

Witness Name: Catherine Fielding

Statement No.: WITN0207001

Dated: 3 · 4 · 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF CATHERINE FIELDING

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 25 January 2019.

I, Catherine Fielding, will say as follows: -

Section 1. Introduction

1. My name is Catherine Fielding. My date of birth is GRO-C 1942 and my address is known to the Inquiry. I am a retired and live alone. I intend to speak about my infection with 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 our lives together.
2. I confirm that I do not have legal representation.

Section 2. How Infected

3. In 1965, I had a miscarriage. I know my mother went with me to the hospital, the North Road Hospital, Aberystwyth, which has since closed down. I was unconscious before I left my hometown. I woke up

many hours later. There was a doctor by my bed who explained I had a miscarriage and that I had received a blood transfusion. I was not made aware of any of the risks at the time, as I was unconscious. I don't recall my mother mentioning that she was appraised of any risk either. I didn't question anything because I didn't want to talk about it; I was in shock and I have a habit of burying things deep in order to cope with them.

4. In 2012, 47 years later, I was diagnosed with Hepatitis C. I had no tattoos, piercings or drug use and the specialist later confirmed my blood transfusion as the likely source of infection from my medical records, and that the virus had mutated into genotype K. As far as I am aware, I am the only person in Wales with this strain of Hepatitis C.
5. My diagnosis with Hepatitis C came after I had a terrible mouth infection. I was in a lot of pain. The first GP I saw attributed it to alcohol abuse. However, I did not think this was right and consulted my daughter's partner who is a GP. He said this wasn't likely to be true and advised me to change surgery. I did so and saw another GP who only advised me to cut out alcohol altogether which I did. Despite this change, tests showed my platelets were still enlarged.
6. I saw a third GP, called Dr Ibrahim in Ystwyth, and he took my blood and confirmed Hepatitis C infection. He did not tell me he was testing for Hepatitis C and so it came as a shock when he told me I was infected and I was very upset. I telephoned my daughter's partner, the GP and he was shocked, too, and also upset. He seemed very worried for my grandchildren and the implications for them and this in turn affected me.
7. I was referred to Donna Blinston who is a specialist in blood born viruses for Hywel Dda Local Health Board. She told me more about the infection and provided leaflets for me to learn more about it. She

advised me on diet changes and other ways to manage my infection. She was excellent. She told me that as I was a young woman when I was infected, I would have fought it better than an older individual or a man. She has emailed consultants across the world about my infection, as it is so unusual.

8. Had I been aware of my infections sooner, I would have cut alcohol out of my diet sooner. I used to enjoy a couple of glasses of wine in the evening and I do miss it, but I know now that your liver cannot take it when you have Hepatitis C.

Section 3. Other Infections

9. As far as I am aware, I am only infected with Hepatitis C. I do not know if I have been tested for HIV, but I presume so and have never thought to ask.

Section 4. Consent

10. When I was tested for Hepatitis C by Dr Ibrahim, I was not informed that this was what he was testing for, which did surprise me. Otherwise, I believe to the best of my knowledge that I have always consented to testing and treatment. I do not believe, to the best of my knowledge, that I have been a part of any research or tested for this purpose.

Section 5. Impact

11. Over the years between my infection and diagnosis I had some unexplained illness. I would wake up on many mornings with a headache and feeling like I had a hangover. I was always tired. However, I never knew why and just put it down to general fatigue; I was a woman bringing up three daughters by myself. I would also

bruise easily. My GP suspected that I had leukaemia, but it just came back as anaemia.

12. I still suffer from these symptoms. I have lost a lot of teeth due to the Hepatitis C. My joints ache and, at one point, my GP thought I had arthritis but it wasn't, though I do now have arthritis. I find I can't walk as much now so I don't do much or travel. After my dogs died of old age I wanted to get some more for the companionship and because I love dogs, but with the Hepatitis C I do not feel I could care for them properly any more.
13. My taste has changed; a lot of foods I used to enjoy I no longer like. I have also had to change my diet. I am a vegetarian by choice, though this does help with Hepatitis C as certain foods like red meat can be difficult for the liver to process. I have had to cut down on fat, sugar and carbohydrates. I have to restrict how much pasta, potatoes and cake and such that I have. This can be quite restrictive. I find I can no longer eat in restaurants because the menus do not have suitable options. I also find it difficult eating with family as my diet is restrictive and I find it difficult when the grandchildren visit as they like chips so I cook them and the smell is tempting, but I know I can't have them.
14. I have suffered severe liver damage and I have cirrhosis. It has been suggested by Donna Blinston that I have a liver transplant. I was surprised to discover I was bad enough to be considered for one. However, a consultant at Newport Hospital said I do not need one and refused to put me on the list. I am squeamish, though, and the thought of the pain and discomfort of such an operation means I am not sure I could go through with it even if they would let me.
15. The most serious consequence of my Hepatitis C infection has been my cancer diagnosis. I had a scan that found three cancerous tumours in my liver. I was told it was terminal. For thirteen months I thought I was going to die. I was offered chemo-emobilization that

