18 FEB 2019

Witness Name: Lee Simpson
Statement No.: WITN0323001
Exhibits:
Dated:

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF LEE SIMPSON

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 10th December 2018

I, Lee Simpson, will say as follows: -

Section 1. Introduction

1. My name is Lee Simpson. My date of birth and address are known to the Inquiry. I intend to speak about how I was infected with Hepatitis C through blood transfusions I received in 1989 following a motorbike accident.

2. I work part-time as a Security Officer. I have been married to my wife, Diana, for approximately 11 years. We have two children together: GRO-C aged 10, and GRO-C, aged 7. My mother, Pauline Simpson ("Mum"), lives nearby and helps us a great deal.

3. Being infected with Hepatitis C has had a serious impact on my physical and mental health. I received treatment for the infection in 2011. Although this treatment was successful and the virus is no longer active, I still suffer

from ongoing side effects of that treatment. I often feel exhausted and have to spend a significant part of each day resting. These side effects continue to affect my quality of life and have an ongoing impact on my family.

Section 2. How Infected

4. On 11 December 1989, when I was 19 years old, I was seriously injured in a motorbike accident. I was driving the motorbike and my girlfriend at the time was sitting on the back. We were driving on a dual carriageway towards Derby and there were two young children playing chicken on the road. They ran out in front of me and one of them hit me in the chest. I held onto the motorbike with my left hand as it went down, which caused my arm to spin around, damaging the nerves. I lost use of my left arm as a result. I was wearing a helmet at the time and was not speeding but, because the impact was so severe, I sustained further injuries as I hit the ground. I shattered my right wrist and fingers and punctured both of my lungs. I also broke my nose, a cheekbone, both of my collarbones and a number of ribs.

5. My girlfriend at the time, who was on the back of the bike, only received a small scratch on her ankle and was not seriously injured.

6. I was taken by ambulance to the Derbyshire Royal Infirmary ("the Hospital"), which has since closed. My aorta had been punctured in the accident and so I was losing blood quickly. It was a life-or-death situation. I still have a scar from where they had to open my chest during an emergency operation to find where the damage was.

7. I was given three blood transfusions at the Hospital, one after the other. I was unconscious at the time of receiving the transfusions and so was not given any information or advice about the risk of being exposed to infection. Mum was at the Hospital at the time but she has told me that she was also not informed of the risks.

8. Following the accident, I was in a coma for many weeks and was on life support. The doctors at the Hospital told Mum that I was brain dead and suggested that my life support should be switched off. Mum later told me that she had seen a tear coming down my face and was convinced that I would wake up. She refused to let them switch off the life support.

9. Eventually, I regained consciousness. They called me "the miracle man" at the Hospital as they had never known anyone to survive after sustaining such serious injuries. In total, I spent three and a half months at the Hospital as an inpatient, most of that time in intensive care. I had to have physiotherapy, hydrotherapy and occupational therapy.

10. After I was discharged, I stayed at my Mum and Dad's house but my treatment continued for about 18 months.

11. I married Diana in 2008 and our first son, GRO-C, was born in 2008 GRO-C GRO-C GRO-C GRO-C

12. Shortly after the blood test, around October 2010, I received a telephone call from GRO-C while we were on a family day out at a farm. They told me that they had received the results of my blood test and they showed that I had Hepatitis C. They did not ask me to come in so they could tell me in private. They just told me over the telephone. It came as such a shock and I had a panic attack upon receiving the news. At this stage, I did not know how I had been infected. They just told me that it was important that I make an appointment with a liver specialist so I could get treatment.

13. I was referred to Dr Austin, a liver specialist at the Derbyshire Royal Hospital. Dr Austin was very good to me and I feel that he kept me well informed. He told me that Hepatitis C was a blood infection and that I would have been infected through the blood transfusions I received in 1989. I was

told that I had cirrhosis, scarring on my liver, from the Hepatitis C and that this would not get any better. Dr Austin also explained that I would need to have a liver biopsy and then receive treatment in order to rid the Hepatitis C from my blood. He did warn me, however, that the treatment may not be successful.

14. I believe it was also Dr Austin who told me about how the infection could be passed to others. He told me that the infection was very contagious and could be transmitted through sexual intercourse and blood. GRO-C GRO-C GRO-C GRO-C Dr Austin advised that Diana and I would need to take precautions and use protection to make sure the infection was not passed on to her. The fact that I could pass it on made us very nervous and I was worried about the possibility of passing it on to others if I had cuts on my hands.

15. I have never taken drugs in my life and have never used dirty needles. There is no way I could have contracted Hepatitis C from someone or somewhere else.

