

Witness Name: Mrs Sandra Gaye Nowak
Statement No.: WITN1950001
Exhibits: 0
Dated: 14 February 2019

**WRITTEN STATEMENT OF MRS SANDRA GAYE NOWAK
INFECTED BLOOD INQUIRY**

Section 1: Introduction

1. My official name is Sandra Gaye Nowak, but I never use the name Sandra, I am known as Gaye. My address and date of birth details are known to the Inquiry.
2. I married Peter Nowak on 11 August 1979, we had two daughters together. Peter passed away on 28 December 2005. His death certificate states that he died from liver cirrhosis and hepatitis C infection. I am making this statement in Peter's memory.
3. At the moment I am still living in the house that I used to live in with my husband Peter. I have a new partner who lives with me. My eldest daughter also lives with me along with her husband; they are here to save some money for a deposit to buy a house of their own. My youngest daughter lives in GRO-C
4. I have a swimming school business that I run from home.

Section 2: How Affected

5. Peter was a very gentle, kind and loving man. He was really easy going, easy to get along with, really lovely. He made me feel really loved. He adored his children; our two girls. He was an amazing father and a really good family man. The family was his life; our life. He used to love sport and to paint. He painted a portrait of the girls when they were young, which we will cherish forever. He loved badminton and cricket and he was a football goalkeeper. He loved to water and jet-ski.
6. I met Peter when I was 17. I remember that he sent me a six foot valentine card to get me to notice him. Soon after he went to Norway and I thought that was it but he came back. I met him again when I was nineteen. We got engaged two years later and married four years after that; when I was 23 and he was 27. We were besotted with each other.
7. On 16 October 1979; only two months following our marriage, Peter was involved in a very serious car crash. The fire brigade and ambulance(s) were unable to get him out of the car and tried for three or four hours. I have pictures of the emergency services there at the time. It turned out that he lost a lot of blood and had to have blood transfused at the scene. When the emergency services managed to free him he was taken to St Peter's Hospital in Chertsey. I was teaching aerobics at the time, my father came to tell me and we drove to the hospital. When I arrived he was in intensive care and I was told that he was involved in a serious accident and that he had been given blood at the scene. Peter remained in intensive for three days, he was then admitted to the orthopaedic ward; he was in hospital until 9 January 1980, almost three months. His injuries included a broken shoulder; lacerations a very serious burn from the oil on his left leg, he also broke his right leg. He was wearing a leather jacket at the time which protected his face from injury.
8. Peter did not have haemophilia, so this is not relevant.

9. I have indicated above that Peter received a blood transfusion which resulted in him being given infected blood. The blood was transfused on 16 October 1979. The ambulance(s) which stocked the blood that he received came from St Peter's Hospital in Chertsey. I do not know how many units he was given. There are no other ways that Peter could have become infected. He was not an intravenous drug user, he was not sexually promiscuous, and he never had a tattoo. The blood transfusion is the only explanation for his infection.
10. Peter was unconscious at the time that the blood was transfused and he was alone so there was no-one to consult. Therefore neither Peter nor I were informed or advised before receiving the blood transfusion about the risk of being exposed to infection. Following the accident; when I turned up at the hospital, I remember that a medic told me that Peter had been transfused with blood at the scene, even at that point there was no mention of any risk of him being exposed to infection. Peter himself was never told afterwards that there was risk of infection to him of receiving the blood transfusion.
11. Peter was infected with hepatitis C.
12. Peter became seriously ill one day in August 2005; he had been experiencing serious flu-like symptoms for about two months prior to that which eventually led to him collapsing on the floor that particular day. I took him to the doctors. The doctor sent him straight to Frimley Park Hospital in Frimley, Camberley. We had no idea what was wrong with him. He had lots of tests at the hospital. It took quite a while for us to receive the results. Perhaps two weeks. The test results revealed that he had hepatitis C.
13. I think that the consultant that was looking after Peter at Frimley Park informed him that he had the hepatitis C. I remember that as a family we were all taken into a side room in the hospital and informed together about the infection. Being taken into the side room scared me; I was worried about what we were going to be told. We were told that the infection affected the liver and that it was serious and that Peter had developed cirrhosis of the liver. I do not recall being told anything else at that time but I do know that I was relieved that they

had found out what was wrong with Peter; there was a name and a cure for it. I was very, very wrong. To me, this was the beginning of our nightmare.

