

Witness Name: David Aitchison

Statement No.: WITN5888001

Exhibits: Nil

Dated:

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF DAVID AITCHISON

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 14 September 2021.

I, David Aitchison, will say as follows: -

Section 1. Introduction

1. My name is David Aitchison. My date of birth is GRO-C 1955 and my address is known to the Inquiry.

2. I am a severe haemophiliac. I have haemophilia A. It is a hereditary condition: GRO-C I intend to speak about my infection with HIV and hepatitis C ("HCV") that I got as a result of treatment with blood products. In particular, I will speak about the nature of my illness, how the illness affected me (including countless knock-on complications), the treatment I received and the severe impact it had on my life and my family.

3. I married my wife, Jeanette, in 2004. But we met when I was 24 and she was 18 – and have been together since 1979. My wife is a nurse. We had some amazing times together in our 20s. But from when I was about 40 onwards, my health significantly deteriorated and it has greatly affected our quality of life. She has been an incredible source of support for me.
4. I started my working life in the family garage office. My haemophilia meant that my options were limited from the outset. I also worked British Sugar for a couple of years but that job was not suitable for me given my condition. After that I worked in the accounts and sales department in Hughes Rentals until about 1996, where I had to stop after a serious illness which I will describe later. I have also previously been self-employed, but unfortunately, I cannot work anymore.
5. I confirm that I have chosen not to be legally represented and that I am happy for the Inquiry team to assist me with my statement.

Section 2. How Infected

6. I was diagnosed with severe haemophilia A as a baby (when I was around two years old) in the aftermath of several bruises appearing on me. At first, clinicians suspected that my parents were abusing me because they could not explain how I was bruising so frequently. Eventually, I was diagnosed at Addenbrooke's Hospital in Cambridge.
7. At first, my treatment was not much - I would just apply ice to it. If it was a major bleed, I would go into Norwich Hospital. The average length of stay in hospital for those bleeds would be for around 3 weeks. I would estimate that I was having blood transfusions every few weeks. I had cryoprecipitate for the first time in my early teens. In my late teens, I started to self-inject Factor VIII for the first time.
8. We were not explicitly warned of any risks associated with my treatment with blood products, over and above the general warning that

accompanies any medical treatment. I was not aware that there was a risk that I could contract HIV and hepatitis C through blood and blood products.

9. In or around summer 1985, I found out that I had been infected with HIV. My infected blood products came from the Norfolk and Norwich Hospital. That was single-handedly one of the worst experiences I've ever had: the manner in which I was told about my HIV positive status was appalling. I got a call from the Norfolk and Norwich Hospital telling me I had to do some blood tests but they would not tell me why. When we went to collect the test results, I was told my results before I even had a chance to sit down in the consultation room. They told me I was HIV positive in a really cold and uncompassionate way. They told me there was no treatment available and I was not given any information about infection management. It was a horrendous experience. It was treated like any other appointment: it was no longer than three minutes in total. You would think it is in their Code of Conduct to behave better and communicate with compassion. It was incredibly shoddy and exacerbated my stress significantly. I was also upset that Jeanette was not allowed in the appointment with me for emotional support – she had to sit outside, despite the fact that we had been together for 6 to 7 years at that point.

10. I was officially diagnosed with hepatitis C between 2001 and 2002 although apparently it had been detected a long while before then. It was a long while before we knew about that. I do not know when I contracted it – no one knows when it happened. It is a bit of mystery. Once or twice, I'd seen 'Hep C positive' on my medical notes, but we were not told about it. I just concluded that because I was so ill with everything else, they didn't think it was relevant to tell us about it. I wish they had told us as soon as they knew about it, especially if it meant that I could have started some treatment for it earlier.

Section 3. Other Infections

11. I believe I was infected with HIV and HCV as a result of my treatment with blood and blood products. I do not believe I have received any other infections from blood and blood products.
12. We did receive a letter about vCJD and a potential exposure to it. I think someone at Addenbrooke's Hospital asked me whether I would want to know about vCJD if I had it. I said no – I have enough to deal with as it is.

Section 4. Consent

13. To confirmed I have not been tested or treated for anything against my will or without my consent for the purposes of research.

