

Witness Name: D M Eden
Statement No: WITN1745001
Exhibits: WITN1745002-3
Dated: March 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF DOROTHY MAY EDEN

I, Dorothy May Eden will say as follows:-

Section 1. Introduction

1. My name is Dorothy May Eden and I live at
 was born on 1950. I am a retired police welfare officer and I am married with two adult children.
2. I make this statement as an affected person being the youngest sister of Frederick George Paintin (Fred) who was born on 1942 and died on 18 January 2000. His death certificate cites his causes of death as a) Hepatoma, b) Hepatitis C and c) Infected blood products. A copy of this is attached as Exhibit WITN1745002. All my siblings are unfortunately deceased.
3. This statement has been prepared without the benefit of access to my brother's full medical records.

Section 2. How Affected

4. Fred suffered from severe Haemophilia A with a 0% clotting factor from birth.
5. When he was younger and had bleeds he would be in bed for long periods of time. He had to rest which would make the bleeds settle. His joints had been very affected by bleeds and he ended up with his legs in callipers. Our older half brother died of haemophilia. I am not a carrier of the haemophilia gene.
6. Fred received all his treatment from The Churchill Hospital and The John Radcliffe, Oxford. He was treated by Dr Rizza, Dr Mathers, Dr Trowell, Dr Giogrande and Dr Keeling.
7. Prior to 1985 he received blood transfusions and plasma but after 1985 he received Factor VIII for his bleeds. He was unable to administer it to himself as he had needle phobia. The local doctors would come out to him and administer it. Our GP Dr Thorogood was so supportive; he was the doctor that insisted that infected blood products be put on his death certificate. I attach as Exhibit WITN1745003 a copy of the list of Factor VIII treatments Fred received between 1985 and 2000.
8. Factor VIII concentrate was seen as a revolutionary treatment at the time. There was no indication or no information given to him in relation to a risk of infection as a result of receiving Factor VIII. He had been going to the Churchill Hospital for plasma prior to Factor VIII which was about 30 miles away from where he lived. From 1985 onwards the Factor VIII was kept in Fred's home in their fridge. This changed Fred's life. Throughout his life Fred had had weeks of bedrest and was in continuous pain. Suddenly he was able to have an injection and be able to walk properly, go on holiday, go to work.
9. My sister in law is Barbara Jean Paintin (Barbara) and my niece is Louisa Michelle Paintin (Lou). We are a very close family and we were all together when we gave our statements for the Inquiry.

10. I understand from Barbara that it was in the early 1970's when he contracted hepatitis B. I have seen the document exhibited to Barbara's statement dated 8 February 1973 which shows the diagnosis of Serum Hepatitis signed by Dr Loe from The Infectious Disease Department, The Slade Hospital, Oxford.

11. I do not know the exact date when he contracted Hepatitis C (HCV) and I do not know the specific date when Fred was told about it. I do know however that there is a big implication that if you have Hepatitis C that you are a drug user or that you are promiscuous; my brother was neither of these.

Section 3. Other Infections.

12. I know that he was notified by letter that he was exposed to the risk of vCJD. I know that he was HIV antibody negative.

Section 4. Consent.

13. I know that Fred went regularly to the hospital for tests. I am not aware of what tests he was having and I am not sure whether he knew or not that his blood was being tested for infection.

14. Fred had been used as a guinea pig in his life so it would not surprise me if his bloods were tested without his knowledge. When he was 9 years old he had to have his appendix removed. He required a blood transfusion during the operation. I understand that he was the first person to receive blood on the operating table from a live donor. This had never been done previously in the UK.

Section 5. Impact

15. I remember back in 1986 when there were a lot of stories in the press about HIV; Fred reassured our parents and us that everything was ok. He used to joke and say that he must have been the only one in the area who was HIV clear as the papers implied that ALL haemophiliacs were infected. He always used to say that without Factor VIII he would not have lived as long as he did but now we know what we do I am bitter about what happened to him. He trusted his doctors and whilst he was not naïve he was honest and he never thought anybody would have done him wrong.
16. Fred was asymptomatic with Hepatitis C until the late 1990s when he had long periods of jaundice.
17. In 1998 Fred went on the liver transplant list.
18. He was asked to go on a low sodium diet and whilst he lost a lot of weight; his liver function improved. We were on standby for a liver transplant and he did everything right to prepare his body for it. Physically he improved and was not critical enough and therefore in November 1999 he was taken off the transplant list. It felt like he had been offered the chance of a new life, as he said to me, Haemophilia free then suddenly this was taken away from him. He was not given any support and left to his own devices. I feel quite bitter that he was taken off the list as, on 21st December 1999, an ultrasound showed a tumour present. He was then told at that stage that he was too poorly for a transplant.
19. He appeared to deteriorate from that moment on. Physically I saw a difference in him when he was told he was no longer eligible for a transplant.
20. Just before Christmas 1999 I went with Barbara and Fred to see Dr Trowell. She said in a very matter of fact manner that there was nothing they could do for him. He crumpled in the chair. At that stage Barbara was too emotional; she was unable to cope and walked out of the room. Dr Trowell said that they