14. In around November 2005 Peter had found his way to Kings College Hospital for treatment; he was transferred there directly from Frimley Park as his condition was deteriorating. He had really low blood pressure which was very difficult to control and which posed serious threat to his life. We were told at Kings that Peter would need a liver transplant and he would die if he did not have one.
15. I believe that Peter should have been told about the risk of receiving the blood transfusion when recovering from the accident at St Peter's Hospital in Chertsey, then he could have had a chance.
16. I think that Frimley Park Hospital should have discussed with Peter and me first whether they should share the information about his infection with our girls, but they did not. They discussed the hepatitis C with our daughters present in that side room; at the time, they were only 15 and 18 years old. I am disappointed and very angry that we did not know about the seriousness of it all and how it was going to cost Peter his life and devastate us all. This was never ever conveyed to us. I am very angry that we were never told how the infection was transmitted to him.
17. I do not recall being given information about the risks of the transmission of the infection to me and the girls. I do recall being told that we needed to be tested and that we should not share razors. My feelings on this are that this information was provided much too late. At this point, Peter and I had been married for 26 years and apart from the first two months of our marriage; the period before his accident, for the remainder of all of that period of time he carried the infection. All throughout our marriage. We had two children together. We were never aware of the need to be cautious or to use protection, so being told 26 years later that we should get tested seemed crazy. Thankfully our tests were negative.

Section 3: Other infections

18. As far as I know, Peter was only infected with hepatitis C but I cannot be certain.

Section 4: Consent

19. I believe that Peter was treated without his consent, without his knowledge and without being given adequate or full information. At the time he received the transfusion he was unconscious so could not have consented but I believe that he could and should have been provided with information during his recovery or if not then; a short time later. This information should have included what risks there might have been to him in receiving the blood, this would have avoided him losing his life so young.
20. I do not believe that Peter was treated or tested for the purposes of research.

Section 5: Impact

21. The impact of the infection on Peter and his life was immense.
22. The physical and mental effects: Peter sustained a major injury to his left leg from the accident in 1979 from which he never properly recovered from the injury. He had a continuous open wound that he had to dress almost every day. It is my belief that this wound did not heal because of the hepatitis C. The leg injury that he sustained has made it difficult to untangle symptoms that he might have been having as a result of it and symptoms he might have been having as a result of the hepatitis C. As we did not know that he was carrying the virus, we always attributed his symptoms to his leg injury. Looking back now; with the knowledge I now have, his symptoms cannot have been wholly attributable to his leg injury. The hepatitis C must have been contributing to

how he was feeling. It cannot be right that he only experienced hepatitis C symptoms two months before he collapsed in August 2005. I know Peter became very tired, very easily, he became depressed (although it was not diagnosed), and he became more aggressive and angry, which was totally out of character for him. I write with great sadness that the girls recall that their dad used to shout sometimes, when this too was completely out of character for him. I know he experienced flu-like symptoms which were severe and included shaking and chronic fatigue. I used to get frustrated with him because I thought he was being lazy. I feel so sad about this now. Peter was a qualified graphic designer; he worked in advertising and marketing. Eventually he worked for himself from home; he had his own agency. As the years ticked by, I became aware of him becoming more apathetic, he also lacked the ability to concentrate and lost confidence in his work. He eventually stopped working.

23. In August 2005 when we were told that he had contracted hepatitis C, we were also told that it had progressed to cirrhosis and that he urgently needed a liver transplant. All I remember is he kept getting infections in hospital and he struggled to fight them as his liver was so severely damaged. Peter passed away from this condition only four months later, in December 2005.
24. I have explained this above. My lovely husband died very suddenly and as a family we were completely and utterly in shock and devastated.
25. My husband was never treated for the hepatitis C. It must have been too late. I think they were just keeping him comfortable for as long as they could. There was talk of a liver transplant but that never happened. I am not sure it was ever a realistic option. Peter never came home again; not properly, after being admitted to Frimley Park in August 2005, he was allowed out of hospital on 23 December 2005 for a couple of days, I think that he was allowed home because they knew it was going to be his last Christmas. He became more seriously ill in the early hours of the morning of 28 December. The night before, we had been discussing his liver transplant and how receiving one would serve to extend his life, not save it. We had been told the hepatitis C would just come