Section 5. Impact

14. In the first two to three years after my HIV diagnosis (in 1985), I watched bewildered and horrified as other young men in the same clinic as me suddenly passed away. At this stage, I was well and the full impact of the disease did not hit us until I developed shingles in the late 1980s and was admitted immediately with great panic to hospital.
15. On that day, the awful realisation hit home that I could die so easily from any of these opportunistic infections. For 36 years that grip of fear has never gone away – it has been relentless as so frequently, one problem is followed by another. With every little infection, you worried that it was going to be the fatal one. We lived with that fear, worry and stress for years. That's just how our life was. I spend so much of my life in hospital waiting rooms, as the very caring doctors juggle with all of my NHS acquired diseases. They all marvel at my positive attitude that has managed to get me through so many close shaves, but they will never understand and realise how very frightened I am by my condition. The

impact it has on me is to the extent that I cannot even speak to my wife about it in any detail without becoming agitated – after 42 years together – because then it becomes too real and I cannot cope.

16. Every time I went to the hospital, I would feel physically sick. There was always a constant anticipation of things that could go wrong. As the hospital appointments were so frequent, I would have that feeling very often. I could not do this without Jeanette. But I do try to do as much as I can without getting her involved.

17. I got seriously ill in 1996 after a bowel infection led to a perforated bowel abscess. That caused peritonitis. I was in hospital for about five months and was given a 10% chance of survival. As a result of my haemophilia and HIV, there were many complications from having surgery. At one point, I was essentially sent home to die because there was not much more that they could do with my large open herniated abdominal wound. Eventually, after three months of intense pain and immobility, I got a successful skin graft at a burns hospital in London. They managed to close my open wound. After that, I faced a long and hard battle to recover.

18. As a result of peritonitis in 1996, my bowels are in a terrible condition. I have had a stoma bag ever since having a colostomy. I can no longer do flights above three hours anymore because of that. The enjoyment has gone from going to football matches too. The toilets are too small to use and there are huge queues for it. Whilst I do still have a season ticket, there are matches I cannot attend because of this.

19. I had a really bad car accident in 1998 in which my skin graft split. When I was laying on the floor at the scene of the accident, all the medical staff took a step back once they realised I had HIV. That was emotionally tough to deal with.

20. In 2000, I was diagnosed with Type II diabetes which I control with insulin and some tablets. I also have osteoporosis. As a result of my

haemophilia, my knee, ankle and elbow joints have severely degenerated. I have continually use Fentanyl patches to control the pain. Sometimes, I can have up to 7 appointments in one week given all the various health conditions I have.

21. By the time I got to Addenbrooke's Hospital to have the interferon treatment in 2006, I already had cirrhosis of the liver. This was identified by Dr Graham Alexander and his team after a liver biopsy. As I had so many other problems, I was scheduled to go on this treatment for a year with breaks (or 'drug holidays') in between. It affected every level of my life. After 4 or 5 months, they said the virus was no longer detectable. We continued until month 11 when it was deemed satisfactory to stop that treatment. For the last ten years, I have been going to Addenbrooke's Hospital twice a year for ultrasounds and MRIs – and everything is stable now in relation to hepatitis C.

22. I had some significant side-effects from the interferon treatment including flu-like symptoms and tiredness. It was tough to continuously go back and forth between Addenbrooke's and home. It was over two hours away. When we started to do blood tests at James Paget Hospital, it made my trips to Addenbrooke's less frequent.

23. The worst thing for my wife was that she could not say anything to anyone. Her parents would just worry too much. She did tell them once – at a particularly low point – but she regretted it because it caused them so much grief. If she spoke to them for support, it would just end up being her giving them support rather than the other way around. Being around my wife's parents was quite difficult because they were worried about whether I would infect her. The fear was justified because so many people were dying – and so quickly too. Her dad was even very apprehensive about her marrying me because of my HIV positive status. He didn't approve of our marriage and that's why we put it in on hold for so long (only getting married in 2004).

24. Keeping things from my best friends was difficult. Now, telling them would not be an issue. But, at the time, the stigma was huge. People would look at you and walk away. They would not drink out of the same cup, for example. It was such a taboo thing: people thought that if you touched someone, you would get HIV. I'm an open person by nature, so it's been tough and unnatural for me to keep it from others. I didn't even tell my brother. That was awful. But my mum – who I had told – told my brother in desperation. We went for years not knowing that he knew. Eventually, we told my brother but then realised that they already knew.

