

ANONYMOUS

Witness Name:

GRO-B

Statement No.: WITN7059001

Exhibits: WITN7059002 – WITN7059008

Dated:

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

Section 1. Introduction

1. My name is GRO-B my date of birth is GRO-B 1986 and my address is known to the Inquiry.
2. I have two daughters, GRO-B and GRO-B, who are 4 and 7 years old. I'm an GRO-B.
3. I intend to speak about my nan, GRO-B: G and her experience contracting hepatitis C via a blood transfusion, the treatment she received, and the impact it has had on her life and our family's life. My mum, GRO-B, has provided a witness statement in detail about what happened to my nan

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I would like to request that my statement is read in conjunction with my mum's because the focus of my statement is on the impact of nan's infection.

Section 2. How Affected

4. My nan was like a mum to me. My mum is great but she worked nights a lot so my nan did a lot of the school runs and cooked our tea. She would often be looking after us. We are a really close family and I was very close to my nan.
5. My nan was infected by a blood transfusion a long time ago. Until recently I was not aware of when or how this came about. After review of my nan's medical records, I am aware that she was given blood for amenia and menorrhagia in December 1977 [WITN7059002]. I have exhibited a document from the time which outlines that she was admitted 1 December to 9 December 1977 at the Bristol Royal Infirmary which outlines that there was a transfusion of blood to increase her haemoglobin levels [WITN7059003]. She did not find out she had been infected for a long time. She was diagnosed with hepatitis C 35 years later, in September 2002. WITN7059002 is a letter from my nan's branch surgery to her main surgery, dated 26 September 2002, which explains that my nan went to her GP regarding her tiredness. The GP undertook raised ALT levels which led to a hepatitis C test proving she was positive. I believe that the doctor who diagnosed my nan made the link between her infection and the blood transfusion, as can be seen within WITN7059002. Either way, we pretty much knew from the outset that the hep C was from the transfusion.

6. At the time of her diagnosis I was 16 years old and had just moved away to

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ristol for an

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GRO-B I was away from home for the first time in my life. My mum rang me to tell me what was going on. I don't often cry but at that point I did. My mum explained that my nan might not be around much longer, possibly it might be 12 months. That was difficult.

7. I was young when my nan was first diagnosed and so I was kept away from a lot of the information given about the virus. One thing I do remember was being told it was transmitted by blood and other bodily fluids. I think my grandad was tested for hepatitis C but I can't recall if the rest of my family and myself were tested. After that I'm not sure what happened, medically, but I came home every weekend to see my nan. I feared she did not have long left.

Section 3. Other Infections

8. My nan was infected with hepatitis C, only.

Section 4. Consent

9. For information on consent, I would request that my mum's witness statement is read.

Section 5. Impact

10. My nan underwent various forms of treatment over the years. Each came with different side-effects. Prior to review of my nan's medical records I was not aware of the different types of treatment but I knew it included tablets and injections, at one point she had to inject herself in her stomach. I know she didn't like to do it to herself so my mum or I used to help her with that. The differences between

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the symptoms of the hepatitis C and the side-effects of the treatment were not always obvious

11. The first round of treatment my nan started was on 17 July 2003 for Interferon and Ribavirin. I have exhibited a letter from my nan's hepatologist to her GP practice, dated 17 July 2003, which explains that she was to start the treatment for either 6 or 12 months based on her genotype [WITN7059004]. The second round of treatment she started was in around April of 2016. I have exhibited a letter from my nan's hepatology nurse to her GP, dated 18 August 2016, which explains that she was on a 12 week course of Viekirax, Exviera and Ribavirin [WITN7059005].
12. One thing that my nan always complained about was tingly feet, it really annoyed her. The impression I got was that it was like pins and needles. It's bad enough when you have that for 15 to 20 seconds but she was continually getting it throughout the day. Whether she was on the bus, in her bed trying to sleep or walking around shopping, she had pins and needles. I don't think 'tingly feet' sounds bad on its own but when you imagine it being 24 hours a day, that must be painful and frustrating. We used to speak about it every week for years and years. It also meant her feet went a bit numb and so she was often tripping as a result. I have exhibited a letter from my nan's hepatology nurse to her GP, dated 13 May 2009, which explains that the pain in her feet was likely due to peripheral neuropathy caused by her Interferon treatment [WITN7059006].
13. I remember my nan being very tired. I saw her all the time – at least weekly, if not more, and especially so when I moved back to my family. I would often walk in the back door and she would be asleep in the middle of the day. She used to be shocked, waking up to find us standing there, but then she got so used to it