back. So we were discussing how we might manage the whole thing. There was no mention of treatment for Peter. That night Peter went to bed by himself, and woke me up because he was so unwell. I rang Kings Hospital. They told me to drive him to the hospital and because he was being treated in the private wing I was told that I should drive him straight there. We waited a couple of hours for our daughters to come back from where they had been. I then drove Peter to Kings. The journey turned into a complete nightmare. I got lost on the way to the hospital and had to stop to ask people for directions, all while my husband was collapsing in the car. When I eventually arrived there was no-one there to help us. I had to go to look for the porter to come to help me and when I eventually found him he helped me to put Peter onto a trolley. I knew Peter needed help urgently and I actually had to leave him with the porter while I parked the car. BY the time I arrived on the ward Peter was being resuscitated and he died five minutes later. He died on the 28 December 2005.

26. As far as we were aware the only option available to Peter was a liver transplant. Kings mentioned this when Peter was transferred there in the autumn of 2005, from Frimley Park. Kings said that we would have to go onto a list in order to get a liver transplant but it transpired that the criteria for him to get onto the list was set so high that it was very difficult for him to meet. I had to fight really hard for him just to get onto the list. I took a friend with me to make sure that we put forward the best case for him so as to increase his chances. We found out within days that he had made the list and were so relieved; but, we did not realise how seriously ill he was already. We were never told how long he might have to wait for a transplant but we knew it was difficult to get one. I recall being angry and frustrated because around that time, I knew that George Best had received one and he had abused his body whereas Peter never did. Peter died before he was able to have a transplant. In fact just a matter of weeks after being placed onto the list.
27. My husband was denied the opportunity to clear the virus and to be well again and to receive the treatment he could have had, because he was never told that there was risk of receiving a blood transfusion and not followed up after

receiving one. He was not contacted about the fact that he might have had an infection when the system knew that blood transfusions had become contaminated with the viruses; he was not put on an emergency transplant list when he was first diagnosed or when the medical team must have known that he was very seriously ill.

28. He did not receive any treatment!
29. This is irrelevant because he did not know he had the infection until four months before he died.
30. I was aware of a significant change in Peter's personality in around 2002. He seemed lazy to me and unable to get work. He was also angry and would suddenly shout. I did not like the person that he was becoming. I was aware that he had stopped contributing to our family; both financially and practically. I felt a huge financial, practical and emotional burden. I also learned that he had got into a significant amount of debt; despite the fact that he had experience of work and had built up his own business, he was somehow unable to focus on his work, yet I was holding down two jobs. Looking back now, the debt made sense because he had stopped working. So our relationship as a couple changed. It had stopped working. We slept in separate beds. Peter's social life was his family life; as a family we did everything together which made it more devastating when he could no longer. The hepatitis C had a terrible impact on our family. Once diagnosed our lives revolved around hospital visits, in an attempt to be with him. This was the end of family and social life as we knew it and it became our mission just to try and save Peter. Looking back now and knowing what I do, it all makes sense and I understand what he went through.
31. The true impact of this did not really hit me until I knew about the diagnosis and understood what it meant, but even at that I did not realise the seriousness of it, that Peter was going to die. The impact since his death on everyone has been huge.

32. The impact on me is that I suddenly became a single parent and a widow. I was totally responsible for everything.
33. I was responsible for the mortgage, for a debt of £50,000, for the care and support of my grieving children, for the running of my business which I had to build up in order to survive, for the financial support and care of my elderly mother, for husband's burial, and the list goes on. I was determined to ensure that there was as little upheaval as possible to my daughters' lives. I did not want them to experience further loss.
34. I developed a massive fear of being ill, a fear that I still have. I was frightened because I could not get ill; I had to work to keep everything going. I was under massive stress and constantly worried about money. I had panic attacks. I worked two jobs.
35. The stress and pressure made me very angry and bitter. I constantly asked myself why this had happened to our family. It completely changed my life, our lives. I lost my husband, my best friend, someone that I had loved and been with for 30 years. We lost our plans and our dreams together. I did not know how I was going to get by.
36. One of the worst things is that I felt and still feel an enormous amount of guilt for feeling the anger and frustration towards Peter that I did when all along he was secretly suffering the consequences of such a serious illness. I could have been so much more understanding had I known and I would have loved the opportunity to have made things right. Now I am left with this lingering guilt; it has been with me ever since he passed away. I have felt bad about myself because I did not know. I am sure I would have reacted differently had I known. We could have planned this. We would have taken different steps.
37. I now have a feeling of being trapped all the time. It sounds awful but I am jealous of people who have normal lives.

