

Witness Name: Allan Mayze

Statement No: WITN2713001

Exhibits: 0

Dated: 6 May 2021

## **INFECTED BLOOD INQUIRY**

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### **FIRST WRITTEN STATEMENT OF ALLAN MAYZE**

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#### **Section 1. Introduction**

1. My name is Allan Mayze. My date of birth is GRO-C 1950. My address is known to the Inquiry.
2. I am the husband of Susan Mayze (Sue) who received contaminated blood during an operation 1983. She was diagnosed with hepatitis C in January 2014 and after a liver biopsy a few months later she was also told she had Cirrhosis.
3. Sue has provided a full witness statement to the Inquiry as an infected individual. Her witness number is W1932.
4. I make this statement as an affected individual in relation to the impact on me of Sue receiving contaminated blood. Sue's statement deals with the circumstances of her infection and the way in which the hepatitis C, the treatment and the resulting medical conditions impacted on her. I ask that the Infected Blood Inquiry considers my witness statement alongside Sue's witness statement.

5. Sue and I have known each other since Sue was 15. We married in 1975 and have a son.

### **Section 5. Impact**

6. In 2004 we moved from London to Kent. Within a few years of us being here Sue started getting very stressed at work. Sometimes I would have to walk on eggshells around her, sometimes we would have an argument that would just come out of the blue. On other days she would be ok.
7. Sue has always been the family secretary; she was in charge of all of the paperwork and was usually very organised. But in the years before she was diagnosed she started bringing work home and I could see that she was struggling.
8. Sue was coming home from work increasingly stressed and crying every day. She was very snappy and things were quite trying for both me and our son as we didn't know what was wrong with her or what to do about the situation. We tried to be sympathetic to how she was feeling but it was extremely difficult dealing with the constant bickering, alternated with bouts of crying. I think at that time we all believed it was down to depression we didn't know at that stage she had Hep C.
9. Sue had been told by the GP for a few years running since 2005 that her liver levels were a bit raised and that they would keep an eye on it. She was given an ultrasound around 2007 and told she had a fatty liver, but not to worry about it. She asked if there was anything she could do to help improve the situation and was told no. No advice was given about eating or drinking to help prevent any further damage and it angers me to know that if something had been investigated more at that time, she may not have been so seriously ill as she became.
10. Sue eventually went to the GP and saw Dr Nilan (unfortunately he is no longer at the practice) about the way she was feeling and also by this

time her legs and feet were getting very swollen. He suggested blood tests and also arranged for an appointment with a Gastroenterologist at Maidstone Hospital. The doctor we saw on our first visit to Maidstone gave us some details about Hep C and asked Sue about her medical history including, alcohol consumption, recreational drugs, sexual partners and had she had any blood transfusions. He had a very nice manner and all his questions were asked in a general way and didn't make us feel concerned or particularly anxious. We were told not to worry and would be given the blood tests results at our next appointment when they would have a better idea of what may be causing Sue's problems.

11. Sometime later Sue received a phone call at work from her GP Dr Nilan and he asked her if she had had a follow up letter from Maidstone. When she said she hadn't heard anything from them, he was very surprised and said unfortunately you have tested positive for Hep C and he wanted to see us that afternoon to discuss things with us. He did his best to explain what he could and offered his apologies, and he gave Sue a copy of the letter he had received from Maidstone. Sue has exhibited this to her statement.
12. Sue and I were both a bit shell shocked and I had a million questions going round in my head, one of which was why hadn't this been picked up on before, especially knowing she had had quite a few operations since the transfusion and had dozens of blood tests over the years. Just thinking about what we have all been through and how much our lives have changed makes me feel so angry. I wanted answers then and still do.
13. I had not heard of hepatitis C before and I did not know anything about people being infected through contaminated blood. I started doing my own research. The doctors tell you to keep to the English websites but these sites hardly give any information. I found out much more from the American sites, I started to learn about how this whole scandal came

about and got more of an insight into who knew what when. There are still lots of unanswered questions of course but I found out more from these websites than we ever did from Sue's doctors or through the NHS. This is how I found out that she could end up getting cancer, the risk of cancer was not explained on the UK sites and the doctors had not told us that this could happen.

