

ANONYMOUS

Witness Name

GRO-B

Statement No.: WITN6871001

Exhibits: WITN6871002-005

Dated: 14th October 2021

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF

GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 3rd September 2021.

I, **GRO-B** will say as follows: -

Section 1. Introduction

1. My name is **GRO-B** My date of birth is **GRO-B** 1963, and my address is known to the Inquiry. I was with my late partner **GRO-B: P** for around twenty years. I am a housewife and mother to two children from a previous relationship **GRO-B** and **GRO-B** I intend to speak about my partner **P** who was born on **GRO-B** 1971 and passed away on **GRO-B** **GRO-B** 2021 from hepatitis C. I exhibit an extract of his Death Certificate under **WITN6871002**. I will speak in particular about the nature of his illness,

ANONYMOUS

how the illness affected him, and the impact it had on his and our lives together as a family.

2. I wish to remain anonymous for this statement.

Section 2. How Affected

3. [P] was a very kind and loving person. He had a lot of drive and always worked very hard. All I can say is that I loved him very much and I miss him a lot.
4. [P] worked as a forklift driver and warehouse worker for [GRO-B] a soft drinks company, before having to leave work due to his poor health.
5. My husband was infected with hepatitis C after receiving a blood transfusion as a child around the age of ten, in the early 1980s. He had attended Ninewells Hospital in Dundee due to blocked bowels and required an operation. As part of this operation and its aftercare, he received a blood transfusion. I know that when he was recovering from his operation, three footballers came to see him and took photos with [P]. You can see the blood bag attached to [P] in this photo. I exhibit a copy of this photograph under **WITN6871003**.
6. I do not believe that either [P] or his family were informed of there being a risk of infection from receiving the blood transfusion.
7. [P] was diagnosed with hepatitis C around seven years ago, sometime in October 2014. I cannot say exactly when he received his diagnosis, but I exhibit a letter from [P]'s medical records under **WITN6871004** which notes his diagnosis having been discovered on 14 October 2014. This is a letter from a doctor at [P]'s GP surgery called Dr [GRO-B] to a colleague dated 15 October 2014. This letter discusses his recent hepatitis C diagnosis and under the heading of "active problems" [P]'s hepatitis C is recorded as having been found on 14 October 2014. Around this time, [P] had his gallbladder

ANONYMOUS

removed at St James' Hospital, Leeds. After he had returned home, he was asked to attend his GP for a blood test. This test revealed that he had contracted hepatitis C and he was given his diagnosis at a further appointment with his GP once those test results had come back. I was not there with [P] when he received his diagnosis, so I can only say what he told me himself following the appointment.

8. I cannot say what information [P] was given about the infection.
9. I don't know whether the information [P] was given was enough for him to understand and manage the infection. All I can say is that he wasn't happy about his diagnosis and was very concerned about where he had contracted the infection from. He just thought he was going to die; I don't think he understood what it all meant.
10. I cannot say whether information about his infection should have been provided to him earlier.
11. I cannot comment on the way [P] received his diagnosis or the tone of that conversation as he did not discuss that with me.
12. [P] did receive information about the risks of cross infection, but I cannot remember exactly what he was told.

Section 3. Other infections

13. [P] did not contract any other infections other than hepatitis C.

Section 4. Consent

14. I do not know whether [P] was ever treated or tested without his knowledge, consent, without being given full or adequate information or for the purposes of research.

Section 5. Impact

15. Mentally, the infection and his diagnosis made [P] very depressed. He saw a counsellor once for his depression but didn't go back as he didn't feel it was helped. [P] was prescribed Mirtazapine for his depression by his GP. I exhibit a note of this prescription under **WITN6871004**. This is a letter which notes his prescription for Mirtazapine under his current medications as an acute prescription. Brain fog was something that affected him quite a lot as well and he really struggled to focus on anything. [P] also suffered from quite bad mood swings, and he could get very angry during these. He could be totally fine one minute, and then he would just go off on one. [P] ultimately felt that his diagnosis was a death sentence, he wouldn't listen to you when you tried to talk it through with him. I remember he would sit at the computer for hours looking up the infection and what it all meant, it felt like he was obsessed with it.
16. In terms of the physical impact, [P] suffered from really bad night sweats. I remember there were times where I would have to change the sheets twice a night because of how much he would sweat. These night sweats started a little bit before his diagnosis, but I would say they got increasingly worse after his infection was discovered. I exhibit a letter to [P]'s GP discussing this issue with night sweats under **WITN6871005**. This is letter from [P]'s Consultant, Dr Lewthwaite, to his GP, Dr [GRO-B] dated 24 August 2016. In this letter Dr Lewthwaite describes how [P] continues to experience "drenching" night sweats. He also suffered from insomnia a great deal and would often really struggle to get to sleep. Similar with the night sweats, [P] had been struggling with his sleep shortly before his diagnosis, but it became a more serious issue for him after his diagnosis. [P] was also admitted to St James' Hospital, Leeds, with jaundice twice shortly before he died. I believe both of these admissions were only a few months before he died. Fatigue was another issue for [P], and he often struggled to even get from his bed to the bathroom. He suffered from diabetes as well, and that paired with the fatigue from his infection made it very difficult for him to move around or even walk.

