

Witness Name: Richard Dudley-Smith

Statement No: WITN1199001

Exhibits: 0

Dated: January 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF RICHARD NICHOLAS DUDLEY-SMITH

I, Richard Nicholas Dudley-Smith, will say as follows:-

Section 1. Introduction

1. My name is Richard Nicholas Dudley-Smith, date of birth GRO-C 1963 and I live at GRO-C with my civil partner, Mark Ward.
2. Mark was infected with many pathogens including HIV and Hepatitis C after being treated with contaminated Factor VIII. I believe that the correct medical term for Mark is "super infected".
3. Mark has also produced a statement for the Inquiry at **WITN1591001**.

Section 2. How Affected

4. I did not meet Mark until 2003; years after he was infected. The details of Mark's infections and diagnoses are set out in his statement.
5. I met Mark in a bar in Gran Canaria on 30 April 2003 when I was on holiday. There was an immediate connection and as such, Mark was very upfront and

told me about his Haemophilia and HIV status almost immediately. We had had a few drinks but being told something like that sobers you up very quickly; it's not something you expect to hear within an hour of meeting somebody!

6. I had heard of Haemophilia but didn't know much about it other than that it was blood related. At that stage Mark still considered his infections to be a big accident. I also knew lots of people who were HIV positive so it didn't bother me too much.
7. When we returned home from our holidays we stayed in touch. My head was telling me to be wary and not get involved because of what Mark had told me, but it was impossible to deny the connection that we both felt.
8. We spoke on the phone every couple of nights and got to know each other by phone. We also met up when we could.
9. Within nine months we had moved in together and I was fully aware of the circumstances in which his infections had arisen.

Section 3. Other Infections

10. Mark was told before we met that he may have been exposed to vCJD and a raft of other pathogens.

Section 4. Consent

11. As addressed in Mark's statement, he did not consent to being tested for HIV or Hepatitis C or any of the other pathogens he has been exposed to.

Section 5. Impact of the Infection

12. When we got together, my first reaction was to protect Mark but he was adamant that he didn't want to be wrapped in cotton wool. For the most part, Mark does what he wants to do. If he wants to do something he will do it and

pay the price later when his joints hurt, but he doesn't want to be limited or defined by his illnesses.

13. I now feel that it is Mark who tries to protect me as I'm sure he keeps a lot of the problems with his mental health to himself. He is so focused on helping other people that he often neglects his own health.
14. There have been 10 or 12 occasions where Mark has had what would now be called a crisis. Each one feels a bit more difficult to come back from and leaves us both feeling very vulnerable. There have been 3 or 4 occasions when he has walked out of the house with the intention of leaving and letting nature take its course. This is obviously extremely difficult for me to cope with.
15. On one occasion on a Sunday evening we went looking for help and sat with the drunks in A&E at the Royal Sussex County Hospital for several hours waiting for the on-call mental health specialist. As the evening wore on and the waiting room became more crowded we were told the on-call specialist was currently at a different hospital with no idea of how long they might take to get to us so we gave up and went back home. We both sat and cried when we got home, I felt completely lost, I didn't know how to help him.
16. I recall one Sunday when Mark refused to get out of bed and was extremely low. He said to me 'look after the boys for me' as he planned to stop taking his treatment and just let his health decline naturally until the end. I didn't know what to say, at that moment I couldn't help him.
17. I am a sound engineer and build radio stations for special events; a job that often requires me to stay away for a few nights at a time. Whenever I go away for work I speak to Mark on the phone every night. Almost every time I am away something happens that upsets Mark and I make sure I stay on the phone with him until he is okay. It makes me feel so helpless that it's all I can do. Mark's triggers are usually dealing with the MacFarlane Trust, DWP, EIBSS or something to do with his campaigning.

18. Mark worries about letting people down. He spends his time fighting for people who have no voice of their own and when he feels he is not being listened to that pushes up his anxiety levels.
19. People don't realise that when Mark raises his voice and appears to be angry or ranting it is just his anxiety. I can't do anything but wait for him to blow it out and then help him when he is calmer. I do feel that there is an onus on me to help Mark manage his anxiety but I have not discussed this with him as I would never want him to feel that he is a burden to me. He has been hurt by enough people and I am 100% here to support him.
20. When Mark has anxiety attacks, it is very difficult for me and there can be the urge to retreat. For me his anxiety is like standing in front of a jet blast. He remains fully focused on the issue at hand but his voice rises in pitch and volume. It is testament to the strength of our relationship that we have stayed together.
21. I think this is why we go away so often as when we go on holiday it takes us out of the reality of our everyday environment; we can close the door on our normal life and Mark's illness and live a more normal life, despite the fact we can't escape the fact that Mark has to take his HIV medication twice a day. It is also good because it helps us meet new people from different backgrounds/places.
22. When we meet new people, Mark doesn't tell them about his condition until he feels comfortable to tell them about, in his words, his 'dirty secret'. The people we have told have generally been brilliant and are incredibly supportive towards him and his well-being but Mark has very much been made to feel throughout his life that his illness is something to be ashamed of. This has not been helped by the discrimination he has suffered for being one of the few gay haemophiliacs affected by this terrible scandal.
23. Mark's condition has an inevitable effect on our sex life. In all other areas our relationship is very strong but that side of our relationship has really suffered.