Section 3. Other Infections

16. As far as I am aware, I did not receive any infection other than Hepatitis C from the blood transfusions

Section 4. Consent

17. As far as I am aware, I was not tested or treated without my knowledge or consent or for research purposes. I do not recall having any blood tests before 2010 GRO-C and so I believe that this would have been the first time doctors became aware that I had been infected with Hepatitis C.

Section 5. Impact

18. After I was diagnosed with Hepatitis C, I had to have a liver biopsy which was very painful. They warned me about what they were going to do beforehand and I was awake during the procedure. It was frightening and horrible.

19. I started treatment in early 2011. This was Interferon and I was given it at the Derbyshire Royal Hospital. The first stage of treatment involved having regular injections in my stomach over a period of three months. I was given the option of doing the injections myself or getting them done at the hospital. At first, I received the injections at the hospital but then they gave us a sharps box and Diana learnt how to administer the injections at home. The injections were very painful and would leave bruises on my stomach. After the three months of injections, I was on medication for six months I can't remember the name of it now.

20. During the treatment, I was very ill and exhausted. However, we had been warned that the treatment had serious side effects so we were prepared for this.

21. When I completed the treatment, they advised me that it had been a success. I was told that the Hepatitis C would still be in my blood but that it was no longer active. We thought that I would be able to go back to a relatively normal life. However, the fatigue that I had experienced during treatment did not get any better. Although we were prepared for the serious side effects during treatment, we were not prepared for these to continue even after the treatment had been a success. No one had told us that the side effects could be permanent, not even Dr Austin.

22. The treatment has left me with fatigue, exhaustion and headaches which have become worse over time. I now need to rest for a significant part of each day. I spoke to my doctor about this in mid 2018 and was told that

there is no realistic expectation of me getting any better than I am now. I did not expect that I would have to live with fatigue and exhaustion for life.

23. The worst thing, however, is the stress and panic that I have been through. I had a panic attack when I was first told over the telephone that I had been infected. I had never experienced a panic attack before but now I suffer from them regularly. I also suffer from depression, anxiety and paranoia. I find I am extremely impatient and often intolerant of others. I do not like these feelings but find it difficult to control. It was definitely after the Hepatitis diagnosis that I developed these symptoms.

24. When I was first diagnosed, the doctors could not give me any assurances that the treatment would be a success. They said because I had been infected so long ago, it might not be possible to clear it from my blood. Because of this, we thought it was more likely that the treatment would not be a success and I had to accept that I might have it for the rest of my life. It was difficult to cope with this at the time.

25. When I was receiving treatment, I had to go to a hospital where almost everyone else was an alcoholic or drug-user. I had to listen to people talking about biopsies and how painful they were. I had to discuss what I was going through with people who were there because they had drug and alcohol problems. When people were visiting the hospital, they looked at me in the same way. They know people are in there because they are alcoholics and drug-users and they painted me with the same brush. It made me feel dirty.

26. Because there was a risk of me passing on the infection to others, I felt that I had to be completely honest with everyone. My family were very good to me and they understood what I was going through. Diana was always there for me but we found it difficult and embarrassing having to explain to her side of the family that I had been infected. Even though they were understanding, I still felt dirty and as though I had done something wrong.

27. When I found out that I had been infected, I was working as a Security Officer at the Derby Central Library. My manager at the time was very good to me. I took six months off while I was receiving treatment and was able to come back to work on a phased return, working only a few hours a day. When I returned, I thought that it was only fair that I explain to my colleagues the reason why I had been away. I felt like I owed it to them to be honest but I found it embarrassing and difficult having to explain to people that I had Hepatitis C. Once everyone found out, I felt as though some of my colleagues started avoiding me. They would not want to shake my hand, come close to me or share a mug with me. It took my confidence out of me and drained me. I genuinely felt like people did not want to be near me.

28. I also had to tell my dentist and GP. It is embarrassing having to discuss it in front of a secretary or dental nurse who I do not know. There is a stigma around Hepatitis C and people assume that you must be a drug-user. Everyone thinks of it in a dirty way. I do not want to be thought of in that way but people automatically think the worst.

29. Even now, the doctors and dentists bring it up and tell me that, although it is not active, I still have Hepatitis C. Hearing that still upsets me and makes me feel depressed.

30. My family has also been seriously affected by the infection and the ongoing side effects of my treatment. It has been difficult for Diana, particularly before I cleared the infection. She wanted to support me as much as she could but we did not want her to be infected. We were very rarely intimate. We tried to use precautions initially but then Diana became pregnant with our second son, GRO-, and she had to get tested again. The tests came back clear but, after this, she felt she had to avoid me as she had to protect not only herself but also the baby. It put our relationship under a lot of pressure and we had a lot of arguments. We almost split up a couple of times, both during and after my treatment.

31. The Hepatitis C has affected our family life quite seriously. It is frustrating that I have to spend so much time resting and do not have the energy to play with my children or take them to the park. Diana has to take the kids out on her own and we cannot do things as a family.

