

Witness Name: GRO-B

Statement No.: WITN3123001

Exhibits: None

Dated: October 2020

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B

1. I, GRO-B will say as follows: -

Section 1: Introduction

2. My name is GRO-B. I was born on GRO-B. I am married to GRO-B. I have a daughter called GRO-B and I had one son called GRO-B. S died as the result of infections contracted from infected blood products administered to him to treat his haemophilia. During the course of this statement I intend to discuss the events leading up to S's death and the impact of his death. This statement is made from my recollection of events. I have not yet received copies of S's medical records.

Section 2: How affected

4. My son S was born in 1976. My father was a haemophiliac and I am a carrier of the illness. As a result of this we were aware of the condition. S was born in Lewisham Hospital ("Lewisham") even though we lived in GRO-B. The intention behind this was that S could be tested immediately after his birth for haemophilia, as Lewisham had a specialist Haemophilia Centre. Despite the fact that I was induced and Lewisham had plenty of warning, S was not tested upon birth.
5. My daughter, GRO-B, was two years old when S was born and she was not happy about having a new baby around the house. I recall that once, whilst S was still in the womb, he kicked GRO-B while she was sat on my lap. He was a large baby, 9lb 5oz.
6. S was not diagnosed with haemophilia until 1977. We had a year with no real trouble beyond some minor bruises. We had placed cotton wool pads on the corners of tables as a sensible precaution, but that was all. We considered this to be fairly normal for a house with a young child.
7. S was diagnosed as a moderate haemophiliac with 4% clotting agent in his blood in 1977. My nephew is also a haemophiliac but his condition is severe and my father's haemophilia was also considered severe. As I know this condition is hereditary, and that the severity of the illness is usually the same in each family, I do not know if a doctor made a mistake at some point. My father lived and worked, including as a security guard, well into his 60's with little or no treatment early in his life, although I recall he had had snake venom, amongst other treatments. Whilst he had some troubles with his knees and had to walk with a stick, life was not overly difficult for him and he managed. My daughter does not remember him as being particularly frail or disabled, just as being grandad.
8. Similarly, S initially led a normal life. He played football, biked, went to cubs and his condition was not bad while he was young. He was an outgoing, friendly and adventurous child, and I remember him once getting onto another child's bike and zooming off down the road. He did not let his haemophilia change his life and we were happy for him to live normally. My daughter remembers specifically not being allowed to hit him, although he was not allowed to hit her either.
9. Having said this, S's haemophilia naturally led to him suffering from some bleeds and medical complications. Someone at his school once hit him and he had two black eyes. When his baby teeth came through, he bled badly. He needed a bowl to catch the blood and we had to take him to the hospital. Some of his teeth were removed and his mouth had to be stitched, but in general he was healthy and well.

10. [S] always received treatment in the form of Factor VIII blood product. This was administered in Lewisham at the Haemophilia Centre. By the time home treatments became available he had already been diagnosed with HIV and so he was always treated at hospital and never at home. I remember them often having difficulty locating the veins in his hands and arms. I cannot recall the first time he received Factor VIII treatment but it was probably 1978.
11. During his childhood [S] was generally healthy, and if he bled we took him to Lewisham for treatment and then brought him home. It became part of normal life. During his early childhood, he was also one of the biggest in his class and was tall for his age.
12. However, in 1982 [S] had developed something strange on his thumbnail. It was an unknown growth which the doctors could not identify, followed closely by Chicken Pox. He was very unwell at this time and my daughter [GRO-B] had to stay with her aunty. It was an awful time and [S] had to have the nail removed. I do know that he received two injections of Factor VIII in quick succession following the removal of the nail.
13. Subsequent to this he had a large number of colds, stomach bugs and illnesses which progressively became worse over the next three years. I recall him once reaching a temperature of 104 degrees. No-one else in the house was ill; we had all been eating the same food and my daughter attended the same school.
14. The following three years saw [S] falling ill increasingly often. He needed antibiotics to treat his conditions and taking care of him became more time consuming. I do not know if he was infected before or after the nail incident or if indeed this incident was when he received the infected blood product.
15. On 13 March 1985 [S] had blood tests, and on 1 April 1985, I received a letter in the post with the results. This letter informed me that [S] had been infected through blood products and had contracted HIV. The letter did not offer me any counselling or support and said little beyond "he's HIV positive. Yours sincerely". Unfortunately, I tore the letter up immediately. I just did not want to see it.
16. [S]'s diagnosis with HIV was absolutely devastating. He was just under nine years old and we had no way to tell him. We thought that it meant that he was going to die, and we had no idea how we could tell our eight-year-old son "you're going to die". We could not tell his sister [GRO-B] either.
17. We were never told of any of the implications of HIV and subsequent to his diagnosis, the information that we were given about it by the doctors was very, very limited. I do recall that we were told that there was a five-year incubation period and therefore the year 1990 became my target. I thought if we could get him past 1990 then he would be alright. I took this on board and it was very important to me, although subsequently I have learnt that it was incorrect advice.
18. We were also given no information about the transmission of the infection and while we were always good at washing our hands and being fastidiously clean, this was as a result of our lifestyle rather than from medical advice.
19. [S] began to miss more and more school in order to go to Lewisham for treatment. I remember once being told by Dr Whitmore, Consultant in charge of [S]'s treatment at Lewisham, that [S] should not go on a school journey. This was in the spring of 1986 and [S] was 10 years old at the time. We knew that this was because of the HIV, and that they could not risk [S] injuring himself and infecting one of the other children. I did not see how this risk was any different from the risk he posed or faced in the playground, but Dr Whitmore held the keys to the Factor VIII treatment as he was the Consultant prescribing it to [S] and so we did not feel we could argue with him. As far as [S] was concerned, he was not allowed on the school trip because of his haemophilia. However, this was very upsetting for him, as the whole school year went except for him.
20. [S]'s condition steadily deteriorated with him catching various illnesses that Dr Whitmore could not diagnose. I recall someone at Lewisham once commenting that I looked happier that day, to which I responded that this was because they had diagnosed [S] with Tuberculosis ("TB"). I knew that they could treat TB and so this was huge progress compared to them fighting unknown illnesses.
21. By 1988, [S] was vomiting frequently and we had all become used to helping to manage his symptoms. He suffered from bad (haemophilia) nosebleeds, diarrhoea, vomiting and I can remember him crying during these episodes. And they say "beware bodily fluids".
22. My daughter, [GRO-B], has reminded me that [S] suffered from a perianal