would shrink, but not cure, my cancer. I could not be treated for Hepatitis C during this time. I decided to undergo the chemo-emobilization, which was horrible. They put a tube into the main artery in my thigh and blasted chemotherapy at the tumours and sealed everything off.

16. During the treatment, I had to lie completely flat and still and continue doing so for four hours after the treatment. I had awful back ache. After the chemo-emobilization, I had a fever and so it was decided I could not undergo this treatment again as it would be too risky. The treatment did work and the tumours shrank. However, it was only when I was treated for Hepatitis C they went away completely.
17. I have been clear of cancer for my last two scans. I have to wait another six months before my next test. This is annoying and extremely worrying because I am concerned the cancer will come back as my Hepatitis C infection is active again and the cancer was caused by the Hepatitis C.
18. Mentally, the impact of the Hepatitis C infection has been hard to deal with. I find I am not able to talk to people about it and I don't ask questions or listen much as then I don't have to think about it or acknowledge it. I tend to push things to the back of my mind and ignore it.
19. I find it hard to deal with the thought of the dirty blood I was given and the type of people who donated the blood that I was given. I have struggled with this when I have needed subsequent transfusions. I feel dirty.
20. I thought I was dying for thirteen months. I prepared my house for sale, not wanting the children to have to deal with this. I have put it up for sale now anyway as I feel I need to be closer to my family.

21. After my Hepatitis C treatment failed twice, I am now losing hope that it will work. I was tempted to refuse treatment this time, but my specialist Donna Blinston, has been excellent and encouraged me. She monitors me every three months and I can phone her at any time.
22. My other medical care has been impacted by my Hepatitis C. Whilst my dentist and other doctors have been alright and treated me, I have always had to be treated last, which is humiliating. I do understand that this is to minimise the risk of infection, but I find it difficult to deal with. I do not like taking medication, so I have avoided taking painkillers that were prescribed to me because I don't want them to interact with the Hepatitis C medication.
23. I have felt the impact of the stigma associated with Hepatitis C. I have deliberately limited the number of people who know about my infection. I have not even told my siblings. I did tell a friend about my infection and she backed away from me. Whilst I understand why she did it, it still hurts and I feel dirty. I have avoided telling people since. Nurses would ask me how I got Hepatitis C because, in their own words, I don't look like the sort that would have Hepatitis C because I am not a drug user. I was isolated during transfusions and, whilst I understand this minimises the risk of infection, it does make me feel dirty and alone. One consultant explained that it wasn't a bad thing to be isolated as I was safer if, for example, a mad axe man came in! What did that mean?
24. My education and work were not impacted by my infection. My education happened before I was infected and I retired before my infection became obviously symptomatic.
25. Financially, I have had to spend quite a bit of money attending appointments. I have always lived close to the poverty line and have not been able to have many holidays. I have not been since my

infection was diagnosed. I was considering going to Italy, but the travel insurance would be very expensive.

26. My Hepatitis C infection has impacted my family. I do not think they have ever accepted how hard the treatments are and I have felt the need to keep things from them to protect them, especially my daughters

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27. One of my daughters has come to appointments with me, especially when I had switched off when I thought the cancer was going to kill me. She is quite vocal and questions aspects of my treatment. My daughters were initially afraid for their children when we discovered my infection. I saw the look on one daughter's face when my grandchild kissed me and she was horrified. This was incredibly upsetting and caused me a great deal of anguish.

28. I remember a time when I picked my granddaughter up from school and she went to hold my hand, but I remembered I had a cut on my hand and pulled away. The look of hurt on her face was one that I will never forget

29. I have always been very careful since my diagnosis. I do constantly worry, though, about the time when I did not know I was infected. I was infected when pregnant and throughout my children's childhood. I

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I think some, even my daughter's partner, the GP, feel I should not have contact with my grandchildren. I don't see them as much now, anyway.