38. I also feel like I lost a part of my daughters and we all lost our family. It became too hard for us to spend time together because of the grief. We withdrew from each other to try to cope. Our dynamic has completely changed. Every milestone has become so upsetting. I feel a massive loss, a void that will never be filled. I will not share any family events with my husband ever again for example: graduations, birthdays, exam results, engagements, our family get together. This is massive. 13 years later, I expected to have recovered somewhat from this but it remains very, very difficult. I have tried to make things better for the girls but the milestones still feel like huge hurdles. My eldest got married in December 2017; not having Peter there to give her away has had a terrible impact on her, on all of us. We tried to cope and to connect with him and his memory but it has been so difficult. It has had a terrible impact on our family. The pain that my children have suffered and continue to suffer upsets me so much; so much more than my own pain. I have felt it very hard to move forward in my life because I feel I have to protect them. I struggle to be my own person.
39. My daughters' lives have been shattered by the loss of their father.
40. They have felt guilt because their relationship with their father changed, because his personality changed. Of course we did not know why at the time. When he became angry the girls felt it was their fault when actually it was hepatitis C's fault. They could not understand his behaviour.
41. When Peter first went into hospital, my eldest daughter received her A Level results, she was very happy that she had managed to get into Loughborough this was particularly so as it something that her dad very much wanted her to achieve. She was so pleased that she had made her dad so proud but when she left to go to university so it was so hard for her to leave her father, so sick. I had to drive her to university by myself and without my husband, her dad by our side. I feel emotional now thinking of the joy that my daughter got in getting to Loughborough but despair that he could not share it properly with her dad. I

take comfort that at least he knew that she got there and that he would have been so very proud of her. But looking back now I realise the significance of this journey since it was the very first that we were spending an important family event without Peter.

42. The girls were devastated that they were not with Peter when he died, and he died at Christmas. So, the Christmases have been significant for the wrong reasons; they have become shrouded in sadness. We struggle to celebrate it now which makes it even more difficult when everyone around us is.

43. My daughters [GRO-C] [GRO-C] They miss their father every single day. They have suffered greatly.

44. Our eldest daughter [GRO-C] which she has learned to manage over the years. She is a writer and she has written a blog about her father. I include some of what she has written below:

"In one moment, my family was torn apart and my world became something entirely different";

"In one fell swoop he swapped a traumatic and sudden death for a slow fade, subjecting him to a life lived unwittingly under the spectre of death for 30 years";

"My sister and I were left without a father. My mother had her husband stolen from her. Not just on that day but the decades in which he suffered silently with symptoms that were impossible to pin down".

"Not only have we had to cope with the loss of our dad but we have faced all the anguish borne of the darkness surrounding the way he died".

45. Our youngest daughter was only 15 when her dad died; she became very angry with the world and very difficult to cope with. In fact I would say that at

times, she was out of control and I found her very difficult to deal with alone. I just did not know what to do. She also managed to get into university, an achievement that her dad would have been proud of. Unfortunately, this was the start of her mental breakdown. When he died she would not see anyone and I suppose that her emotions were not able to cope. This eventually resulted in the meltdown. It was terrifying at times as she was suicidal and I had no-one to share it with. I am almost certain this would not have happened if Peter had been alive. She was diagnosed with depression and had to miss almost one year of university. She did get her degree in the end; but it was very tough, and perhaps not the one that she deserved. The depression did not get better and eventually we managed to get psychiatric help and psychotherapy. It took nearly two years to get this help and she was tested for various illnesses but with no conclusion. Thankfully now, with tablets and therapy she is much better but this whole issue went on for five years and throughout it she could not work and I had to step in to help. The impact on the girls has been immense and extremely worrying on all of us.

