

Witness Name: S Carbery
Statement No: WITN3229001
Exhibits: 0
Dated: May 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF STUART CARBERY

I, Stuart Carbery, will say as follows:-

Section 1. Introduction

1. My name is Stuart Carbery of [GRO-C] Manchester, [GRO-C]
My date of birth is [GRO-C] 1982. I have a life-long partner of 10 years
and we have a daughter aged 7.
2. I prepare this statement as an affected son in relation to my late father Russell
Eric Carbery (DOB: [GRO-C] 1954, DOD: [GRO-C] 1993) who received
contaminated blood products.
3. **This statement has been prepared without the benefit of access to my
late father's full medical records.**

Section 2. How Affected

4. I was aged 10 when my father passed away. I do not have a huge amount of
memories to look back on. My father suffered from Haemophilia A and used to
have Factor VIII concentrate.

5. It was explained to me as a child that my father would bruise more easily than the average person which may cause internal bleeding.
6. I recall my father received home treatment. I do not know whether any information or advice was provided to my father in relation to risks of infection following receiving blood products. Factor VIII enabled him to lead a normal life and he was told that it would stop his bleeding.
7. My father was infected with HIV and Hepatitis C as a result of receiving contaminated blood products.
8. I do not know how my father found out about having HIV.
9. His health condition was deteriorating and my mother, who was a nurse practitioner, had read up about the Non-A Non-B Hepatitis. She had seen my father exhibit many of the symptoms. She asked questions of his doctors on whether my father had it.
10. At the time, Hepatitis C was not very well known to the community. HIV at the time was more manageable than Hepatitis C which was a silent killer. If you could have a liver transplant then this would aid you from Hepatitis C. My father was too far down the line and he was not eligible for the liver transplant.
11. I do not recall which treatment my father had received or whether he received any at all.
12. I was told about contaminated blood towards the end of my father's life. My older sister Paula Wakefield and I were sat down by my mother in the living room whilst my father was upstairs at the time. She explained what was happening to my father. She told us that our father's treatment had gone wrong which meant that his health was deteriorating and that he would die very soon. I do recall that AIDS was mentioned within that conversation and that my father contracted AIDS from the contaminated blood products. At that time, I did not really understand what AIDS meant and I recall that my parents were protective of us surrounding the stigma and the media. I remember that

in my consciousness the stigma as I recall that Freddie Mercury passed away in 1991.

13. Subconsciously, my father was attending hospitals more often and he stayed over night at the hospitals. Retrospectively, he decided to come home so that he could die at home.

Section 3. Other Infections.

14. I am not aware of any other infections.

Section 4. Consent.

15. I believe my father was tested or treated without his knowledge.

Section 5. Impact

16. In terms of how this all affected me: I had to switch schools half way through my first year of juniors (4th year) where I attended

GRO-C

 Primary School.
17. Consequently, I found out that my parents were getting death threats following finding out that my father had AIDS at that time. Nobody really understood the difference between AIDS and HIV. The parents of the other children stated that they would take their children out of school if I stayed.
18. The parents of the other children were aware that my father had Haemophilia and I believe they must have put the two together even though we didn't tell anyone about his diagnosis.
19. There was an ominous newspaper article "Gays, Druggies and Haemophiliacs" which explained that those groups of people were to blame for HIV.

20. My parents continued to receive death threats until my mother started to campaign.
21. My mother campaigned heavily and was the original secretary for the Manor House Group. When a lot of documents disappeared that managed to come back to light, there were many conflicts between the Manor House Group GRO-C and she stopped campaigning.
22. Growing up, there was a stigma attached to me. I have a particular memory of my last day of school. Although at the time I did not consider this as bullying, I remember a lot of children shying away from me. In retrospect, this was because their parents told them that I had AIDS because my father had it. But there was no discussion or understanding about how AIDS was contracted at that time.
23. When my parents found out that my father had HIV, they decided to use separate utensils at my maternal grandparent's home. This was out of the fear of transmitting the virus and it proves the little knowledge available at that time.
24. After I changed school, life improved. It was drilled into me not to mention Haemophilia, HIV or AIDS. I was told to just say that my father was poorly. My father passed away between my 5th and 6th year in the summer when I was going into my last year at Primary School.
25. I remember we were having a conversation in a group of about 3 or 4 children following my father's death and one of the girls came across snotty talking about her father being a fireman. I laughed about the comment and she said *"At least I have a dad"* which was very hurtful.
26. I remember going to a school trip to Butlin's and all the boys stayed in one dormitory. We were talking about sex and condoms. I was educated a little bit more about how AIDS was transmitted as at the time I was undergoing numerous blood tests to check whether I had been infected and I was aware that if you wore a condom it was less likely that you would transmit it. I

explained this in confidence and told my friend that my father was a haemophiliac and that he was infected through blood products. My friend then went to speak to his mother who spread it to the rest of the parents which caused another issue at the school.