25. We have some really brilliant friends who have supported us through so much, but none of them know about my HIV (although they do know about the HCV). I think one or two friends (who have medical backgrounds) may have guessed it. I didn't want to tell them initially because it was a taboo topic. I knew how others treated me – for example, in the aftermath of my car accident described above – that meant I could not tell them. The only people who know of my HIV status are my mother, Jeanette's parents and our two brothers. Not being able to tell people has caused so many feelings of isolation, particularly at crisis times, when you cannot tell them the real reason for why you are tearing your hair out.

26. My mum was a fantastic support. She's 92 years old now. She did everything to help me and it made a massive difference to me. I wore callipers for ten years – but I only continued to wear them because of my mother. I walk badly now, but I can still get from A to B and my mother was a huge help in achieving that. My mum was also brilliant when I needed IV treatment at home and she would come over to do it when my wife was at work. It was remarkable especially because she really hated needles.

27. Jeanette and I do not have children as a result of my HIV infection. Our doctor, Dr Terry Mitchell, told us not to think about children. At the time, I was not really bothered because I didn't want children at the time. But

as I got older, and my friends started to have children, I started to want it. I watched longingly as our brothers and friends started their own families and I saw all the joy it created for them. But I could not bring children into that environment with my health conditions. I really struggle with the fact that I could not have children. I really wanted to nurture and bring kids into this world. I think that's something really special. I have four nieces who I adore, but of course, it isn't the same as having your own children. Not being able to have children is the biggest impact on me.

28. All of my illnesses and complications from them have taken a toll on me.

Physically and mentally I am frail which is tragic because I am a strong and positive person by nature. As a result of my ill health, I have not been able to work since 1996 which I find hard as I loved work and being around people. I am really upset that I had to give up work. I never told my employer about either my hepatitis C or HIV infection. They were pretty good regarding my frequent hospital appointments but I stopped working before it became a serious problem.

29. I found it tough that I had to entirely depend on my wife and I worried about the constant pressure on her to work full-time as well as caring for me. I've been with my wife for 42 years, and since being diagnosed in my twenties, we have spent our lives sitting on the outside of normality.

30. Even ordinary, everyday things like planning an evening out, or taking a short break away is very difficult because of my chronic conditions. Just walking down the road can be difficult as I have to concentrate on not tripping or falling over on any uneven surface. I would say that for every good day there are 3 bad days and I will come to a complete standstill. Often, if we do plan events or social commitments, we have to cancel them at the last minute due to a sudden and unexpected deterioration in my health. That uncertainty and pressure of letting people down means that we tend not to arrange many social events anymore.

31. Once we went on a cruise, and the insurance premium was extremely high. In the early days, it was a real struggle to go on holiday. Sometimes, I felt like I'd rather not go on holidays just to avoid having to explain my condition to the person on the other end of the telephone.

32. Our lives have been very weird. Our relationship has been like brother and sister for around 30 years. We drifted along. It's not done our relationship as husband and wife any good. I think we've been through so much together that I certainly respect my wife a lot and I could not have got through it without her. I think we have dealt with so many problems over the years, that we've blocked many things out. It's a coping mechanism for everything traumatic that has happened.

Section 6. Treatment/Care/Support

33. There was a haematologist doctor that I've never forgiven for his shoddy care. I wasn't given full and adequate information when I was diagnosed with HIV. My wife asked for me to be moved to James Paget Hospital because a really good colleague of my wife's, Dr Terry Mitchell, was there. He was fantastic – the quality of care was excellent. Although they couldn't offer much treatment, they were a good listening ear. He was very empathetic. [REDACTED] GRO-C

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34.

[REDACTED] GRO-C

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Out of all the bad things and experiences, at least we had him. Especially when I remember how I was callously told that I was infected with HIV (as I mentioned earlier in the statement), I am grateful to have been under the care of Dr Mitchell.