ANONYMOUS

17. There could have been a lot more issues that [P] was suffering from because of his infection but I can't be sure because he rarely spoke about his infection. He was a very proud man and really didn't talk to many people about his infection. He even made me promise never to tell anyone about it.
18. I know that [P] was told his Liver Function Tests were always quite high after his diagnosis, so he had some liver issues as a result of the infection. [P] also developed asthma in the last few years of his life, I thought that was quite a strange thing to develop at his age, but I couldn't say for certain whether that was something that stemmed from his infection.
19. As [P]'s infection developed after his diagnosis, I felt his health just plummeted.
20. I know that [P] was given medication to treat his infection at one stage from St James' Hospital, but I cannot remember exactly what this medication was. I think this was around two years after his diagnosis. Throughout his treatment, [P] was told that the medication was working and was showing to be successful. After he had completed the treatment, he was told that he had cleared the virus, but he didn't receive any follow-up care after he had finished the treatment. They had told him that once he had completed his treatment, they would arrange for him to have some blood tests to check on the success of the treatment, but they never did. I had thought they were meant to test him every six months or so, but they never got back in touch to arrange that [P] had no follow-up care whatsoever.
21. When [P] was receiving the medication to treat the infection, he would get very bad headaches and his brain fog seemed to get a lot worse as well. I remember there were times during the treatment where [P] struggled to remember what he was doing or what he had just been saying if we talking to each other.

ANONYMOUS

22. I remember [P] was initially told that he would not be able to receive treatment for a year or two after his diagnosis. His doctor at St James', Dr Penelope Lewthwaite, had said that the NHS couldn't afford to provide him treatment immediately as the tablets cost "as much as a house". Dr Lewthwaite was always very open and honest; she would always tell us exactly what was going on. She told us that it wasn't that they didn't want to treat him, just that the NHS would not pay for medication that was this expensive. Dr Lewthwaite told us that if any cheaper treatment became available, [P] would be first in line for it. I don't know if the treatment [P] eventually received was the same one Dr Lewthwaite had said was too expensive initially, or if it was a cheaper alternative treatment. All I know is that it took around two years for [P] to receive treatment.
23. I don't know if [P] could have received treatment earlier than he did, but I know it would have given him some peace of mind if it had been addressed as soon as possible.
24. I remember that because of [P]'s infected status, he had to have his blood samples marked as being infected when he went for testing. I don't think [P] liked that very much, but he had to put up with it. [P] understood that his infection was something that other medical professionals had to be made aware of, so it wasn't a massive thing for him.
25. [P]'s infection heavily impacted our private and family life. Romantically, I think we would be maybe kiss once now and again but there was very little intimacy after he was diagnosed. [P] was very scared about passing his infection on to me.
26. [P]'s fear about infecting other people meant that he always made sure everyone used their own cups, plates and cutlery. Even when people who didn't know [P] came round to the house, he made them use separate things. They often didn't know why he asked them to do this but he was worried about passing on the infection, so he insisted.

ANONYMOUS

27. [P]'s infection got to a stage where he was too unwell to go out or move much further than the bathroom, so we barely went out. Our family and social life really took a tumble when he started to get unwell. There was a point where we couldn't even get him downstairs from his bedroom because we wouldn't have been able to get him back up the stairs afterward. Being trapped in the house like that totally destroyed his self-esteem, he had no get up and go to do anything.
28. [P]'s infection was something that affected our whole household. We would always have to help him move around or get to the toilet and so we rarely got a lot of sleep when [P] was very unwell. There were times where he needed one of us to be up with him all night and that was hard on us all.
29. For me, it was heart-breaking seeing [P] suffer through his infection. I didn't want him to see how it was affecting me, so I always tried to put on a brave face. I remember he would always say things like, you shouldn't have to be doing this or this shouldn't be happening to you, so I did what I had to for us to have as a good a life as we could.
30. The stigma of the infection was something that weighed on [P]'s mind a lot. He didn't want people to think that he was a dirty person, or a person that used drugs, or someone that was having unprotected sex with multiple people. So, he hid his infection from most people, even the majority of his family, for a very long time. It took him years to tell anyone in his family about it, and he only told one of our sons about it. I think the stress of keeping the infection a secret was something that affected us both quite a lot.
31. [P] had to stop working because of his health. His employer did not know about his infection. They knew about his diabetes because the mobility issues stemming from that eventually meant that [P] lost his driving and forklift license, but not about the infection. As his health began to deteriorate, he started taking more and more time off until eventually he was on sick leave for the last few years of his employment. Shortly before he died, his work had

ANONYMOUS

been arranging for him to be placed on a sickness pension plan. That is something I am still trying to follow up on with his employers as they say there are a lot of procedures and insurance considerations they are working through.

32. Financially, [P] not being able to work full-time made our lives very difficult. I remember we had to sell our car at one stage for a much lower price than we had bought it for. We were basically living on pennies for a time.

Section 6. Treatment, Care and Support

33. Other than the two-year wait to begin his treatment, I don't think [P] ever faced any difficulties in accessing treatment, care, or support because of his infection.
34. [P] did not receive any kind of psychological support or counselling as a result of his infection. The counsellor I mentioned him seeing was in relation to family matter years before his diagnosis. I think if [P] had been offered counselling for his infection, it would have been something he would have benefitted from, but I don't think he would have gone. Counselling wasn't really his thing.

Section 7. Financial Assistance

35. I know that [P] received money from the Skipton Fund. I think he received a one-off payment of around £25,000 from them maybe six or seven years ago. I think [P] was told about Skipton by his GP. She filled out all the forms for the application and the process was very straightforward as far as I can remember.
36. [P] also receives around £2,000 a month from SIBSS, which he was transferred over to when Skipton shut down. I am in the process of arranging the payments to be made to me following his death but have not completed

ANONYMOUS

that process yet. I am not sure how P applied to SIBSS or how he found the process of applying.

37. I don't remember there being any issue with applying to either of the funds, as far as I know.

Section 8. Other Issues

38. I have nothing else to bring to the Inquiry's attention.

ANONYMOUS

Statement of Truth

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

Signed

GRO-B

Dated Dec 16, 2021