46. The girls have experienced stigma associated with their father being diagnosed with the hepatitis C and from the medical profession. For privacy reasons I feel unable to share the information with the Inquiry.

47. Peter's father outlived him. This must have had a serious impact on him. More broadly everyone was shocked; they could not understand how this could have happened to him.

48. There were work related and financial effects:

Peter withdrew from work. It seemed to me that he was living in a world of his own. He was unable to work for a period of around two years. As a result we had to take out loans to cover the loss of salary.

We were unable to sell the house or re-mortgage because my mother owned half of the house and lived with us. I also could not think about destabilising my

daughters' lives further. I have needed to protect their stability as much as possible. In any event, my mother would not let me sell the house. I also knew that this house was my only pension so I had to keep going. When Peter died, he died with around £50,000 worth of debt. I had to pay this off. I have had to bear the financial responsibility for everything that we had shared the responsibility for together when Peter was alive. The detail is provided further up.

Section 6: Treatment/Care/Support

49. I believe that Peter could have had a liver transplant when he was diagnosed in 2005, and for whatever reason that did not happen.
50. Initially I was not offered any counselling or psychological support as a consequence of what happened. It was only years later; through the Hepatitis C Trust, that I received some counselling support. They contributed £900 towards my counselling and although I am grateful for it, it was not enough. At £45 per session the £900 did not last long. I had to pay for the rest myself as I needed to carry on. Counselling was never made available to Peter.

Section 7: Financial Assistance

51. Peter was never told he could have financial assistance at all, so he never received any payments from any fund.
52. I have received financial assistance from the Skipton Fund, from Caxton and from England Infected Blood Support Scheme (EIBSS). I never knew about the funds that were available, a friend who is a social worker stumbled upon some information about it and she told me. It was pure chance that I found out.
53. I believe I have received:

£25,000 from the Skipton Fund on 8 August 2006;

£25,000 from the Skipton Fund on 27 April 2011;

£10,000 from the Skipton Fund on 7 March 2017;

Winter funeral allowance of £500 per year from Caxton beginning in December 2015 and from EIBSS in December 2018.

54. I had to fill in some forms for the Skipton Fund and send Peter's death certificate. I think that it was fairly straight forward. I think the process was the same for Caxton as it was for Skipton. I did not have to do anything for EIBSS when they took over.
55. I do not recall facing obstacles or difficulties in applying or obtaining financial assistance from the funds; however, I have never really known what we are entitled to, that information has never been provided. It seems a bit of mystery to me.
56. I am not aware of there being any preconditions imposed on the making of the application or in the granting of the financial assistance.
57. I found the Skipton Fund quite empathetic and I was sad that Skipton became EIBSS; it worried me that it was changing, especially given the fact that the NHS was going to run it. I cannot see how they can be independent and truly operate in the best interests of those who have been infected and affected by this.

Section 8: Other Issues

58. I do not think that this question is relevant to me.

59. I do not have any further documents to pass onto the Inquiry here.
60. I want the Inquiry to uncover the truth; to find out what went on; why my husband was given contaminated blood and the problem was hidden from us for decades? I want the Inquiry to deliver justice for my husband and my family. I want the Inquiry to find out why my husband suffered an unnecessary death when illness could have been picked up and dealt with much sooner.
61. I am now 63 and I still have to work hard to live, I cannot give up work to be able to retire. I still feel like I have so much responsibility with my work, my business, my mother and my girls that I am not able to give up work. I think that this would have been very different had Peter been alive. This Inquiry has brought back so many difficult emotions and although I am still sad, I am excited that at last we might get justice not just for Peter's death for all those who have been infected and affected by the travesty. The Inquiry has given me the strength to fight hard, I have met so many lovely people in this fight and at last; after having spent 13 years of dealing with this alone, I no longer feel so alone.
62. As a family, we did not know that my husband was infected for 26 years. I believe this shows that information was withheld from us by the medical profession.
63. We requested Peter's medical records from St. Peter's around six months after he passed away. The hospital advised they did not keep records after a period of eight years has elapsed from the previous treatment. We are currently requesting further records and are hopeful they will provide an insight into what happened.

Statement of Truth

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

Signed:

GRO-C

Full Name:

SANDRA SIME NOWAK

Date:

14 / 02 / 2019