

Witness Name: Carole Alder

Statement No.: WITN3615001

Dated: 28 August 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF CAROLE ALDER

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 1 August 2019.

I, Carole Alder, will say as follows: -

Section 1. Introduction

1. My name is Carole Alder. My date of birth is GRO-C 1947 and I reside in GRO-C I am married and retired with two adult children.
2. I intend to speak about my Hepatitis C infection. In particular, the nature of my illness, how the illness affected me, the treatment I received and the impact it had on my family and our lives together.
3. This witness statement has been prepared without the benefit of access to my full medical records.

Section 2. How Infected

4. I received blood transfusions on GRO-C 1974 at Northwick Park Hospital Maternity Wing in Harrow, Middlesex. I was experiencing a difficult pregnancy with my second child and had haemorrhaged severely in hospital prior to giving birth. The transfusions were requested by the on call Consultant Gynaecologist. My son was then born 10 weeks premature.
5. I was not given any prior information regarding any risk of infection that these transfusions might contain. The consultant made the decision as an emergency, stating that action was required to save the life of my child and myself as I was extremely ill at that particular time, having haemorrhaged severely.
6. I think I was given at least two blood transfusions. To my knowledge, I was infected with Hepatitis C as a result of these blood transfusions. This is the only occasion on which I have received a blood transfusion. The specialist consultant I later saw at St Mark's Hospital said that the transfusions I received would have been unscreened blood and were therefore almost certainly how I contracted the disease.
7. I was diagnosed with Hep C by my GP in 2011/2012 following a stomach infection. I was not responding to treatment and was further investigated with a blood test for my liver function, to rule out Hep C. My GP was not expecting the test to come back as positive, as I had no history of liver problems. A second positive blood test for Hep C meant I was referred to a specialist unit at St Mark's Hospital for further diagnosis. I also had an ultrasound scan arranged.
8. The GP had little information to give me, but assured me that the hospital would provide specialist care. St Mark's were quite exceptional

and provided excellent support, information and care, however, it was a long wait of several months to get to the right specialist department.

9. Following the initial diagnosis my anxieties were not helped by looking at Google, etc. and I was very concerned that I would be infecting my family, my grandchildren especially. It also was difficult to talk about with anyone and I felt isolated. Information from the hospital at this stage would have helped, as the delay in being referred and then getting the appointment was some months (possibly up to six months). I cared for my grandchildren one day a week and feared I would be passing the infection to them.
10. I was disappointed by the long wait for the hospital appointment and, had I been younger, this would have really affected my work. Earlier information on the illness may have helped but you would also need the support of the Hepatitis nurse to explain the treatment possibilities.
11. Once I started attending the hospital I felt I could cope with the diagnosis. The news that my genotype (3A) was able to be treated gave me hope. Before that I was not sure of the outcome as the results of tests needed professional explanations.
12. When I was first diagnosed, my GP did not explain the risks. A short appointment would not have been long enough, but I think it is such a little known area that until you reach the Consultant level and they explain the genotype, treatment and tests, you are very much on your own.
13. After the hospital visit, my husband had to arrange with the GP to have a Hep C test himself. This was negative but again this gave more weeks of delay and uncertainty for the family.

Section 3. Other Infections

14. The hospital recommended I take an HIV test and this was thankfully negative. I am not sure how I would have reacted to a positive result; this would have really been difficult and extremely devastating for the whole family.

Section 4. Consent

15. I do not recall specifically consenting to the transfusions, but I would have agreed to them anyway given the consultant's advice and how ill I was.
16. I do not believe that I have been treated or tested without my knowledge or consent, or for the purposes of research. Although, as outlined above, I would have liked to receive more information about my diagnosis at an earlier stage.

Section 5. Impact

17. The only symptom I noticed that may have been related to my Hep C diagnosis was that my memory wasn't as good as it had been. I started to write down things I needed to remember, to make sure I did them.
18. I started treatment on 14 January 2013. I received the Interferon and Ribavirin course of 6 months treatment, tablets and injections. I had to wait for the treatment to be approved by N.I.C.E (National Institute for Health and Care Excellence) and this did delay the start of the treatment for several more weeks.