Section 6. Treatment/Care/Support

30. The treatment I had for my Hepatitis C was incredibly difficult and has not yet been fully successful. Initially, I was treated with injections of Ribavirin and Interferon that I administered myself. This treatment was incredibly difficult. On several occasions my bone marrow crashed and I was not producing red blood cells. I had to go to hospital and have blood transfusions four or five times, and each time I had four-unit transfusions. Unfortunately, Donna Blinston was on maternity leave when I had my first round of treatment, otherwise I think I would have had an easier time of it.
31. The treatment was very hard on my body. I remember times I couldn't sleep as my heart was pumping so hard and loud and I found it very frightening. It turned out I have a strong aversion to these treatments. I had to be taken off the treatment because of how badly I reacted, despite them wanting the treatment to go on for longer. My body began rejecting the blood transfusions. In the end, the treatment did work and cleared me of the Hepatitis C virus for a short time.
32. I had to undergo further treatment when the Hepatitis C virus returned. I now have to take Ribavirin, Interferon and another drug called Maviret -100mg (glecaprevir and pibrentasvir).
33. I spend most of the time while undergoing treatment lying in bed just drifting in and out. There are a lot of gaps in my memory from time undergoing treatment because it makes me so ill. I do wonder if it is all worth it and I am not sure I would undergo a further round of treatment if this one is not successful.
34. To have this round of treatment, my case had to go before a medical panel to decide if I would get it. Donna Blinston told me that one member of the panel did not want me to have the treatment. I was really surprised to learn that they did not want me to get treatment for

an illness they gave me! I have faced other obstacles to treatment as I have sometimes had to drive a long way to get my medication or to get to appointments. I know there is a shortage of my treatment in Wales and with Brexit it is expected there will be a further delay in getting treatment. This is a worry.

35. I have never been offered psychological support or counselling before, but Donna Blinston recently offered it to me. I am a very private person and I don't know if I could cope with counselling. However, as time goes on, this is affecting me more and more. I have become convinced I will never beat this virus. Donna Blinston has also given me this impression, that it would be hard to cure the Hepatitis C. Although she remains upbeat, I can read between the lines and I know Hepatitis C has given me what should have been terminal cancer before.

Section 7. Financial Assistance

36. I have received financial assistance from the Skipton fund. Donna Blinston told me about the funds. I applied with her help shortly after my diagnosis. I was encouraged to claim by another doctor, too. I was rejected at first but Donna went through my medical records for a week and helped me with the appeal. I was successful on the appeal and I was awarded £20,000.
37. I did not initially apply for the second stage payment, though my liver was cirrhotic. Dr Canavan, my specialist had said it would not be worthwhile for me as there was minimal damage. However, I did not think that was true. I applied for the stage two payment when I developed cancer and received £50,000 in 2017. I used some of the money I received to buy out my ex-husbands share of the home.
38. I also applied and received financial assistance from Caxton. I felt I had to beg for the money and it was hard to get it. I feel it should not

have been like that. I remember a time I applied for help with my car because I could not afford to repair it but needed the car. Caxton requested I send them quotes, but this was difficult without a car to get around. When I found a repair company, Caxton contacted them directly, which in a way told the repair company I had Hepatitis C, which made me uncomfortable. As I've said even some of my immediate family don't know I found the process very frustrating. I don't think I should have had to beg nor have had my personal information broadcast and I was really upset about it.

- 39. I now receive payments every three months of about £4,000 from the Welsh NHS system. I think it is unfair that we get less than those in Scotland and feel it should all be done from Westminster as they were in charge at the time.
- 40. I do not think there were any preconditions to getting the money.

Section 8. Other Issues

- 41. I am very grateful I have never donated blood, though I did want to when young as they were desperate for blood then. I am sure they would have caught my infection had I donated blood, so I am glad I have not infected anyone else in this manner.
- 42. I would like to know why when the Government realised that infected blood was used in transfusions, leading to many becoming infected with HCV, there was nothing done to alert them. If my diagnosis had been made prior to 2012 and treatment received earlier, I may have avoided some of the problems I have had, including my cancer. I would also have been stronger and more able to fight some of the side effects of the treatments and the associated difficulties these presented to myself and my family.

43. I do want to see people punished for what they have done wrong. I have been told the Inquiry will be a whitewash and I don't expect much to come from it, though I hope it will.
44. Other countries have dealt with this far sooner so why didn't we? Those responsible have been punished elsewhere. I get the feeling that whoever in the system allowed this to happen just doesn't care. Whilst an inquiry twenty years ago would not have cured me, I feel it would have shown that people cared and it is more likely that those involved could have been brought to account.

Statement of Truth

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

Signed GRO-C

Dated 3.4.2019