14. Sue started treatment, interferon and Ribavirin in August 2014. I went with her to all of her appointments. We were not warned about the possible side effects of this treatment. I have always questioned whether the dose that they gave Sue was right. The levels of the virus came down so quickly but it affected her so badly that it had to be stopped within 9 weeks. She was in such a state. Her personality changed and she was so confused, she wasn't making any sense.
15. It was really difficult to see Sue like that. She was so unwell but they just kept discharging her. At home Sue's behaviour became like nothing I had ever seen in her or anyone else. She did strange things like staring at the ceiling, talking nonsense and she was not able to carry out the simplest of tasks like washing or dressing herself and did not even know how to get into bed, she would just stand there staring at the bed for an hour or more until I would have to pick her up and put her in bed myself. On other occasions she would be at the other extreme and be constantly emptying the cupboards, moving things around, or emptying all her tablets onto the table and mixing them all up together in a big pile. She had to be watched constantly. I had been told help was available if needed but when I tried to get anything there was always an excuse and I was left for months to deal with her on my own. I was almost at breaking point. Then Sue got more and more confused and non-responsive which turned out to be because her platelet levels had dropped to 16 and the hospital rang me and said they were sending an ambulance as she was in danger of going into a coma.

16. Sue was in and out of Maidstone Hospital several times from late September through to November 2014. I knew she had to be in hospital as she was too ill to be at home but I was worried about her care at Maidstone because I just didn't think they knew how to deal with Sue's encephalopathy. On the 3<sup>rd</sup> admission I had to call the emergency doctor at home and when he came, he said Sue would need to be readmitted to Maidstone Hospital, as she was already under the care of Dr Bird. He wrote a letter for me to give to A&E so we could be fast tracked to get Sue seen urgently. When the ambulance came the paramedic was insistent, she was taking Sue to Medway Hospital and I nearly came to blows with her. I showed her the letter and she reluctantly agreed.
17. Lots of things just weren't right when she was in Maidstone Hospital. The doctors would not listen to me, they would ask Sue questions but she would not answer them properly because most of the time she did not know what was going on. But if I gave them the answers they would just ignore me.
18. They would leave her sitting on the toilet, her legs were so swollen that she could not move and would just sit there until someone came to get her. On one occasion I went up to the hospital to visit her, she was sitting stark naked on the bed with the curtains open. All of the staff were just walking past like nothing was happening. I asked her what she was doing and she told me not to worry about it and that it was alright. She just was not in her right mind.
19. She was supposed to be on a low salt diet but the staff at the hospital would let her fill in her own menu requests and so she just ordered whatever she wanted and they would give it to her. We had to put a stop to that, once we realised that was happening either me or my cousin Jackie would go up to the hospital every day and fill out the sheet for her.

20. On the 3<sup>rd</sup> admission to Maidstone A&E, despite the fast track letter I had given to the senior nurse, which she ignored, we were just told to sit and wait. It was 7 hours before Sue was eventually seen by a lady doctor. As Sue had not had anything to eat or her epilepsy medication since the night before she subsequently had a seizure and bit her tongue. started to bleed. She started bleeding from her mouth. I told the staff that she had hepatitis C, they all stood back and I had to pick her up and carry her round to put her on the bed. She was then left in A&E all day before being admitted to the ward when she should have been fast tracked.
21. Eventually in November 2014 she was moved to Kings and the care improved, as far as I am concerned they saved her life. However I still felt as if we were messed around a bit by the doctors there, they would talk to Sue but they would not listen to me. This was very frustrating because they would ignore me even when it was clear that she was confused and I would tell them that the answers she was giving them were not true.
22. This period was exhausting for all of us. I would visit Sue every other day. At this time my mother was in the late stages of dementia and living in Somerset with my sister. I could not see her as much as I would have liked before she died. I was travelling the five hour round trip to Kings every other day and it was just too much to travel to see my mother on the other days.
23. The doctors at Kings wanted to discharge Sue before Christmas 2014 but in my mind she was not ready. I told them that we could not go back to the way that things were before, she was not ready to be at home and out of hospital. The doctors were not happy but it was the right decision for Sue.
24. She was eventually discharged on 2 January 2015. I was told by a nurse that Sue no longer had hepatitis C. In February when we saw Dr Agarwal at the follow up appointment, he said he was sorry but we had been

misinformed about Sue being clear of Hep C at discharge, and that unfortunately she was still infectious.