abscess and had to go in for an operation in 1988. I have tried not to think about the worst of S's illnesses since his death. I think I must have blocked this memory until my daughter reminded me. He was extremely traumatised, upset and embarrassed by this event and I can remember him being mortified by being looked at by the doctors. It was humiliating and painful for him.

23. At some point during S's treatment for his HIV, S was transferred from Lewisham to St Mary's Hospital ("St Mary's"). This followed his diagnosis with AIDS, which occurred prior to 1989. I believe that Lewisham got out of their depth with S's complex illnesses and they referred him to St Mary's, as it had a specialist clinic. At St Mary's S was treated by Professor Levin and a consultant, Sam Walters who dealt with the HIV and the AIDS that it had now developed into. There was a huge amount of stigma associated with HIV and AIDS at the time and I can remember one of the nurses there saying that the only patient that she had seen with AIDS was a "rent boy".
24. S's treatment for his HIV and ongoing symptoms was very traumatic, and required a huge array of different drugs and medications to be administered throughout the day. By way of example, in my notes from October 1991, I have recorded that S was receiving 26 drug treatments throughout the average day, across 12 hours of treatment. This was at home with me treating him.
25. St Mary's began to treat S with Azidothymidine ("AZT") treatment for his HIV, which sadly did not work for him. I remember another boy at St Mary's who was also suffering from AIDS and he survived with the treatment for his HIV. However, he was never as ill as S and S continued to get worse despite AZT treatment.
26. By 1989 S was undergoing a variety of tests and scans to attempt to diagnose each condition. I remember kidney scans and endoscopies, which caused more harm than good, and provided us with no further details. He was also suffering from terrible thrush which formed in a rash about his throat and mouth. The thrush made eating and swallowing incredibly painful for S. Eventually he had to be prescribed pain killers to allow him to swallow. However, as a result of his difficulty, he lost his appetite and suffered significant weight loss.
27. It was in 1989 that my husband and I informed S and his sister about his diagnosis with HIV. We had tried to keep it from him for as long as possible in order to protect him. S never really acknowledged his illness. He really, really wanted to live. As he kept bouncing back and recovering from his various infections, the doctors thought that their treatment must be working.
28. In 1990, as his health deteriorated further, S was given a gastrostomy and he had regular sputum tests. Every time he underwent treatment or surgery, his haemophilia meant that he faced additional risks. Frustratingly, the tests never returned any clear results, apart from diagnoses for TB, Listeria and Shingles. Following intravenous injections to treat his ulcers the doctors told us that they had diagnosed S with "failure to thrive". He never talked about his condition and seemed determined to carry on.
29. He missed months at a time of school and he still scored at the top of his class. He was a clever and popular boy: he was never bullied. My daughter recalls a time when one of the boys in S's class approached her in a shopping centre. The boy had a bad reputation in school and my daughter GRO-B confessed that she was worried that he was going to mug her. However, he had approached to ask how S was doing. This was a sign of his character, he was a very popular boy, very funny and a genuinely lovely person.
30. By 1991 S had been admitted to St Mary's on multiple occasions. That year he contracted numerous infections. He also suffered with shingles, episodes of spitting blood, spasms of the oesophagus, a dystonic reaction to the drugs, ulcers and thrush. He was subjected to blood cultures, painkillers and a variety of tests. Alongside S's normal transfusions and treatments, he was given gamma globulins every two weeks as well, throughout the year. He also began to suffer from paranoia and depression. At one stage he was given a bone marrow biopsy which was really awful and actually achieved nothing.
31. Despite his diagnosis with HIV and associated symptoms S took his GCSEs in 1992 as he wanted a chance at life. He wanted to do things with his life and he never ever gave up. He took six GCSEs but received no dispensation from the exam boards for his condition. I can remember that children with hay fever used to get extra time in the exams. However, S and his sister, who

