

Witness Name: E A Burkert

Statement No: WITN1125004

Exhibit No: WITN1125005-13

Dated: August 2019

INFECTED BLOOD INQUIRY

SECOND WRITTEN STATEMENT OF EILEEN ANNE BURKERT

I, Eileen Anne Burkert will say as follows:-

Section 1. Introduction

1. My name is Eileen Anne Burkert. I live at GRO-C
GRO-C My date of birth is GRO-C 1968. I currently work as a support assistant in a special needs school.
2. I make this second statement in relation to my father Edward Burkert who was born on GRO-C 1937 and died on 15th April 1992. He was 54 years old and died as a result of receiving contaminated blood products.
3. This witness statement has been prepared without the benefit of access to his full medical notes and records.
4. This statement is made supplemental to my witness statement submitted to the Inquiry in February 2019.

SECTION 2. HOW AFFECTED

5. My father was born on [GRO-C] 1937. I have a photo of him in shorts when he is about 2 years old showing his knees and then another photo of him when he is about 5 years old which shows how protruding his joints are. It is interesting to note that whilst my dad's haemophilia data records show that his haemophilia was moderate there is reference in my medical records when I gave birth to my son that my father's haemophilia was severe.
6. Dad was placed into the Barnardo's children home when he was a small boy. I had heard that it was because his mum and dad had parted and that because of his haemophilia my aunt could not look after him.
7. Dad kept in touch with his father and used to cycle together. He met mum and they were married in 1964. My twin sister and brother were born in [GRO-C] 1965 and I was born in [GRO-C] 1968. My first memories were when we lived in a council house. I had not yet started school so I always remember looking forward to dad coming home from work.
8. As far as I can remember dad worked as a gardener, even back then. The opportunity arose for him to take over as the main gardener of the park and the job came with accommodation as it did back then.
9. We moved into the lodge and I remember going to work in the park with my dad most days. I became his little shadow. I did not remember dad going into hospital for any treatment up to this time; he always seemed to be around.
10. He always had a limp as far back as I could remember but he was a very fit, active man.
11. He would put his arms out and I would hold onto him with my arms and legs and he would carry me home from the park.

12. It was then time for me to start school. I remember not settling well and I cried a lot. Mum was pregnant again by this time and in GRO-C 1972 my two younger brothers were born; another set of twins.
13. In 1974 mum and dad split up; my mum left and all five of us stayed with dad. We had to move house and out of a choice of 3 council houses my dad chose one in a small area and not on a large estate.
14. I always had a huge sense of security around dad from my very first memories.
15. Life moved on in a chaotic fashion; the 5 of us driving him mad. Life was a struggle financially but we were very much loved. I remember that we never asked for much but at Christmas he would always make sure that we got what we asked for. He was usually still paying for it until the next Christmas.
16. Even though he had a few stays in hospital for rest with bleeds in to his joints it never stopped from carrying on with gardening. Whilst he was quite a small frame I remember he had a "six pack" and always seemed to be tanned. He didn't wear shorts and always wore zip up ankle boots.
17. I remember that he did put a claim in for disability allowance and he was turned down. I cannot remember when this was but his legs were getting worse. He spoke of having a hip replacement but this never happened. Finally he did get disability allowance with the help from his doctor.
18. One day dad took my sister and I to his hospital and we met with the haematologist. We were taken into a room and told that dad had a serious condition called haemophilia. I remember being very defensive and getting angry; I started to cry. In my eyes my dad was perfect and there was nothing wrong with him.
19. There was talk of my sister and I being tested to see if we were carriers as this could affect us when we were to have children. I did not take much notice

but we had a blood test and that was that as far as I was concerned. I think I was about 12 years old. I am in the process of finding the records for this. I have requested my own medical records from this time but I have been informed that they have been destroyed. My sister and I are both carriers of Haemophilia A.

20. I do not remember having any more blood tests for anything either at the hospital or at the doctor's surgery. As far as I am aware none of us have ever been tested for Hepatitis C.

21. I attended hospital with dad on another occasion. They were showing dad how to inject himself if he had a bleed. There were needles and little bottles around and I asked why I was there. I was told that dad could do this at home and I could help him if he needed me to.

22. One day a mini fridge appeared in our dining room beside the kitchen. Dad was using the dining room as a bedroom at this point and it was easier than going up and down the stairs. We were excited as a fridge to us back then was a luxury.

23. We were told that under no circumstances must we go in it or put anything into it. There was also a yellow sharps bin on top of the unit, not out of reach, but again we were told not to touch it.

24. I am not sure of the date but one day a nurse came and took everything away without any explanation. I don't know if this was explained to dad at the time. I know this happened before 1984 as I left school in 1984 and my recollection of this is from before leaving school.