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happening that she was no longer shocked any more. In the time it took her to get up and ready, she'd have a sit down and be asleep in moments. She was often exhausted whilst we were out. When we went somewhere, like the garden centre or to a cafe for food, she'd just suddenly say 'alright I've had enough for now, take me home.' **GRO-B** I think this was as a result of a number of different factors, the hepatitis C, the treatment and the mental stress. On top of that she never slept well at night, I'm not sure if that was because of the medication or something else but it seemed to be that all of these added up and her sleep was not the best. It massively impacted how she was in the day.

14. I know she had a lot of dental treatment, she had problems with her gums and teeth. I think it was a side-effect of the Interferon treatment.
15. My nan was a cockney, she was a very upbeat woman. She would often talk about the war and I think because of it she had a 'just get on with it' approach, it was very 'keep calm and carry on'. That went away over the years, it got to the point that she was very negative. I don't know if she was on depression medication but she was certainly depressed in her later years. It was as a result of all her symptoms, her tingly feet and exhaustion, the fact that she she couldn't leave the house and the unknown about the virus. She was suffering and it put her brain into a spin.
16. I remember my nan used to say things such as that she was ready to go, she was ready to die and the time was now. When I left her I would say I that I would see her tomorrow and she would say 'if I'm here, I might die in my sleep'. Sometimes she used to be happy go lucky with that statement, laughing as she said it, but other times she was very depressed.

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17. My nan was up and down, there were times during her phases of depression where she wouldn't leave the house. She didn't want to go out, go shopping or grab some food. She used to sit in her home with the heating on full blast in the middle of summer with no windows open, it was like a sauna. We used to go in to open the windows, get her out in the garden and make her a cuppa. Just to try to motivate her to do something rather than just sit in the house. Looking back I realise one of the symptoms must have been feeling cold, it was often 25 plus on the thermostat.
18. One of the medications she took caused her to hallucinate. She would see things that were not there. We would go over to visit her and she would point at dancing rats with hats and she genuinely believed they were in front of her. At the time I remember it being a bit funny but looking back it was awful.
19. I know she was trying some treatment right near the end of her life, and it was to cure the hepatitis C. As outlined at paragraph 11 I now know it was Viekirax, Exviera and Ribavirin [WITN7059005]. It contained new drugs which were not on the market or prescribed to most people. My nan put herself forward for it. This treatment successfully cleared the virus. I have included a letter from my nan's hepatology nurse to her GP, dated 19 April 2017, which confirms that shows the hepatitis C remained not detected [WITN7059007]. It further states that my nan would be discharged from the hepatitis clinic however due to the cirrhosis of her liver she would continue to be followed up for hepatoma surveillance. I'm not medical, and no one has ever explained it to me, but I think the treatment might have triggered something which caused the cancer. It cured her hepatitis C but she was diagnosed with pancreatic cancer. It was a reasonably untested drug so I do worry that her cancer may have been linked to her taking this new medication.