27. As a result of me disclosing this information, my mother suffered with an anxiety GRO-C and she was very upset with me for talking about it. My mother lived through the negative spectrum of HIV, she did not openly speak about it and she was upset that I discussed it. Whereas, my sister and I have been more open about it.
28. I studied Psychology and I feel like my brain has shut a lot of the memories off as a coping mechanism. I was never offered any counselling as a direct result of being affected by the contaminated blood scandal.
29. I did not complete my High School as towards my 4th and 5th year my attendance was dropping. I took a lot of time off school to look after my mother who had just been diagnosed with depression and PTSD. These responsibilities, combined with the fact that I did not enjoy school, meant that I suffered from panic attacks and I refused to go into school. I was never really bullied in High School.
30. After High School, I returned to College to complete my GCSEs. I dropped out of Science and Psychology. I completed my English, Maths and Sociology all at a C grade.
31. I attempted to do my A Levels but I did not manage to finish them so I went back to complete BTEC in ICT but did not complete this either. At this point, I could not go back to College again as I had hit the age limit when it was not free and I could not afford to pay.
32. I was given an ultimatum from my mother to get a job or to get out. My behaviour from age 14 until that point was immature. I think my mother had had enough to try and the situation was her way of trying to get me to do the right thing.

33. I signed onto JSA for one week following which I got a job interview at Barclay's Bank and managed to win that and I was offered a job as a personal banker which I continued for 3 years and then I became a mortgage advisor for the following 2 years.
34. I qualified as a financial advisor in Santander, but I quit this job as I was concerned about the nature of investment advice.
35. As a result, I went into Telesales. Following this, I went into Personal Injury claims and advising on compensation to victims. It was weird; as I learned a lot from that that I understood how my parents were misrepresented in their previous claim.
36. Counselling never worked for my mother. The stress and anguish my parents had gone through was horrendous as my father had been contaminated with this virus through something that was meant to help him lead a normal life.
37. My mother had attended at least 50 funerals as the majority of my father's friends were also affected by this scandal. Yet, no acknowledgement was provided, no apology, no explanation. The fact that my mother seemed to get nowhere after years of campaigning has taken a toll on her and I do not think any form of counselling would help.
38. As a result, my mother has become distant with her grandchildren. I have a daughter who is 7 years old and my sister Paula also has a daughter of the same age. My mother does not feel like she can connect emotionally with anyone. She completely disconnected with her friends because it is very hard for her to speak about her issues. If she had gone on a date, she never continued those relationships romantically as she never fell out of love with my father.
39. She struck up so many connections and friendships within the Haemophilia community and approximately 80% of those connections died. Then my father died. Why would you want to get attached after that? Most of the people she knew died.

40. I know she did not want to put herself in the position of feeling loss again.

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GRO-C

GRO-C

42. I remember being tested after my father had been diagnosed with HIV and after he passed away, my mother, my sister and I attended 6 monthly and 12 monthly blood tests. But because we did not know any different, it was a routine blood check up to us; like a flu jab might be to somebody else.

43. I do not think I was aware of what the blood tests were for.

44. The solicitors did not fight enough for liability to be admitted in the HIV litigation. We are treated so badly like second rate citizens. We were like a third world country. This Inquiry must predominantly be about justice.

45. Furthermore, some people are scared to discuss the financial impact these infections had on people. My father had a job at Inland Revenue but he had to stop working due to the stigma and his illness. I was brought up on a single parent income as my mother had to continue working as a nurse practitioner at St Anne's Hospice. She had to quit her job when my father became too ill. When my father passed away, she did not want to work as a nurse as it reminded her of her experiences in caring for my father and his death. She went to work at various other places following his death such as a catalogue company, call centre, RAC breakdown and working in a library. Mentally, she could not cope anymore. She had fibromyalgia, depression **GRO-C** and diabetes. She is now **GRO-C** retired but she still has to be reviewed every year to see if she is still eligible on payments.