25. I cannot remember dad administering treatment at home from then on.

26. My dad's first positive test for HIV was 22 August 1985.

Section 3. Other Infections

27. I attach as Exhibit WITN1125005 a document from the Haemophilia Society database indicating that dad was at risk from vCJD.

Section 4. Consent

28. It is my belief that my father underwent multiple tests but I cannot be sure that these were without his consent. I am unable to provide any information in this regard as I have been unable to recover the majority of his medical notes and records. He was a very private man and because we were so young he did not tell anything to do with his haemophilia.

Section 5. Impact of the Infection

29. I cannot remember when my dad's behaviour changed but it did. I remember things being very different from the age of 13 until I left home at 22.

30. I cannot put my finger on it but things changed. I had always done the chores but it seemed that I was doing more. Colin and Keith were just children and it felt like they were not getting the same attention that we had up to their age. I never thought that dad was neglecting them as he never had or would but I felt that I needed to make sure they had clean uniform for school, clean underwear and bedding. I recollect being a whizz with the twin tub on Sundays.

31. It seemed like he had had enough in the sense that he he had brought us up but it was his time now.

32. I was still very close to dad but something felt so different but I never asked him why; I respected him. He seemed to be tenser especially when he had had a drink.
33. He would sometimes shout when we were in bed as though someone was there but there wasn't, he would be alone downstairs.
34. I remember my sister commenting on how thin his ankles were and he went mad, shouting at her and telling her off. We were really shocked as he only really used to shout at us if we were all arguing and he would tell us to stop and shut up.
35. I cannot find the words to express how things were different but I could feel it inside.
36. I still say to this day that if I could go back in time the only period of life I would change is from when I was aged 13 to 20. I can only describe these years as uncomfortable and more insecure.
37. There are at least 6 haemophiliacs in our family who have died from HIV and HCV. My uncle Stephen died when I think he was 35 years old in 1988 but I cannot be sure of those dates. I know he attended Treloars college. My dad died in 1992 when he was 54.
38. My uncle Peter died when he was 46 years old in 1996.
39. My 2nd cousin Sandy died aged 45 in 2003 and Charles Duncan died aged 18 in 1986.
40. We had been told that my uncle had Stephen had died from a stroke but I remember thinking that only old people died from a stroke. My aunt told me that uncle Peter used to go for regular blood tests without being informed what they were for.

41. Dad was very popular with his work force in the job he had with Remploy. He was very sociable and would often go out with his co-workers.
42. Suddenly dad became very old looking; I think I noticed this more as I had left home by this time. He had changed his diet. I know this as I would take him and his lady friend shopping and I would comment on the fact that he never bought things he was buying when I lived at home!
43. His main goal was to protect us. His words used to be "if anyone harms my kids I will do time for it". This torments me knowing that he kept his illhealth a secret from us to protect us but that was our dad, our rock and how he was. I can only remember him having one lady friend in all the years he brought us up. He would say "if they don't want my kids then they don't want me". This just showed that he would sacrifice his own happiness to look after us.
44. I remember the day dad was admitted to hospital in April 1992. I got a call at work from his lady friend. At first I thought she was going to ask me what time I would be there the day after to take them shopping. I remember clearly it was a Tuesday as Wednesday was my day off and I often spent it with dad. I was not to know that that phone call would change my life forever.
45. She said not to panic and that dad was in hospital as he had had a stroke. I did panic and I left my car and got a taxi to the hospital. I thought it was strange that my aunts and uncles were there from as far away as GRO-C but my concern was only for dad.
46. Then I heard the words I never ever expected to hear in my whole life that dad had had a bleed to his brain and that he was infected with HIV and had AIDS; we were told that he would not wake up. The doctors asked us to make the decision to turn off the life support machine, nothing felt real.

47. This was a total shock and I remember feeling as though I wasn't really there. We stayed at the hospital overnight until Colin our brother got there the day after. I woke up in the morning and for a split second thought that everything was alright but it wasn't. That was going to be the day that we had to make the decision that my dad's life was to end.
48. Dad had had his last rights read on the 14th April 1992 but as it was happening it felt like I was dreaming. This was my dad lying here. I was thinking who will help me through my life, who will I ask questions to. Who will help me fill in forms, make me laugh and make me feel secure. Who would walk me down the aisle?
49. We could not even send clothes for him to wear in his coffin or put anything with him and worse still they did not allow us to see him again. His funeral was over two weeks later. My sister Carol does not believe that dad was even in the coffin; that he had been taken away and disposed of due to his HIV and HCV.
50. When dad's funeral was over I tormented myself that I had made the wrong decision to have him buried. I felt that he was very much alone and I felt guilty. This feeling changed when my brother Keith died. We decided that Keith should be buried with dad but when we made enquiries about this it came to light that we did not own his grave. This was a terrible blow to us; we were all devastated. In the end to get around this we had Keith cremated and we put his ashes in with dad and Keith's name is on the plaque.
51. I cannot imagine to this day how dad felt when the adverts came on the TV about AIDS. I remember that they were scary and we all used to stop what we were doing to watch them. I cannot begin to imagine what he must have been thinking when we made comments about them.
52. The day after dad died I went to a friend's house; I was in such a state of shock. I remember daring to tell her about the HIV and AIDS. She replied to