was also undergoing exams at the same time and was understandably very traumatised by [S]'s diagnosis and ongoing deterioration, received nothing.

ANONYMOUS

32. By the time of his death in 1993 [S] had developed numerous permanent conditions. One of his legs had stopped working, followed by a hand and the doctors had considered a potential diagnosis of motor neurone disease. He had a large spongy lump on the side of his head. [S] had become less and less mobile, as well as losing most of his sight and speech. He had blood in his spit and stool, and had to undergo a lumbar puncture. He had to use a colostomy bag at the end and he was in such pain that he would scream when touched. Whenever I see television scenes of mothers hugging their children on their hospital beds, I know I could never have done this with [S] he was in too much pain. We had a small suction pump at home that we used to clear his throat.
33. In the end his organs failed. He spent the last three weeks of his life in a coma, possibly assisted by the morphine. On GRO-B 1993 [S] died. We were advised by the GP not to have AIDS written on his death certificate, due to the stigma, but rather to list his cause of death as bronchopneumonia.
34. Before [S]'s death, St Mary's requested his body for a few days after his death in order to assist their research, to which we agreed.

Section 3: Other infections

35. I believe that [S] suffered from various other infections as a consequence of his diagnosis with HIV and AIDS contracted through infected blood product. By the time of his death, his HIV condition had progressed into AIDS and he also seemed to suffer from vCJD infection on the brain. This caused him to suffer hallucinations and he believed that things were crawling all over him. It was extremely traumatic for us all, and he had a trip to Guy's Hospital for brain scans. Questions were raised about toxoplasmosis as a potential diagnosis as well.
36. The doctors never mentioned Hepatitis to us and I do not know if [S] suffered from this condition. If he was tested for it, we were certainly never told.

Section 4: Consent

37. We were never informed of any risks inherent in the taking of Factor VIII blood product. We were told that it was wonderful, and that with the treatment [S] would be able to live a normal life. My daughter remembers finding a Miffi-esque book which we were given about it with the line "with just a little prick you'll feel better".
38. When [S] was tested for HIV, we knew that he was being tested for the condition. This test was a routine procedure at the time for all haemophiliacs.
39. The rest of the family was never offered a test for HIV at the time. Had we been offered I suspect that we would have said no. GRO-B had a test when she was pregnant with her first child, which was routine, not because of family history.
40. Prior to the HIV test and diagnosis, my husband GRO-B had met with Dr Whitmore and had asked about whether or not the Factor VIII treatment [S] was receiving was British. Dr Whitmore promised my husband that [S] only received British product. Subsequently GRO-B has been very angry to find out that this was not true and that [S] instead received infected American blood product. We were given no input on his treatment.
41. In terms of our consent to his treatment, I do not know that we ever gave our consent formally. In terms of the Factor VIII we agreed that he should receive it but it was only ever presented as a good thing and seemingly the only course of treatment. The risk of Hepatitis C or HIV was never presented and it was certainly never put to us as a potential risk.
42. I do not recall ever signing any documents. The consent process possibly went as far as being asked "is this okay?" and us agreeing to it. We thought it was for the best and were never told otherwise.

Section 5: Impact

Impact of the diagnosis on [S]

43. [S] was devastated by the diagnosis, although being the type of person that he was, he just tried to carry on and to get better. He really wanted to live. I

cannot recall his reaction to us telling him about his infection with HIV. I'm sure he cried but I cannot remember any drama and we did not talk about it afterwards. I recall on one occasion, when S was aware of his diagnosis, one of his doctors took him into a room and told him to let it out; to have a really good "swear". However, he didn't.

44. After being reminded I do recall the perianal abscess had a big impact upon S. As his illness advanced it clearly became harder for him and he often cried during episodes of illness.
45. I can also remember that S was particularly upset by not developing at the same rate as other boys his age. As a result of his illness and the drug treatment, he never went through puberty. This worried him a huge amount, as he never really developed. The doctors treated him with testosterone injections at Guy's Hospital in 1991 but unfortunately this did not work. S was very upset about having to accept that this was how he would look, and from the ages of 11 to 16 he continued to look like an 11-year-old boy.