25. When Sue got home she seemed better to everyone else but was still very confused. She could have passed for normal but anyone who knew her knew that she was still really unwell. In a way this was the most difficult time.

26. My head was in turmoil watching the change that had come over Sue. I had to stop researching online, the things that I was finding out about contaminated blood were making me more and more angry. At first I could not believe half of it but I know now that most of it is true.

27. I don't know how to explain the impact that this has had on me. I feel angry, frustrated, helpless. It is something that is completely out of my control. I worry about Sue constantly. She has had epilepsy for the whole time I have known her, but this is different. If she has a fit she is tired the next day but this is never ending, we live from one hospital appointment to another. When she was really ill she was so helpless and was in so much pain, time just seemed to drag on and on. Now I feel as if I am forever waiting for news and I never know whether the news is going to be good or bad.

28. I find the whole subject of the effects and affects of our Contaminated blood experience and Sue's ongoing health issues, almost too much to deal with. Even receiving emails from our solicitor or news about the Inquiry makes me extremely anxious, irritated, angry and emotional because of the memories that haunt me. If it was possible I would prefer to run away and pretend none of this had ever happened. I am a shadow of the man I used to be.

29. I feel robbed of any future plans I may have had because of having to put Sue's needs before my own. I am a very private person and would not want to speak to a medical professional about the way that I feel. I stumble through each day and do the best I can, but I often feel that I

push myself to the point of exhaustion. Sue was always a fairly independent person, I know that having to be reliant on me makes her feel guilty and sad, and is frustrating for both of us.

30. I personally didn't feel any stigma towards me, but I felt angry that Sue had been put in this situation through no fault of her own, and she was terrified to tell anyone for the best part of a year. The impact for us both is felt in almost everything we do, whether its planning for the future or just dealing with everyday things like shopping, cooking, housework, socialising even down to not being able to have a dog because of the amount of medical appointments Sue has. Leaving an animal alone for almost a whole day each time just wouldn't be fair.

31. Our son found it very difficult to talk about and still does, as rather like me the situation made him feel extremely angry. He became somewhat withdrawn and would stay in his room. He rarely visited his mum in the hospital as it upset him to see her the way she was. Plus, he could never get any straight answers from anyone as to what was happening. All he could see was his mum gradually deteriorating and turning into a very frail woman who resembled a very old lady.

32. A couple of years before Sue was diagnosed I started my own business doing tree and forestry work. The company made a loss the first year but I was just starting to make a profit when Sue became ill. In that first year she could not be left alone and so I could not work and I had to shut down the company.

## **Section 8. Other Issues**

33. All I really want from this Inquiry is the truth. I never used to read the newspaper and did not watch much TV. I remember the blood shortage in the 1970s and 1980s; they should have just cancelled all non-urgent operations until they could be sure that the blood was safe. I did not know anything about Hepatitis C until Sue was diagnosed. I cannot understand



how Sue's hepatitis C was not picked up earlier, she had so many blood tests before she was diagnosed, it just does not add up to me.

34. What efforts have they made to inform people about hep C? So many people were infected and died without being told; think of how many people have lost children and partners and siblings. By keeping the contaminated blood scandal quiet the people in charge have helped to spread HIV and Hepatitis C.

35. I do not understand why people were left to find out for themselves. Records have been destroyed and the whole thing has been hidden for so long. It can't really be blamed on the NHS, it goes higher than that. I feel very frustrated, you try to find out the truth but always hit a dead end. If you try to speak to doctors they are like politicians, they skirt round the issue and only give you part of the answer.

36. The Penrose Inquiry was a whitewash. All anyone wants from this Inquiry is answers. Whatever happens with this Inquiry, it is going to come too late for a lot of people.

#### **Statement of Truth**

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

Signed GRO-C

Dated 6/5/21