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20. I had understood that my nan received treatment for her cancer, however after review of my mum's witness statement and my nan's medical records I understand that she did not undergo treatment. I have exhibited a letter from the hepatobiliary surgical unit to my nan's GP which outlines that my nan had an inoperable cancer and chemotherapy was not recommended because it would add minimal time to her life expectancy at the cost of very significant side effects [WITN7059008]. Nurses came out to the house but as a family we looked after her too, we took shift work patterns to make sure she was never alone and always had a friendly face nearby. She was given morphine to help make things more comfortable and she passed away in the house [GRO-B] 2018.
21. The diagnosis of hepatitis C was such a shock on the family. We are all so close. I personally used to cuddle and kiss my nan but with the diagnosis I was worried about doing that. For the rest of her life from that point I wouldn't kiss her. Initially I was too concerned to hug her but after a few years I did. I was 16 when she was first diagnosed and we weren't told a lot about the virus and how it could spread. I didn't know whether I could catch it and so I was always cautious around her. I knew it could be transferred by blood so even something minor like a cut lip could pass it on. Looking back I regret that. I wish I hadn't stopped giving her hugs and kisses.
22. As soon as she was diagnosed I used to worry about her, especially when I worked away a lot. After my grandad passed away in 2009, I worried that my nan was lonely just sitting on her own, when everyone else was working. We all used to ring at any opportunity and she loved that. A lot of people may say we were excessive, but we were rallying around her. Every family has their own way.

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23. **GRO-B** I spent a lot of time in **GRO-B** and back then we wouldn't get a lot of access to communicate with home. I think it was 30 minutes a week. Every single time, my first phone call was back to her and she really liked that. I could explain, to a certain point, what it was I was doing and she used to love hearing about it. She used to tell me all sorts of stories about **GRO-B**

GRO-B

24. We are a close family and I would never complain but there was a lot of running around after my nan which would not have happened if she had not been infected. Nothing is ever an issue in our family so of course we took her about to get food, go shopping or take her out on trips.

25. Work wise, when I eventually got into it, I just cracked on. I would pop back home on the weekends, and I used to make as much effort as I could.

26. When my second daughter was born, my nan was at home. She had been diagnosed with cancer and she wasn't in the best place mentally. We rearranged the house so that she was in the bed downstairs because she could no longer get up the stairs. I had originally fitted a stairlift but she was no longer able to use that. I used to take care of the kids at night after I got home from work, get the tea ready and then put them to bed. Once they were asleep I would try to get about five hours sleep myself and would then go to nan's at about 4 or 5am and sit with her for a few hours. Later in the morning I would go to go to the train station to get to work and during that time she was always on my mind. My job is flat out crazy but I was always thinking about my nan, she never left my thoughts. I remember I was battered at that point. I don't want to complain because I was never not going to do the most I could for my nan. Seeing her like

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that, going downhill, was not nice, especially knowing how chipper she normally was.

27. I remember people at work saying I had black holes for eyes because I had so little sleep between looking after my kids and my nan. I guess my work was affected as a result, although not to the point that I had any trouble with my employers. I did let them know about the situation and they were very understanding. I couldn't always concentrate because I was so tired, but I am the type of person who can operate on five hours of sleep.

28. My brothers and sisters all did everything they could to help too. When my mum would go home for a break from looking after my nan, my siblings and I would be there to make sure nan was not there on her own.. As I had kids they made sure I could go at a reasonable time. She couldn't do a lot for herself at the end, and although she had nurses pop in, we would help her wash and put Vaseline on her lips. She couldn't do much because of the morphine and she struggled to communicate, but she would often squeeze our hand to let us know she was listening. Sometimes she would have a moment of clarity and be able to converse with us too.

29. The kids used to love seeing my nan. I think my youngest is too young to remember her but I'm glad my nan got to hold her. My eldest was coming up to GRO-B when my nan passed and she loved my nan so much. They obviously didn't have a clue about what was happening but I think it was important they spent time together. She was a great nan, and they still speak about her every couple of weeks – it amazes me. There are a lot of photos around the house and perhaps because we spent as much time as we could with her, albeit for a small period of their lives, they do remember her and refer to her as great nan in the

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clouds. When one of the hamsters died, the kids straight away said that great nan was going to look after Rose the hamster.

