

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I, GRO-B will say as follows:-

Section 1. Introduction

1. My name is GRO-B DOB GRO-B and I live at GRO-B
GRO-B
2. My father, GRO-B: F DOB GRO-B died on GRO-B at the age of 50 after being infected with HIV as a result of treatment with contaminated blood products.
3. My mother has also prepared a witness statement for the Inquiry (WITN1776001) and I understand that my siblings also intend to provide statements.
4. This witness statement has been prepared without the benefit of access to my late father's 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. I was only a child when Dad was infected so I do not have any first hand knowledge as to how he was infected; that information will be addressed in Mum's statement.

ANONYMOUS

6. My sister **GRO-B** and I were told about Dad's infection in the autumn of 1984. Mum and Dad sat us down and dropped the bombshell on us as gently as possible.
7. We were told that we weren't allowed to say anything about Dad's illness, including to our younger siblings who were too young to understand what was going on.
8. When Dad started home treating with Factor VIII, I often helped him to administer it as it could be difficult for him to administer on his own and I was the eldest child. In the back of my mind I therefore worry that I was the one who injected the contaminated treatment into him.
9. We were told by Mum and Dad that the routes of transmission were through needles and bodily fluids. Although we thought we would be safe, in the back of my mind I still worried as I didn't feel 100% sure that I was safe from the risk of infection. I also remember the very real fear that Mum would contract the virus.

Section 3. Other Infections

10. I am not aware of what other infections my Dad may have been exposed to.

Section 4. Consent.

11. I do not have any knowledge as to what testing my Dad consented to.

Section 5. Impact

12. Things initially just carried on as normal after we were informed of Dad's diagnosis. There was so much stigma around AIDS at the time. There was the media campaign with the tombstone adverts, which meant there was a horrible atmosphere at school with constant AIDS jokes. This meant we couldn't say anything at all; we just had to sit on it and pretend everything was normal. It was too difficult to go from talking about it at home to not saying anything at school, so it just became easier to not talk about it at all even within the family.
13. The fear of anyone finding out was so bad that we completely turned inwards as a family and shut ourselves off. It was something we never talked about as a family and it is something we still do not talk about.

ANONYMOUS

14. Dad was an incredibly strong person. He had been through a lot with his haemophilia but he had always come through it. He left school and made himself extremely successful and refused to let his haemophilia define him in any way. He had his own car business which he started with a friend, but as he had more children he decided he needed a more steady income and became a manager at Porsche, where one year he was the top salesman in the country. He really was a man to look up to.
15. After his diagnosis and the revelation that he was HIV positive, he pretty much refused to accept it. Dad just tried to carry on as usual, and that set the tone for the family which meant we just blocked everything out and didn't show our emotions and feelings.
16. I had just completed my O levels when I was informed about Dad's diagnosis. I struggled when studying for my A levels as I found it difficult to focus; my mind wasn't really there. I originally thought I would go to university but I left school and started working instead.
17. After working for a bit I decided to enrol at GRO-B as I didn't want to be too far from home. I studied Business Studies and graduated in 1991. Dad was very focused on pushing us and getting us to do our best. I really benefited from him being around which is something my younger brothers missed out on.
18. Dad remained determined that he was going to beat his HIV, right up until the end. The turning point was when his own Dad died. He passed away a year before Dad, and that seemed to knock the fight out of him.
19. I lived at home for a bit after university but then got a job in IT and moved out in or around 1992. I only moved five miles away so I could still get back to see Mum and Dad, but I still felt like I was deserting Mum. We had already downsized by selling the family home as Dad was no longer working and we didn't know how long he was going to live for. Dad wanted to be at home and he refused stay in hospital or consider hospice care so the house was fitted with adaptations to make things as easy for him as possible.
20. I remember he got to the point where he couldn't work anymore. Dad had never taken anything off the state before as he didn't want to 'sponge', it wasn't in his nature, but at this stage he had no other option than to apply for disability benefits. Someone came round to

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assess him and Dad was made to walk down the street to see if he could walk in a straight line down the pavement curb; as he was able to do that he was told that he didn't qualify for benefits.

21. Dad tried to keep everything in but it wasn't always possible, especially when you have five kids. He had spells where he was very angry but we just had to learn when to stay away from him.
22. Right towards the end he became very frail. He ended up bedbound for the last few weeks and had a sort of dementia so he didn't really know where he was. Sometimes you could talk to him but other times he wouldn't even know who you were. He would lash out at Mum and he became convinced that she had caused his illness. This must have been terrible for her to go through.
23. I remember when Dad was very ill one night and we thought he wasn't going to make it through the night. I remember driving down to Cambridge to get **GRO-B** and bring her home. That was an extremely difficult time for us.
24. I don't recall being asked by anybody how Dad died. I don't think many people knew, just very close friends. At that stage I still hadn't told anybody; none of my friends knew. I kept working and nobody at work knew anything so I just carried on. I eventually told one or two people quite a bit after Dad died, but it was extremely difficult to tell people because of the stigma associated with HIV/AIDS.
25. I was very emotionally repressed and probably depressed after Dad's death. I didn't have any relationships until I was in my 30's, and when I did meet a partner it was very difficult having to tell them everything. I have generally had relationships with people who have been divorced and have been through difficult things themselves as I found it easier to relate to them.
26. I find it very difficult to relate to people. Having witnessed everything Dad went through it made me pretty intolerant of listening to other people's problems which just seemed trivial compared to what Dad and the rests of our family had had to endure.
27. My wife and I met in 2006 and we married in 2008; our daughter was born the following year and I also have two step-daughters. There are parts of my Dad that I see in my

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daughter and I want to be able to talk to her about him, but I don't think she is ready to hear about him yet. I wish that Dad could have met my wife and daughter, and that they could have met him so they could see for themselves what a charismatic, funny man he was. I wish he could see where we are as a family and what we have all become.

28. Family has always been very important to me. We have always been a close family and coming from a big family, I always wanted a family of my own. Despite everything we went through, I had so many great memories from growing up. My Dad was a very funny man and we had a lot of memories together and good times. It is important to hold on to those memories.

29. Although there is less of a stigma from the younger generation I still feel the stigma because it was my generation and generations above who experienced it first hand. What happened to Dad has defined all of our lives and it will continue to do so until the day we die. It happened 35 years ago now, and whilst time helps a little bit it is still very difficult.

30. My siblings continue to struggle and have ongoing problems, and I still find it staggering how my Mum managed to raise five children and support us all whilst also having to care for Dad and then deal with his premature death.

31. After Dad died I became very low. I got to the point where I thought nothing can ever happen that will be that bad again. That may sound like it could be a positive thing, but initially my reaction was to not let anybody in. It is only with time that I have been able to look on that and take the positive out of it. Now I think I am generally quite a positive person and try to enjoy the small things in life and over time that has put me in a much better place.

Section 6. Treatment/Care/Support

32. It was suggested by a previous partner that I should have some counselling. This was in or around 2001 and I went for 5-6 sessions of counselling which I arranged myself. I did not have any counselling before this.

Section 7. Financial Assistance

33. Personally I have had no financial assistance although I believe that Mum had some support through the MacFarlane Trust.

Section 8. Other Issues

34. There have been Inquiries in the past and you wonder whether they are actually ever going to get the bottom of it. We have refrained from getting involved in the past because it is so difficult to drag everything back up, but now feels like the right time for Dad's voice to be heard; it is what he would have wanted.

35. I would like to apply for anonymity.

36. If the Inquiry would like to hear from me then I would consider giving oral evidence.

Statement of Truth

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

Signed.....

GRO-B

Dated.....

25/3/19