would do anything for him to facilitate his wishes as she said he now had a matter of weeks to live. She asked him where he would like to go for his palliative care. He said he would like to go to Ellen Badger Hospital and Dr Trowell said she would speak to his Dr, Dr. Thorogood for this to happen. This was where he had been born and where he died.

21. After that meeting Fred asked me to look after Barbara and Lou but particularly to look out for Lou.

22. I feel angry that he went to the Ellen Badger Hospital to die. This was a geriatric hospital. I was desperate for Fred to go to the Myton Hospice but I know that he chose the Ellen Badger and we honoured his wish. In my opinion the medical practitioners should not have let him go there to die. We were washing and cleaning him because the hospital did not know how to handle a haemophiliac.

23. Fred deteriorated very quickly towards the end of his life. He became very jaundiced and he lost a lot of weight. It was horrendous to watch him shrivel.

24. He died on the 18th January 2000. I saw a letter from Dr Thorogood that said Fred had died peacefully but I disagree. I have seen other members of my family die and others but I have never seen anyone die like Fred did. He was agitated and in much pain; his death was not peaceful. They attempted to alleviate the pain with drugs but they were not strong enough.

25. When Dr Thorogood issued the death certificate it was in a sealed envelope. I am aware that all death certificates are in a sealed envelope until opened by the Registrar. We were not fully aware of his Hepatitis C infection until the death certificate was read to us.

26. I recall thinking that the Coroner may ask for a post mortem due to the circumstances in which Fred passed; he was only 57 years old and had died in a geriatric hospital with haemophilia. However, this was not required.

27. I loved Fred to bits; he was my big brother. Mentally he was an extremely strong character but not in a macho-way. He never complained at all. He was a wonderful, smart and determined man. He always said to all of us that "*life was for living*". He hated fuss and emotion. He used to worry about his family and not about himself.
28. He had always thought that he would not be able to have a family because of his haemophilia so he was very protective of his daughter Lou and he was so proud of her. He was a very private man and was very protective of his family. He did not want to worry us all. He protected our parents as well; he was very close to them.
29. Whilst his death has had an impact on all of us; it has had a huge impact on Lou who, as a consequence, has suffered manic depression. In fact I feel the impact on her has been catastrophic and has drastically changed her life. I have watched the huge change that it has had on her. She was a highly successful career woman but then she started looking into why her father had died and became involved in campaigning to secure the truth. She has been unable to return to gainful employment.
30. I moved in next door to Fred and Barbara (my brother in law lived there) and as I was able to drive I used to take him to the hospital for his treatment, for the last 2 months of his life I did not leave his side.. I have therefore been able to see close at hand the effect his death has had on both Barbara and Lou. I am happy that I am able to give this statement to the Inquiry but it is all down to Lou's hard work and investigations that I feel I am in this position to do so.

Section 6. Treatment/Care/Support

31. I do not know whether any treatment was offered to Fred in terms of counselling. I do know that he would not have gone to it even if they had as he was such a strong, proud man.

32. I believe having seen them and discussing them with Barbara that his medical records are inaccurate; they also have information relating to other patients. They show that Fred received FVIII on 6 March 2000 but this was two months after his death so this is clearly wrong.

Section 7. Financial Assistance

33. Fred was Company Secretary of Hood Norton Brewery and he worked up until three months of his death. His company had been very good to him in the past. He never let his haemophilia and his treatment affect his work. The company paid for his funeral.

34. I understand that my sister in law has received payments from the Skipton Fund but I am not able to give any detail. I have not received any financial assistance.

Section 8. Other Issues

35. I am very sceptical to this day about the validity of any test results.

Anonymity, disclosure and redaction

36. I do not wish to have anonymity and understand that this statement will be published and disclosed as part of the Inquiry. I am happy to give oral evidence if the Inquiry requires me to do so.

Statement of Truth

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

Signed...D M Eden...
Dorothy May Eden

GRO-C

Dated.....21st March 2019.....