

Witness Name: Collette Poole

Statement No.: WITN5689001

Exhibits: **NII**

Dated:

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF COLLETTE POOLE

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 26 March 2021.

I, Collette Poole, will say as follows: -

Section 1. Introduction

1. My name is Collette Poole. My date of birth is GRO-C1979. I am the partner of Mark Shaw who has also provided a statement to the Inquiry. **(See WITN4999001)** Mark and I have been together for around 16 years. When I left school, I briefly worked as a nursery teacher for a few months. I have since been unable to work due to long term health issues.
2. I intend to speak about my partner, Mark and his infection with Hepatitis C (HCV) believed to have been contracted from blood transfusions following corrective surgery for a tonsillectomy in 1988. In particular, I intend to discuss the nature of his illness, how the illness affected him,

the treatment received and the impact it had on him and our lives together.

3. I can confirm that I do not have legal representation and that I have had the anonymity provisions explained to me and I am happy as Mark was to have my story made public.

Section 2. How Affected

4. I met Mark 17 years ago in Manchester. He was upfront with me and told me a couple of weeks after we met that he had Hepatitis C. He told me that he had a tonsillectomy in 1988. The operation did not go to plan, following which he had corrective surgery whereby he was given a blood transfusion. I have known Mark for 17 years and during that time have heard him discuss what happened on a number of occasions. He has stuck to that story all this time. I trust that this was the source of his infection.
5. About five to six years ago, Mark had a blood test at Maidstone Hospital in Kent. I recall his liver function test was very high at seven or eight thousand. He was later offered treatment for his HCV which I believe came in a tablet form. However, Mark was aware from an earlier treatment he received before I met him that there could be severe side effects. At the time, I had also just been discharged from hospital having suffered a heart attack and was solely dependent on Mark to take care of me.
6. As a result, Mark declined treatment. He was worried that the potential side effects of the new medication would prevent him from looking after me. I also have angina, pericarditis, diabetes, high cholesterol and high blood pressure. Additionally, I have mental health problems. I am bipolar and suffer from emotionally unstable disorder. It's easier to list what I don't have! Marks priority has always been caring for me, I'm sure sometimes to the detriment of his own health.

7. I am currently under hospital treatment for my heart and am scheduled for a heart scan next week. Mark and I live with my brother who is my official carer although Mark undertakes the vast majority of my care. It has been difficult in the last few weeks as Mark has done nothing but sleep. He keeps complaining that he feels very drained and that he aches all over. He also says that his liver is killing him. I really am afraid for him.
8. I keep urging Mark to see a doctor. I have been with him for so long that I know when there is something wrong. He is not himself, he is a poorly man. As I am now living with my brother as well as Mark, I have someone to take care of me so that he can go ahead and seek treatment. Otherwise, the HCV will kill him. He is stubborn but he does give in eventually and I will keep at him until he gets treatment.

Section 3. Other Infections

9. I am not aware if Mark has been tested for HIV. A few years ago, when Mark and I were living in Chatham in Kent, I had problems with my liver. I told the consultant that Mark was positive for Hepatitis C. Because I had been with him for 17 years, they decided to test me for the virus, to which I consented. I was also tested for Hepatitis A and B, together with HIV, all of which were negative. I believe I was also tested for another virus, the name of which I cannot recollect.

Section 4. Consent

10. I do not know whether Mark consented to being tested for HCV. It is not something he has mentioned. As referred to above, I consented to be tested for Hepatitis and HIV viruses.

Section 5. Impact

11. When I met Mark in the mid 2000s', he was fit and healthy. Although he had HCV, the effects of the virus had not yet manifested. He appeared to be a healthy man and was muscular, confident and attractive. He was very upfront and as I've said, told me about his infection in the first two weeks of meeting him. He is not the same person as the man I first met. HCV has changed him physically and psychologically. It has dragged him down.
12. I am aware that after his diagnosis, Mark tried to kill himself. He told me that he was in a flat with a few other people [GRO-C] [GRO-C] He only did this once. He was living on the streets at the time and no longer speaking to his family. I think a combination of factors culminating in his diagnosis, triggered Mark to feel that his life was no longer worth living.
13. Mark's immune system is very poor. If he gets a cut, he can bleed for 10 to 15 minutes. If someone has a cold, he will be guaranteed to catch it and will take several weeks to recover – always longer than normal. He has also been lethargic for years which has worsened more recently. There are days when he cannot get out of bed at all. He sleeps all the time. It makes me feel guilty that he is suffering himself but continues to try to get out of bed to help me. It should be the other way around.
14. He also has periods of jaundice where his skin turns yellow. In the last six months, he has developed bodily rashes, particularly over his torso, back and legs. He scratches himself so much that he makes himself bleed. In addition, he seems to be sensitive to light. We bought a new light for outside the bedroom which he claims hurts his eyes.
15. One of the worst symptoms is the frequent night sweats which are absolutely horrible. The moment he gets into bed and covers himself

up, he is instantly boiling. I have to move to the other side of the bed because he is too hot. He experiences this every night. I call him Sonic the Hedgehog because the sweat causes his hair stick up all over the place. But it is no laughing matter his clothing and the bed can be soaking in no time with perspiration.