24. My father died at the age of 57. I am approaching that age now and I am reminded of one of the things Mark Simmons (social worker at the Queen Elizabeth Hospital in Birmingham) said to us in the early days of our relationship. He said *"you mustn't assume Mark will go first."* I worry about what will happen to Mark if I do go first.
25. When I go to medical appointments with Mark, I tend to just sit and listen instead of getting involved unless I have something I need to say.
26. I have experienced stigma as a result of Mark's infections. I've been with him in consultations where my presence has not even been acknowledged. On one occasion, at the Queen Elizabeth Hospital in Birmingham, I was asked to leave the room before Dr Wilde would even examine Mark.
27. Similarly, at the Royal Free there was a definite feeling that I was invisible to everyone in the room – I was never asked anything. When Mark transferred his care to St Thomas' I was shocked when I was in the room with him and the consultant actually asked me a question about how I felt.
28. I was in the room at the Royal Free when Dr Dusheiko said to him 'what do you want me to do, drill a hole in your head?'. I was absolutely astonished that a doctor would say something like that to a patient; I found it extremely rude, unprofessional and frankly shocking.
29. Today as I write this document Mark is preparing his own witness statement. To do this he is re-living those events again having already done so last week when speaking to the solicitors at our home. I can't help while he goes through this process apart from making tea!

Section 6. Treatment/care/support

30. We were never really given any advice as a couple regarding safety and possible routes of transmission. I did sit down with GRO-D the social worker at the Royal Free, who had a very quick discussion with me about Mark's infection; however I left feeling that it was essentially a wasted half an hour of my life.

31. In heterosexual relationships the girlfriends and wives are typically given Hepatitis B injections. I was never offered this and had to arrange for the injections myself.

32. I also know that wives and girlfriends have typically been offered training on how to administer treatment to their partner; again no one has ever offered to teach me how to administer Factor VIII to Mark.

33. I see a counsellor every couple of weeks independently of Mark. I have done this for around 12-13 years. I don't remember a specific incident that prompted me to see a counsellor, but it was after Mark had gone to a very dark place on several occasions.

34. For both Mark and I counselling was something that we arranged ourselves – neither the Royal Free or any of the support schemes did nothing to help.

35. Despite being asked on several occasions the Royal Free would not add me as Mark's partner (and later next of kin) on his medical notes. Even at the time of him transferring his care in 2014 his address and phone number were listed as the old Birmingham details and with his Mum as next of kin. We also had to fight the MacFarlane Trust over the same issue.

Section 7. Financial Assistance

36. A lot of Mark's triggers have come from how he has been treated by the various financial assistance schemes that have been set up to support him. When you have to fight the people that are supposed to help you it really takes its toll. It is bad enough that Mark has had to fight the MacFarlane Trust and the Haemophilia Society for LGBT recognition without him also having to fight for the financial support he's entitled to.

37. When the Macfarlane Trust started it was an organisation that seemed to genuinely want to help. They helped the beneficiaries obtain mortgages and

did what they could to provide financial support. As time went on, this care and openness was gradually eroded.

38. When our home was flooded as the result of a water leak we called the Trust telling them we would need help but we weren't sure exactly with what at that stage because we hadn't spoken with our insurance company. Eventually it turned out that we needed the kitchen replaced and the insurers were difficult about it so we called the MacFarlane Trust but they refused to provide any support as apparently the rules had changed.
39. Initially, before I knew him. Mark always said he wouldn't ask for help because he was working and he felt there were others more deserving. However, when it came to the time that he/we really needed help, they were unwilling to provide it. We eventually had to have the work done and pay for it on a credit card.
40. Similarly, when we needed the sofas replaced the MacFarlane Trust were only willing to offer a loan to us; I'm not even sure they were registered with the FCA as a loan provider.
41. I have reached the point where I don't want anything to do with the Schemes. They are completely unwilling to help. They pay the monthly sum as they are legally required to do, but provide nothing above this. It seems to me that they do everything they can to put people off applying for help by making it difficult so that they can go back to the Government with money still in reserve and say that nobody wants it.
42. Even the tone of the DWP and EIBSS letters are incredibly aggressive. When we receive letters from them that say 'you must do this' and 'you must do that' it feels very hostile and confirms your opinion that they aren't there to help you.

43. I want the language that is used by the EIBSS, DWP and other Government organisations to be reconsidered. The letters received from them are extremely aggressive and demanding, and it puts a lot of people off seeking help. These schemes are supposedly here to help people, so people shouldn't be put off seeking help. This should be looked generally but also with particular reference to the LGBT community.

44. I also think a lot of the medical professionals need training in general bedside manner, as we have consistently encountered rude and unprofessional staff.

45. Finally, the Government has put the care of complex patients like Mark into the hands of their GP. This is nonsense – their care is being run by the people who know least about their conditions. The way in which complex care patients are dealt with by the NHS requires wholesale review.

Anonymity

46. I do not wish to remain anonymous.

47. I would like 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 R DUDLEY-SMITH

Dated 23/01/2019