46. They had a mortgage at the house we were living in at the time and my father had life insurance. Since he has been diagnosed with AIDS, it automatically rendered his policy void which meant that he could not have a mortgage. The house had to be sold and no alternative was given to my parents.. The knock on effect this has had was ongoing. We went from having a middle-class lifestyle to being on a red line and not having anything at all.

47. In another world or another universe, I would have had a stable upbringing. The psychological and financial impact which had been combined has led to an unfulfilled life and an unfulfilled career on my part.

48. I have a fairly decent professional career. But there has always been an element of doubt and a feeling of failure amplified as a result of everything that we had gone through. I believe had my father never been infected, we would have had a more stable upbringing.

49. My father's [GRO-C] was also infected as a result of receiving contaminated blood products. However, I can count on one hand how many times I saw him. He was not very [GRO-C] which worsened from his infections. [GRO-C]
[GRO-C]

50. [GRO-C] and my father were quite close but after being infected [GRO-C] went off the rails. After my father died, we did not hear anything from [GRO-C]. My mother found out that he was in [GRO-C] before he died. At that time he had a new partner whom he had another child with, and did not let my mother know when the funeral happened.

51. My father had an older sister called Lesley and a younger sister called Michelle whom he was very close to. [GRO-C]
[GRO-C]
[GRO-C]

52. [GRO-C] and [GRO-C] did not know about each other until last year.

Section 6. Treatment/Care/Support

53. My mother speaks well of the Haemophilia Centre at Manchester Royal Infirmary and the staff there.

54. I was never offered any psychological support or counselling as a result of my father's infections or passing.

55. My mother received counselling, but I do not believe this has helped her.

Section 7. Financial Assistance

56. Different schemes were set up such as the MacFarlane Trust but everyone was treated differently. We had to apply for funding and for grants for a computer when I was at either school or college.

57. My mother also had dealings with the MacFarlane Trust. She applied for grants for items such as fridge freezer, washing machine, trips abroad for school. She did not want us missing out. She stopped applying at some point as it felt too much like begging towards the end.

58. My mother was refused any help from the MacFarlane Trust to help with finances and she was forced to go bankrupt.

59. My mother has received payments from The Skipton Fund. She receives regular monthly payments.

60. My mother gets extremely anxious when anything like this comes up as it has shaped her life. There is an element of financial uncertainty but I believe the government should make assurances to people so that they feel more financially stable but none of this has happened. There is no security at all. It is appalling. Words are words and they are meaningless. They tried to justify that someone lives beyond the poverty line and is not eligible.

61. The Government told them that they had this package of compensation set up but in order for this to be distributed; everybody had to sign a waiver or nobody would receive anything. They were railroaded into signing it.

Section 8. Other Issues

62. I am a part of the Fatherless Generation Group.

63. I believe that the Government should take responsibility for the past Governments' actions. My mother had always said that **GRO-D** in particular knew a lot more than he ever let on and he should therefore be taken to task for that. I am aware that many people wish to see him give evidence at the Inquiry. Other people who we would like to give evidence to the Inquiry would be **GRO-D** and **GRO-D**

GRO-D

64. If we are talking about full justice, I am not ashamed to say that in order to get full justice; you can never replace someone's life but financially, you can replace what they would have produced. Whether we like it or not, money enables you to do things in life.

65. I look at other people same age as me who had a stable family, they are not rich but have a stable upbringing and they have had so much more of a comfort blanket around them which has cushioned them and allowed them to develop and enjoy life.

66. Had my mother and father had the mortgage continue I would have had financial security and be able to put a deposit down on a property myself. It would have enabled me to go down a different path in life.

67. Your path has an impact on what you do. My childhood trauma in relation to my father has disabled me, my lifelong partner and our daughter from having a better life.

68. The Trusts and the Government should enable the families to live a reasonable lifestyle but there is no guarantee of a lifetime income. It has never been offered. I would like to see security offered to people. I would like to know that my mother is well looked after.

Anonymity, disclosure and redaction

69. I do not wish to apply for anonymity and understand that my statement will be disclosed and published as part of the Inquiry.

70. I would be prepared to give oral evidence to the Inquiry.

Statement of Truth

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

Signed..

GRO-C

Dated..

04-08-2019