19. There was no other available treatment that I was aware of. St Mark's is a highly specialised unit and would have known what was then currently available and if practical in my case.
20. The treatment itself would have been difficult without support, as my husband was able to do the injections into the stomach for me. I arranged that I would have the injections on a Sunday so that they had worn off for me to work later in the week. At the time, I was self-employed and working Thursdays and Fridays.
21. I felt very tired and slightly unwell for a couple of days after each injection but as I got used to the regime, I coped very much better.
22. The only ongoing complication that I am currently aware of has been the thinning of my hair. This started with the Hepatitis C treatment and has never really recovered. I did find when I had the treatment I was much more short tempered and agitated which could be difficult and I had to control the panic feelings and anxiety.
23. Each blood test returned better results once treatment started. I have a letter dated 4 June 2014 which confirmed that I had a negative viral load. I continue to have annual blood tests, which have all been clear.
24. My dentist is aware that I have had the condition and always checks that I am still clear from the results of annual blood tests before treating me.
25. It was very difficult to tell the family what was wrong to start with as I was quite emotional myself. It took me a month or two to tell them. The grandchildren were only young and I made sure that they had no reason to suspect I wasn't well, as this may have frightened them. I looked after two grandchildren one day each week so this had to be

managed carefully. I was not sure if I had already infected anyone else in the family, and I am not sure even now, 8 years later, if I could have.

26. The trauma of realising that you may not be able to be cured, you may have infected other family members and that you can't talk about your illness fearing social exclusion is quite overwhelming. My family were exceptionally supportive and loving which made all the difference.
27. The stigma of having Hep C was very upsetting, in that I could only tell a very few close friends and family what was wrong. Based on what I had read on Google, I was under the impression Hep C was largely a sexually transmitted disease. I didn't want to tell people what was wrong because of the connotation with this. Friends that did not know had their own ideas of why I was having treatment and this could be very awkward on occasions.
28. Because I was semi-retired when the infection was diagnosed and my husband had also retired, the symptoms and treatment could be managed quite effectively. We were very fortunate to live so close to St Mark's Hospital where I was treated.
29. My family were naturally concerned but we were able to cope together extremely well, we work as a team normally and this helped enormously. However, it did restrict going to visit family abroad, I was concerned about travel insurance and whether I would have been covered. This was a problem, as they didn't understand nor believe the restriction of my health problems.

Section 6. Treatment/Care/Support

30. I was able to be treated at St Mark's Hospital in Northwick Park. This is a highly specialist unit and is very close to where we live, which made travelling and attendance very easy.

31. The nurses were exceptional and I had a Hep C specialist nurse who explained very clearly about the treatment. I could phone or text her personal mobile and she would reply very quickly if I had a question. She would book appointments for me, and each visit to the hospital was with her and the continuity was really supportive.

32. I was not offered any counselling in relation to my diagnosis, but I'm sure I would have received it had I asked the nurse for it. She was extremely supportive and explained everything really helpfully. Most of all she said, "if you're not well, or if there's something you don't understand, we're here".

Section 7. Financial Assistance

33. I have only just found out that there is an official England Infected Blood Support Scheme and I have made enquiries about this but this is at a very early stage.

34. I first heard about the EIBSS from the Hepatitis C Trust counsellors a few weeks ago, when I called them to ask about the Inquiry. I am in the process of preparing an application for the EIBSS.

35. I have not previously applied for any financial assistance in relation to my Hep C diagnosis.

Section 8. Other Issues

36. I have no further evidence to give or issues to raise, I am just grateful to have been treated successfully.

Anonymity

37. I do not wish for my evidence to remain anonymous.

38. I would be interested in giving oral evidence to the Inquiry, depending on location and timeframes.

Statement of Truth

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

Signed _____ GRO-C _____

Dated _____ 31/8/19. _____