32. Having Hepatitis C has also impacted my family and I financially. Because of the fatigue, I can no longer work full time hours. I currently work 16 hours a week and even that is tiring for me. Diana cannot work as she is my carer and looks after the children. I feel like I have let Diana and my family down.

Section 6. Treatment/Care/Support

33. During my treatment, I did have some difficulties in relation to transport to and from the hospital but I do not feel that I faced any significant obstacles in accessing treatment. As far as I am aware, I was not denied any treatment that ought to have been made available to me.

34. I was not offered any counselling or psychological support and no one spoke to me about the psychological consequences of being infected. I only remember being informed of the physical effects. I also do not believe anyone spoke to me about how to manage the stigma of being infected and I was not offered any emotional support in relation to this.

35. The only psychological support I have received since being infected was offered by my previous employer when I was struggling with anxiety and depression. I was referred to occupational health and attended a few counselling sessions.

36. I have not attended any support groups. I do not have the energy for it and I am not as sociable as I used to be. I just want to spend time with my family and my pets. I would not want to discuss it and bring it back up. Every time I have to talk about, it I have to relive it all again.

Section 7. Financial Assistance

37. While I was receiving treatment in 2011, someone at the hospital mentioned that I may be able to receive financial assistance from the Skipton Fund by way of a lump sum payment of £20,000. I contacted the Fund and had to fill out an application form. I did not experience any major problems when applying for this initial lump sum payment but it did take me a while to get together the necessary documents. We had to request my medical records from Dr Austin and get him to fill in a statement. There was a fee of £250 for this that we had to pay upfront out of our own pocket. This was later reimbursed but not until we had provided a receipt from Dr Austin, which took us a while to get. This is the only difficulty we experienced in relation to this initial application.

38. My application was successful and I received the payment of £20,000 late in 2011. I received the payment a lot quicker than we expected. We noticed the money in our bank account before we received the letter saying our application had been accepted.

39. Following this, I received a regular payment of £250 per month. We started receiving this payment in late 2012 but it was not backdated. I think it is unfair that this was not backdated when there are others who have been receiving this financial support for years. It is not our fault that we were not informed earlier about this assistance.

40. We then, in about mid to late 2017 received a letter saying that we could be eligible for a higher level of financial assistance if the infection still impacted my life. I understand this was typically for individuals whose treatment had been unsuccessful and were still suffering from cirrhosis of the liver. However, they decided the higher level could also be given to people like me who were still impacted by fatigue and exhaustion. We started receiving the higher amount from October 2017 and they backdated it to April 2017.

41. More recently, in around October 2018, they introduced a child and working element which increased the monthly payment by £600. I now receive

approximately £2,100 pounds per month. We can continue to receive the child and working element only while GRO-C and GRO-C are under 18 years of age and as long as I continue to work. Once I stop working or once both kids have turned 18, whichever is sooner, we will lose the additional £600. We will lose a proportion of this when my eldest son turns 18.

42. We did experience some difficulties when applying for the child and working element and found the application process quite stressful. We had to disclose a lot of personal information and provide them with documentation showing every penny we earn. They wrote to us and advised that they needed to know Diana's employment details and how much she was earning. We told them that Diana was not working and our first application was rejected on this basis. We contacted them by telephone and told them that we did not understand why it was rejected given the payment should be on the basis that I am working, not Diana. The person we spoke to on the telephone agreed that it did not make sense so we reapplied. Our second application was successful.

43. The monthly payments will only continue for the rest of my lifetime and I do not think this is fair. I am not the only one who has been impacted by my infection. Diana does not work as she has to care for me and look after the children. In many ways, she has taken the brunt of it and, emotionally, she has been affected just as much as I have. Because of this, I feel that Diana and the children should continue to get help if something happens to me. They should be secure for life financially because of what they have put us through.

Section 8. Other Issues

44. There is one major thing I cannot understand and which does not seem acceptable to my family and I: if they knew all those years ago that they were bringing infected blood across from overseas, why was I not called in earlier and blood tested? If I had been alerted to it 20 years ago when they

found out about the risks, I could have received treatment much earlier. The scarring on my liver would not be as bad and I would not have been unknowingly running the risk of passing the infection to others for so many years. I feel that, as soon as they found out about the risks, anyone who received a transfusion during that period should have been called in to be checked for Hepatitis. It worries me that, if we had not found out about the infection ourselves when we were seeking fertility treatment, we may still not know about it now.

45. I also feel very strongly that somebody should have been found to be responsible. I do not understand why they would continue to bring blood into the country if they knew it was infected. In other countries, pharmaceutical companies have been held to account. I do not understand why no one has admitted liability in the United Kingdom. Somebody needs to be made accountable.

Statement of Truth

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

Signed GRO-C

Dated 14 02 2019