16. His weight has fluctuated over the years as well. He puts weight on only for it to disappear rapidly. This may be caused by having a poor appetite and erratic diet. He can go days and days without eating. He will cook for my brother and I but will not always eat himself. At times, he will just have toast for dinner, which is not sufficient. He often chokes on his food; he cannot even eat a cornflake or a sweet without choking.
17. His memory is poor. He can recall things from a few months ago, but anything from years back is more difficult. He needs to think hard. A few years ago, doctors suggested testing his memory but I do not know if this has been pursued. Mark and I have been intermittently separated over the years so I haven't always kept track of the course of his medical treatments.
18. Nevertheless, we have always ended up back together. He can be verbally violent but never physically. He would rather hurt himself than anyone else. He is the nicest person you can meet, but also the hardest person with whom to get along. I've definitely noticed that his personality has changed for the worse in the last eight years or so. These personality changes have been the reason for most of our splits.
19. Mark has always been very open about his HCV even if people do not understand the illness. He doesn't speak to his family. I think this may be at least in part the result of his diagnosis. He doesn't seem to bother with having friends. The friendships he does have do not seem to be affected by his illness.

20. Mark has definitely been subjected to stigma as a result of his HCV status. He is godfather to my niece. When my sister's baby was christened, Mark told my sister's boyfriend's mum about his HCV. She looked at him and walked away. My sister knew all along and was understanding.
21. About 14 years ago, Mark went for a coffee with some friends of mine. He tells me that he offered them a spoon to stir their coffee. They wouldn't use it because they were worried about catching the virus. He is a nice person and so it is upsetting to hear that he is treated in this way. It is his nature to be open but this hasn't always been beneficial to him.
22. I do not make friends easily. As a result, Mark's HCV status hasn't affected my friendships to any great degree. I have a few friends with whom I can be open. This is the first time I have been out in months. At the beginning of the pandemic, I said to Mark, you know your life's a mess when you're in a pandemic and your life doesn't change.
23. I worry about Mark constantly. When he is asleep, there are times he seems to stop breathing. I find myself staring at his chest to check that he is still alive. I have a recurring vision that I will wake up and he will be gone. I feel that I'm living with someone with a death sentence hanging over him. One day I am going to wake up and he won't be there. I know that this is inevitable but I would rather it was later rather than sooner.
24. I am very reliant on Mark for my daily needs. He does absolutely everything for me. He does all the shopping, the cooking and a lot of the cleaning. However, this has become difficult in recent years as he is also unwell. In some ways, he needs his own carer. A few years ago, following a big argument, I moved in with a friend because I struggle to look after myself. I can barely stand up due to my health problems.

25. When we lived in Kent, I had access to a social worker which helped us. Mark and I then moved to Manchester. I informed my social worker who promised to contact her boss to have my paperwork transferred to their offices in Manchester. Mark and I have been up here for a year or so but we are yet to hear anything.

26. Mark and I do not have a sexual relationship. This has been the case for years. We are only intimate once in a blue moon. I think he is reluctant because he is still worried that he will transmit the virus to me. I tell him we can use contraception but he still refuses. I think he has just become so set in his ways – for so long he accepted being celibate because of the infection.

27. In the past Mark worked as a chef. However, due to ongoing health issues resulting from HCV, he has had no long-term employment. I doubt that either restaurants nor catering companies will hire a chef with HCV. It is a shame because he was a talented chef and enjoyed his career. Since I have known him, he has only worked intermittently including volunteer work for various charities.

28. When we lived In Kent, Mark tried to register with a couple of different dentists, some of whom refused to see him. He has been troubled with his teeth because of this. In Chatham, practitioners at Gibraltar House agreed to treat him. They weren't bothered about the HCV. However, it wasn't easy. He had to trawl around to find a dentist who would be willing to provide treatment.

29. A few years ago, Mark broke his fingers. He had to have an operation at Medway Hospital. When he woke up, he was in a room of his own. He doesn't know whether or not this was because of his HCV. He will never be able to confirm this, but when he is treated in a certain manner, particularly by health professionals, he certainly suspects that the HCV may be the cause.

30. Various experiences have knocked my faith in the NHS. When I was 14, my mum died at Wythenshawe Hospital from complications relating to angina. She had gone for a heart bypass when she had a massive heart attack on the operating table. They didn't try to revive her but just left her to die. Years later, I met Mark only to discover that he had been given HCV by the NHS. A friend of mine in Kent with known mental health issues killed herself. I felt that the NHS didn't do enough to help.

31. Nevertheless, by the same token, the health service have saved my life. I have had three heart attacks and they have saved me; I have been unwell in other circumstances and they have saved me. As a result, I have very mixed feelings towards the care provided.

Section 6. Treatment/Care/Support

32. Neither Mark nor I have ever been offered counselling or psychological support regarding the circumstances surrounding his infection with HCV. Whilst on one hand, I don't think his illness has affected me as such, I worry about his prognosis on a daily basis. To be honest it's a worry I could do without.

33. I do wonder as well about treatment. I know Mark declined it before and has not tried to get treated of late for his HCV. However, he sees a GP, he has tests for other things. Why is nothing actually offered to him? No one steps up and says to him; you need to get treatment for the sake of your health. There must be a record that he has this deadly disease and that it will kill him if left untreated.

Section 7. Financial Assistance

34. I am aware that Mark tried to apply to the Skipton Fund but that his application was refused. As Mark and I have been intermittently separated over the years, I have not always been privy to such

matters. More information in this regard can be found in Mark's statement.

Statement of Truth

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

Signed GRO-C _____

Dated 8/11-2021 _____