when that doctor never met you during the time you were suffering badly with depression and during the awful treatment for HCV.

44. There were no preconditions imposed on the making of the application for financial assistance.

45. In my view, the amount of financial assistance received should at least for the time being be married to the Scottish scheme as per Sir Brian Langstaff's written request to the Health Minister.

## Other Issues

46. I think the inquiry should address all matters relating to what was known at the time, including government ministers' correspondence, investigating Sir David Owen's missing papers, why I was not notified until 1997 even though I was infected in 1983, and why my treatment was delayed until I wrote in desperation to the health board. I also hope the inquiry will ensure that no evidence is

withheld and said to be 'commercially sensitive' as drug companies must own up to the inquiry.

47. I believe more information was known about contaminated blood than was provided to me and that the government and medical staff withheld that information from me. I do not feel medical officials were candid with me about the infection and were very vague. I was not given enough information about my infection except that I had tested positive for an infection and was referred for treatment (which I could not access for three years).

48. I do not believe my medical records are complete. As set out above, I recall being given a large syringe which contained a yellow liquid by a doctor. The doctor said it was a trial from America and asked me to sign my agreement to it. I was so very ill and thought I was receiving something to get me well. The syringe was injected into my arm. There is no reference to this in my records and no copy of the consent form I signed. My concerns arose after I tested positive for HCV and tried to recall what had happened all those years before.

**Statement of Truth**

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

Signed:

GRO-C

Dated: 23 November 2018