

Witness Name: Toni Poole
Statement No: WITN1471001
Exhibits: 0
Dated: February 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF TONI POOLE

I, Toni Poole will say as follows:-

Section 1. Introduction

1. My name is Toni Poole, DOB [GRO-C] 1973 and I live at [GRO-C]
[GRO-C]
2. My father, [GRO-B:F] DOB [GRO-B] 1938, died on [GRO-B] 1994 after being infected with HIV and Hepatitis C after receiving contaminated blood products.
3. My step-father, [GRO-B: SF] (DOB [GRO-B] 1947), died on [GRO-B] 2015 after being infected with Hepatitis C after receiving contaminated blood products.
4. This witness statement has been prepared without the benefit of access to my late father's or step-father's full medical records. If and in so far as I have been provided with limited records the relevant entries are set out in the medical chronology at the end of this statement.

Section 2. How Affected

5. My father suffered from severe Haemophilia A.
6. I was only a child when my father was infected so I do not have much first hand information from this time. My mother's statement will provide more information.
7. He found out that he had HIV when a doctor said to him 'you do know you have HIV?'
8. My parents had called the hospital six months prior to this and asked about the risk of HIV, but were told that there was nothing to worry about.
9. My dad was later told that he had also been infected with Hepatitis C.

Section 3. Other Infections

10. I am not aware of any other infections that my father may have been exposed to.

Section 4. Consent

11. They tested my father's blood every six months and did not tell my parents what the tests were for. They therefore had no knowledge that he was being tested for HIV and therefore could not have consented to such tests.

Section 5. Impact of the Infection

Dad — F

12. My Dad worked when he could but it was obviously difficult with his haemophilia. Things were sometimes difficult financially, especially as there were three children to care for.

13. My Dad adored us. He was a really proud family man and he doted on us all. He didn't have the best upbringing himself so he really made an effort with his daughters. He was very funny and charismatic. My childhood memories were of a loving, family environment. We had some great family holidays despite my father's mobility restrictions and we were a family leading a normal life. Dad would encourage me to perform well at school, he would check my homework for me and encouraged me to join the police force when I was older.
14. Things started to change when I was around 8-10 years old. I remember my Mum and Dad started to argue when we went to bed and I would sit on the stairs shaking and scared as they argued. I didn't know why they were arguing or what it was about, but Dad became very aggressive which was totally out of character for him. He became paranoid that Mum was seeing other men and would be jealous even if she waved at a neighbour.
15. My Dad was a big man and although he had never been violent before, this started to change. I remember on one occasion I witnessed him pinning my Mum to the bathroom floor by her throat. My Mum was struggling for breath and I thought she was going to die; my sisters and I had to run round to my uncle's house to get him to stop him from killing Mum. He became an angry man and my Mum had to take us to the doctors to explain the seriousness of the situation.
16. Unbeknown to us, he had been diagnosed with HIV around this time. He was prescribed painkillers and Valium and he was changing as a person. It was very frightening to be around and I had no idea why he was now acting this way.
17. Dad changed within himself. He often stayed in bed with bad migraines and pain, and he became extremely withdrawn. I saw this once very funny, happy man turn into someone full of worry, having panic attacks and no longer interested in life.

18. I vaguely remember my Mum and Dad sitting me down and telling me that he had HIV. I was too young to understand what it really meant but I do remember seeing the adverts. I think I was around 11 years old at this time.
19. My Dad was a huge fan of Queen and Freddie Mercury, so when he died in 1991 he became even more withdrawn and shut off.
20. I was told not to say anything about Dad's illness and this was very isolating. I had a hard time at school and was bullied. My friends knew that my Dad was disabled but didn't know what was wrong with him.
21. My Mum went and spoke to the mother of one of the girls who was bullying me. She confided in her and told her the truth about Dad, and shortly after everyone knew that there was someone on our estate had a serious illness. I remember on one occasion my dentist put on his gloves before he saw me and saying 'I'm clean'. I didn't know what he meant at the time but now, looking back, it is clear he was referring to Dad's HIV status.
22. We were given absolutely no advice about possible routes of transmission. I remember on one occasion I used my Dad's shaver to shave as I was a teenager and didn't want to ask for my own. I didn't know that I was putting myself at risk.
23. I was an academic child. In 1990, when I had started my A levels, my Dad became extremely confused. Mum took him to the Queen Elizabeth Hospital after he tried eating a cigarette and when he arrived to the hospital he went into a coma. This had an obvious impact on my education and when I finally went back to sixth form, I was so far behind that I struggled to catch up. I remember telling my history teacher (who was the first person outside of my immediate family I had told) and he suggested I drop history. In the end I had to drop out of sixth form as I simply couldn't catch up.