35. When I was ill in 1996 (as previously discussed), I had a continuous temperature and back ache. At that stage, they thought I was developing some problems related to HIV as my blood test results were all over the place. They thought there was a problem in my bowel. There was a huge bleed after the clinician's examination. My body partially shut down. I was given a 10 per cent chance of surviving. I was even put on a DNR order because of all my other health complications. The impression I got was part of that decision was motivated by a concern for their medical staff who might have been exposed to HIV had they resuscitated him. I know some nurses disagreed with the DNR order put in place for me.

36. I have been offered psychological support in the past but I did not take it. My wife was offered an independent counsellor by the HIV clinic. Although she took it up, it did not go anywhere because other things interfered with continuing with it. I never had any major obstacles to accessing treatment or care.

37. In terms of my dental treatment, initially, my dentist didn't want to treat me. For extractions, as a haemophiliac, I would usually go to the dental hospital. Years ago, everyone was very apprehensive. You would be last on the list, for example. Now the precautions are universal for all patients and so it isn't a big issue. I've sometimes seen a little red 'hazard' or 'high risk' sticker on my medical notes. I thought it was a necessary precaution to take.

Section 7. Financial Assistance

38. I received an initial payment from the Macfarlane Trust of around £30,000. We also received payments from the Skipton Fund. We got a Stage 1 payment from Skipton but faced difficulties getting a Stage 2 payment. Dr Graham Alexander helped us to get us a Stage 2 payment which we received in around 2008 or 2009. I was not eligible for any Caxton grants.

39. I signed a legal waiver for the Macfarlane Trust payments stating that I would not pursue legal action in relation to that. There was not anything similar with the payments from Skipton or elsewhere.
40. I also receive Disability Living Allowance. Initially, it was intended to be an allowance for life. Within the last five years, they've tried to remove that benefit which was a stressful experience.
41. I currently receive a monthly payment of around £3700 from EIBSS. It used to be around £1500 a month for both HIV and hepatitis C payments, but there's been an uplift in the last few years.
42. It's not really about money. It does not make up for what happened to us. But it does greatly help: life is miserable enough as it is, so not having to worry about things like heating helps. My wife thinks the money should have been provided a lot earlier and I agree. Many of the alterations we've had to make in the house to suit my needs, we have had to fund ourselves.
43. I found it really annoying that there was an inconsistency in the payments being given in Scotland and Wales compared to England. It doesn't make any sense for there to have been such discrepancies.

Section 8. Other Issues

44. I feel really annoyed that it's taken so long. I've been down this road so many times and it's led to nowhere. I feel very angry about that. Every year that passes, there will be fewer people still alive to see whether justice will be done. I think we should translate that anger into helping others who have lost loved ones and that's why I'm talking to this Inquiry. It's one of the worst NHS scandals. I think decision-makers need to be more responsible. I do not understand why blood would be sourced from American prisoners. It is totally irresponsible.

45. I'm so angry they could let these criminals in the USA donate blood. I'm usually a placid person, but this gets to me. It's so far-fetched that it's the type of thing you see in a movie. It all comes down to respect. They had no respect for what we've had to deal with. We've been treated like second-rate citizens. At one point, we tried to get Brandon Lewis MP involved. His response was essentially that we've been paid some financial assistance and that was it. They were totally useless.
46. You get fed up of saying the same things and nothing happens. It's hard to believe that people cannot comprehend or grasp what happened. For several years, I could remember – by heart – the batch number of the blood products I received. But, now after so many years, I don't have or remember that information anymore. I burnt all my records because after so many years of recounting my story for it go anywhere, I decided there was no need to keep it any longer.
47. In the last few years, I've come across doctors who have been off with me. I've had to tell them that I got infected with HIV via NHS blood and I was surprised to hear that they hadn't previously known of that as a source of infection.
48. I give training to second year medical students at the University of East Anglia. I instil on students about how important clear and compassionate communication is. I tell them about the negative experiences I had when I was told of my HIV diagnosis in a totally cold, uncompassionate manner. I provide this training to medical students because I do not want other people to be treated in the same way I was.
49. I find it bizarre that, despite my many chronic conditions, I wasn't identified as being 'vulnerable' during the first Covid-19 lockdown. I wasn't officially told to shield until the second lockdown.

Statement of Truth

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

Signed

GRO-C

Dated

9/11/2021