30. Emotionally we all struggled when nan was ill, but my mum was very upset. It was her mum after all. I very rarely show emotion, I am used to keeping it to myself and dealing with it out the way.
31. After nan was diagnosed, I Googled everything and from my research, and the stereotype I already knew of, I could see that hepatitis was associated with drug use, sharing needles and people who drank a lot. As a result, at the time I didn't mention to people that she had hepatitis C but I do now. When she would go in for treatment she was often sitting in the waiting room with drug addicts. She didn't like that because she worried others would think she had used drugs too, but I didn't worry too much because I knew how she had been infected. Nonetheless it used to play on her mind, I used to say, 'nan it doesn't matter what they think'.
32. When I first found out about her diagnosis, I was studying at GRO-B. It was a lot of pressure but I did thankfully pass all my exams despite travelling back home every single week. Sometimes I would just pop in for a cup of tea and cake with nan, on others I would stay for the whole weekend. I don't think I would have done that if she had not been diagnosed with hep C; instead I might have spent more time with the guys on the course but I was concerned that she was going to die and that I didn't have much time left with her. When I was away she was continually on my mind, not a day went by when I didn't think of her.
33. My finances weren't really impacted by my nan's infection. I did spend money on petrol driving back and forth to see her so often and I would often buy her

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shopping. She would try to insist on giving me the money back for this but I never took it because it was nice to be able to do this for her. We used to take her to the hospital appointments which could include taxi costs or parking fees. I think there was more of an impact on our time than on our finances.

34. I always wondered and worried how the infection impacted my nan and grandad.

I don't have many details but I remember worrying about how it affected their relationship. I remember something my nan said about having a little bit of regret. I think she looked back at a point and she thought perhaps she could have done more with grandad. We used to go on holiday together, my mum, dad siblings and grandparents. In the last 16 years after her diagnosis I think my nan regretted not making the most of that time with grandad. I don't think they went away a lot after diagnosis because of the treatment and the side-effects.

35. I am naturally very calm and relaxed as a person; it takes a lot for me to get angry or upset. Very rarely I might get angry at something as a result of something in life that builds up emotion. I think one of those things is my nan and grandad not being here.

Section 6. Treatment/Care/Support

36. I don't remember nan facing difficulties or obstacles in obtaining treatment, although I recall she had a few different treatments over a period of time. I remember my mum used to push heavily to ensure she received support – whether that be from our local council, benefits or the financial support schemes. She ensured nan had a new bath fitted so she wouldn't have to step over the side because she would trip over quite a lot due to her numb feet. We pushed for a stairlift for her as she struggled up and down the stairs. We applied for a chair to help her get out of her seat properly, treatment to help with her feet,

dental treatment, and a heated blanket amongst other things. We weren't always successful but we pushed as much as we could for support to ensure she was comfortable. A hospice reached out to provide support too. I don't think she would have received as much support as she did if we hadn't pushed for it. As the years went, she needed more to help her.

37. I don't recall any counselling or psychological support. Ten years ago it wasn't a thing you did. I know people do it now and see it as normal as jogging but go back to the 2000s and mental health wasn't really spoken about in the same way. My nan might have been offered something that I didn't know about I find that when you speak to family and friends, that is form counselling and I did that a lot with nan. My mum had counselling – I believe she sought out help.

Section 7. Financial Assistance

38. I have heard of the financial support schemes but I know nothing about them apart from that I know she received some support.

Section 8. Other Issues

39. My understanding is that contaminated blood is a massive tragedy with a lot of people involved and a lot of people affected. I would say my two big hopes are that the government admit they messed up and they acknowledge the impact on both infected and affected people. I recognise that at the time they may have thought they were doing things for the right reasons but I would like the Inquiry to investigate whether there was another route they should have been taking. To me, it doesn't seem that difficult to test blood at the time it was donated.. I think it is important that there is an acknowledgment of what they should have done

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and an acknowledgement of the impact on those infected and the hundreds and thousands of family members and others who were affected as a result.

40. My mum said they are looking to provide compensation but I don't know much about it. I don't understand how it could be paid out when my nan is no longer with us. However I believe that recognition of the suffering goes hand in hand with compensation though, and for me is just as important.

Statement of Truth

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

Signed

GRO-B

Dated

1/9/22