24. My maternal grandmother was also staying at home with us because she was unwell at the time, and having both her and my father in the house meant it wasn't a good environment to be in. When Dad returned home after being in a coma he was visibly ill and frail. He would be told about the death of another haemophiliac friend every few weeks, and I could see my father fading away.
25. I needed to get away from it all so I spent months going out and drinking heavily with friends; it was just a form of escapism. Looking back I regret this as it must have put even more stress on my parents. I remember on one occasion my Dad pulled me aside and told me that his liver was in a really bad way and he didn't want me to damage mine.
26. Dad was desperate to have a liver transplant as he wanted to live but he was never going to get that; he was too weak and frail. He quickly deteriorated from being a big strong man to being a frail shadow of his former self.
27. My Dad was a really popular man but most of his friends were haemophiliacs. As they had also been infected, he frequently received phone calls to let him know that one of his friends had passed away. It must have been very frightening for him having to go to his friend's funerals and wonder when it would be him. He was depressed, he had panic attacks and extremely low self esteem and he also became addicted to tranquilizers.
28. I met somebody and moved out because I just needed to leave the house. I greatly regret leaving my mother and father but sub consciously I don't think I could have witnessed the destructive toll that the contaminated blood was having on Dad. I was in a relationship for five years and then married, although we separated in 2003 and divorced in 2007. I do think my desperation to get me away from home led me to make some wrong decisions and having relationships too young.
29. I used to get phone calls from my mother telling me to get to the hospital because Dad wasn't well. I received a call in 1994 from Mum and she told me to get to the hospital quickly. I rushed to the hospital and made it in time to be

at Dad's bedside when he passed away on [GRO-B]1994. Watching Dad die was an experience I never want to discuss or remember.

30. In a way his death was a bit of a relief because it meant he wasn't suffering any more. However, Mum then plunged into deep depression and financial worry. She has since divulged to me that she did consider taking her own life soon after.

31. Dad had to be cremated; he couldn't be buried. My Mum dealt with the funeral arrangements. She was advised not to have HIV put on his death certificate as it could cause problems. She was also told that it was more likely his Hepatitis C infection that caused his death. I tried to help where I could and I considered leaving my husband to move back in with her. I now know she was very depressed at this time and I regret not moving home.

32. When I was younger I wanted to be an estate agent or a police officer, however with everything going on I ended up in retail management which isn't really what I wanted to do.

33. I separated from my first husband and I met my second husband in 2009. We married in 2011 and moved down to Devon. He is extremely understanding and absolutely brilliant.

34. I try to be very open about what happened to my father. I am not afraid of telling people and I believe it is important that people know. I do still have to be careful about whom I tell but I have not really received any negative reactions when I have confided in people as an adult.

35. I try to remember the good times with my father. It is absolutely disgusting the way in which he was treated with absolutely no compassion.

Step-dad – [SF]

36. In 1995, Mum said she wanted me to meet [SF], who I knew as a child and was an old friend of the family through the Haemophilia Society. They started

a relationship and I was thrilled; Mum was only 51 when Dad died so it was a relief knowing that she had a second chance of happiness.

37. [SF] was a haemophiliac infected with Hepatitis C, but this wasn't an issue for Mum or the family. He was an only child, had never been married and had no children of his own. He was willing to take on our family which comprised of three step daughters and six grand children.

38. We adored [SF] and he loved us all back. Mum and [SF] had a wonderful life and were so happy whenever we saw them. They went on many holidays and loved life. This allowed me to concentrate on myself now that Mum was settled and happy.

39. I remarried in 2011 to Dale and I too found love. Dale got on with [SF] as much if not more than his own father and they talked and giggled like children together. Life seemed amazing and the whole family were happy as a united unit. We always joked that [SF] was fitter than all of us and looked so well apart from his bad knees which was caused by his bleeds. He had never even vomited in his life!

40. At the Queen Elizabeth Hospital (QEH) in 2015, [SF] was advised to participate in the Topaz trial in an attempt to clear the virus. They had previously been keeping the liver damage down by milk thistle (a herbal remedy) which was keeping the cirrhosis under control. Mum and Tony were both really reluctant to go on the trial but after the consultant assured them that [SF] was fit and ready, they decided to give it a go.

41. Shortly after starting the trial, [SF] was having breathing difficulties and was rushed into hospital. We rushed over and were informed that [SF] was going into multi organ failure. They were unable to reverse the effects of the drug and he started to go downhill very fast. Mum was distraught and I stayed with her whilst [SF] passed away.

42. The family were utterly heartbroken and Mum was left distraught all over again; she became a shell of her former self.

43. I am not totally sure that it has sunk in yet that **SF** is no longer with us, he was a truly remarkable step-dad and we deeply miss him. He has left a massive void in our family.

Section 6. Treatment/care/support

44. We were offered no support or counselling. If this had happened today the support available would have been so different. I think I was somewhat overlooked in the grieving process because Mum had her own grief to deal with.

Section 7. Financial Assistance

45. I believe my parents received a pay out of £52,000 for which they had to sign a waiver. This is completely insufficient for a family ruined and a life lost.

46. My Mum had to go to a tribunal and basically beg for more money to help pay for our food and basic necessities. They made a joke about 'how do we know you aren't living on caviar?'. This was an absolutely disgusting thing to say to someone who was in clear need of financial help.

Section 8. Other Issues

47. There are no other issues I want to raise to the Inquiry.

Anonymity

48. I do not wish to remain anonymous.

49. I would have liked to give oral evidence to the Inquiry but I don't know think my nerves would hold out. I therefore do not wish to be considered for oral evidence.

Statement of Truth

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

GRO-C

Signed

Dated

27.3.19