me saying that it had been mentioned. I remember panicking and thinking that everyone would know and be disgusted. Fortunately, however, nothing was ever said to my face by anyone.

53. Colin and Keith were only 19 when dad died. Keith took his own life when he was 27. He was a lovely brother and had many friends; we were close and had fun times together. I always see Keith in my eldest son [GRO-C] Keith joined the RAF when he was younger but it did not suit him. He was a "home bird" like me and did not like staying away from home. Keith tried to stop drinking. I took him to shopping when he got paid to make sure he bought food. He was in and out of hospital for alcoholism but just could not stop drinking. I asked him many times why he needed to drink and he used to cry. He did not get angry with me, just himself. To see my baby brother go from being a strong, happy popular young man into a bloated, lost, lonely shell of a person still haunts me. I felt useless; I couldn't make him better and he was alone without his father's security. The youngest twins were 18 months old when mum left so to lose dad at 19 was a hard blow to them as he was their sole parent and their only security through their lives.

Section 6. Treatment/care/support

54. We were given the news about our father's condition before he died in a very matter of fact way. I feel that the seriousness of his infections were downtrodden and I will never get my head around the fact that we were just left to deal with his death without any help, support, counselling or contract from anyone from the day he died. Apart, however, from his doctor asking if any of needed a sedative just before his coffin arrived on the street outside our house on the day of his funeral.

Section 7. Financial Assistance

55. I have now received papers from the solicitors who held all the papers for my dad that were passed from the MacFarlane Trust (MFT) and Skipton Fund. My aunt has told me that the MFT paid £1,000 towards peoples funerals but

we never saw this as we did not get any correspondence from them after dad had died.

MacFarlane Trust

56. I note from the records that the MFT were informed of Dad's death the day after he passed away by Sister Sharpe.

57. The papers set out the regular payments that my dad received from the MFT as follows:

- a. £20.00 per week, paid monthly from January 1988 (he was told that this was the maximum grant that the MFT could pay)
- b. £28.00 per week, paid monthly from October 1990;
- c. £38.00 per week, paid monthly from November 1990.

58. My dad also applied for a holiday grant from MFT. Initially this was turned down because he had received a grant for a holiday in 1988 (the previous year). The MFT told him that the Trustees did not have enough money at their disposal to make grants annually, in respect of holidays, to everyone registered with the Trust. Eventually he was awarded £350 towards the cost of a holiday in August 1989 on the basis that the grant the previous year had only been small and the £350 was the "remainder". Copies of the relevant correspondence are exhibited at WITN1125006.

59. In October 1990 my dad was awarded a grant of £1,500 towards the cost of central heating installation. When he initially applied for this he submitted quotes (as required by the MFT) but was then told that, to consider the request, the MFT needed further information regarding his health and asked for permission to contact his doctor for this information. I note that whenever one of payments were granted and sent the MFT required the beneficiary to sign a reply slip to acknowledge payment.

60. There is now shown to me marked WITN1125007 a copy of the form that beneficiaries had to complete to request a single payment.

Skipton Fund

61. I remember there being only a 7 day window from discovering about the Skipton payment in which to register.

62. When I secured the Stage 1 payment from the Skipton Fund I had to get signed letters from my siblings as proof of who we were. This was on record when I applied for Stage 2 and I did not tell my siblings until it was finalised. We had a gathering on Keith's anniversary and a celebration of the older twin's birthday and I placed a cheque to them inside a birthday card from dad. That day to me felt like dad and Keith were there. There were lots of friends at the house and to me that was the first day in 22 years that I felt I could shout from the rooftops what had happened to dad without feeling a barrier. I remember it being the first time we could all stand in a room together as a family and talk openly about him.

63. My application for the Stage 2 payment was turned down. There is now shown to me at WITN1125008 a copy of the letter confirming this and the notes in respect of the Fund's calculation.

64. I also attach, at WITN1125009 some handwritten notes and an email from Patricia Hewitt to the Skipton Fund regarding the basis on which payments were authorised.

HIV Litigation

65. With regard to the payment from the HIV litigation I am appalled that my two youngest brothers were 18 years and 43 days old when the settlement was announced on 11 December 1990. Dad missed out on so much more because of those 43 days. I feel that no one should have been paid any more or any less than the next person.

66. Copies of the papers I have been provided with regarding the HIV settlement are exhibited at WITN1125010.

Section 8: Other Issues

Medical Records

67. I have tried to locate my dad's medical records. I contacted the haematology department at Leeds Teaching Hospital on 10th October 2018 and I filled in forms for both mine and my dad's records. I received my records from when I had the Chorionic Villus Sampling test when I was pregnant. Also with these records were some of my sisters which I was very surprised to receive and I wonder why our records had been put together.

68. I have also attempted to obtain dad's medical records from the various Trusts but to no avail. I attach copies of the relevant correspondence at WITN1125011.

69. I have been in contact with NHS England PCSE since August 2017. Initially I was told that Dad's records had been destroyed. It took 10 telephone calls/emails and 6 months for me to then be told that I would need to contact someone else for the answers I was seeking. I attach, at WITN1125012 a copy of my correspondence with the Legacy Team which followed. On 11 June 2019, after nearly 2 years of enquiries, I eventually received a letter from Bradford Teaching Hospitals NHS Foundation Trust and I attach a copy of the same at WITN1125013.

70. I have found the whole process very distressing. I have spent a long time and many phone calls attempting to access my father's notes and records.

Other

71. Dad was very popular in our area. I am not sure if it was because he had 5 loud kids and he was raising us on his own; this situation was unique. He was on the local darts team and he was a top player. His darts name was "Tungsten Ted". He played in tournaments and had many trophies, he also met and played Eric Bristow. He used to go out to our local pub at the

weekend and always came home with crisps or peanuts for us when we were little, it was a right treat.

72. Our house was open to everyone; dad welcomed everyone in. My brother Stephen had lots of friends and they all had the most respect for my dad – they laid a huge wreath on the top of his coffin which wrote "FROM YOUR SECOND SONS".

73. We used to go on pub crawls with Dad. He hosted the biggest parties on Boxing Day and he would not let anyone be alone on Christmas Day. I used to love Christmas time; we would make a list for shopping and I would be so excited to go with him. Dad and I used to trim the house up and spend evenings wrapping the presents. He always made it a magical time even though we did not have much. When I left home I used to meet him in the local pub on Friday nights then we would go to town together. Dad was not just dad to me; he was my life and my best friend.

74. I am 50 years old and the day my dad died was the WORST DAY OF MY LIFE.

75. I have mentioned my dad's lady friend. The top and bottom of this is that she took off after dad's funeral and had borrowed money from the family for the funeral. She had also borrowed £500 from my cousin. We went to the social for help with the funeral costs but had to pay it back on the sale of dad's house. I have since received paperwork from the MacFarlane trust, this shows correspondence from them to my dad's lady friend about payments to her and a letter of condolence. We never saw any of this!! It seems dad's funeral was paid for 3 times over!

76. I find it hard to understand how this could happen to my dad and that his untimely death contributed to the death of my baby brother. It has left a huge hole in my life. Dad has only seen one of his grandchildren, Kerry who was 19 months old when he died. My sister in law was expecting their second child

Ross and he was born in November after dad died. We have all been robbed of our dad seeing our children and dad was robbed of seeing them born and growing up.

77. I feel that dad had been dealt the worst cards in life; haemophilia, Dr Barnardo's, struggling as a single parent of 5 children and then being given 2 deadly infections by the NHS. Dad saved the authorities hundreds of thousands of pounds keeping us all together and for what? To be given £23,500 as a thank you.

78. OUR DAD, OUR ROCK has made me into what I am today. I want answers as to how this happened and why it has been hidden away like a dirty secret. It has affected our family in so many ways.

79. I am grateful for this Inquiry as it has opened us up as a family to share feelings that we have hidden from each other for 27 years. His grandchildren have never met him but he is still talked about and thought of in the highest regard. Kerry Anne, Ross Edward, GRO-C are his grandchildren, none of them will forget the impact that their grandad had on their parents lives and they will never forget their Uncle Keith.

80. Dad was an amazing strong, brave man who brought us up to respect. He did everything to protect us from harm right until his very end.

81. Sympathy has never been an option for us. Justice is what we want and must achieve as our ultimate goal in our lives, to thank our dad for who we all are today and what he did for us.

Anonymity

82. I do not wish to remain anonymous and I understand this statement will be published and disclosed as part of the Inquiry.

83. I do wish 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

EILEEN ANNE BURKERT

Dated.....*5th August 2019*.....