Stigma

46. Despite his diagnosis and missing large amounts of schooling due to hospital appointments, S insisted on carrying on with school. Despite being small compared to other pupils, he sat between the popular girls, at their request; he was always funny and well liked. The head teacher told us that we should keep S's diagnosis with HIV a secret at school. After this they offered very little support. One teacher did help my daughter, GRO-B, and another often visited S at home. This support seemed to be from these individuals personally.
47. S experienced stigma in other places as well. This was the period of the tombstone advert on the television and I can remember the public's view that haemophiliacs and people infected with HIV posed a danger to society. I recall S being told that he could not use the toilet while attending Lewisham. This was especially upsetting as Lewisham had the Haemophilia Centre attached to it and so they really should have known better.

Impact on S's father

48. S's death had a significant impact on the family. My husband, GRO-B, threw himself into his work to try and distract himself. However, he was traumatised and depressed, and increasingly withdrew into himself. He was working in London and in the 1990's it was not appropriate to take time out for grieving. He also admitted: "somebody has to keep working". Throwing himself into his work was how my husband coped and during S's illness GRO-B could not acknowledge that he was going to die.
49. I recall two incidents during the treatment when my husband's commitment to his job was difficult to understand. On one occasion S's consultant had to ring him at work and tell him: "you need to be here", in order to get him to come to the hospital. On another occasion, a nurse said to me: "just how ill does S have to be for him to be here?" GRO-B wanted to be there to support us but he knew he had to keep working and his job was his way of coping. He did, though, come every evening after work to see S in hospital.
50. GRO-B was also very angry with Lewisham after it emerged that he had been lied to about the provision of American Factor VIII blood product to S. Our nephew had been treated solely with British factor and was not infected and my husband was very angry about the sharing out of good blood and the bad blood.

Impact on S's sister

51. The impact upon my daughter, GRO-B, has been significant. She has described it as being as though her life was put on hold and has had many appointments with counsellors. It became normal for her to come home from school to find a note saying that we had gone to the hospital and she was given no choice but to cope with the situation. Despite her brother's illness, no-one ever asked GRO-B how she was feeling. Unfortunately, she found herself at the front line at school especially of having to lie about his condition to teachers and friends in order to keep S's HIV a secret.
52. GRO-B has told me about the difficulty she had in perpetuating the lie, as each new development would push an older lie out of her head, and she was constantly having to think on her feet to keep her brother's illness a secret.
53. GRO-B has described this as being an enormous pressure on her to pretend that she was fine and just a normal teenager. She has told me that she felt isolated, as though she were in a bubble and she found she could not relate

to her fellow pupils at school. It was such a big thing in her life that no-one else could relate to and she found herself unable to sympathise with people who were going through minor upsets in comparison to the huge issues she was dealing with. She had friends, but no close friends, and felt that she could not get the sympathy that she would have had if a family member been suffering from something like cancer rather than AIDS.

54. Before we explained [S]'s diagnosis to both [S] and GRO-B in 1989, she did not fully understand what was happening. She has told me that she can recall one incident when [S] was unwell and I had returned to find her caring for [S]. There were bodily fluids everywhere. I was horrified. At the time GRO-B thought that my reaction was a massive overreaction, although she now understands why I reacted as I did.
55. On top of the isolation, secrecy and lies that GRO-B has had to endure, she has also been tested to discover if she is a carrier of haemophilia. This was found negative and she has told me that she found this strangely upsetting, as though she were grieving for a connection that she no longer had with her brother. Upon the birth of her child she also realised that she had lost more than just a brother, that she had lost an uncle to her children as well; possible cousins for her children, as well as nephews and nieces.
56. GRO-B also believes that her education has suffered as a result of her brother's illness. She took her GCSE mock exams shortly after we revealed [S]'s diagnosis to her and she was horrified that one of the English mock questions was about infected blood. She believes that her final exam results were affected, as it was difficult to write essays and do her homework on the end of a hospital bed. However, like her brother she received no support and no dispensation from the school. She has told me that she did not want to bring these things up at the time as she did not want to trouble me and felt that I relied on her for her support.
57. GRO-B has also told me that she felt that if she did not leave for university after her exams, that she would never go. She has described this as trying to cling to normality to get away from the horrors that were waiting at home and that without this she would have sunk. It was hard for her to go away and she called us for one or two hours every day from the payphone at university. She did not feel that leaving university was an option, as if she did, she did not think she would have been able to start afresh.
58. After [S]'s death, GRO-B has been able to reveal [S]'s diagnosis to more people and more friends and has been receiving some support from them. She has told me that she felt that keeping it secret was about protecting [S] and with him gone she does not have to protect him any longer. I know that she has received counselling for this and has found this helpful.
59. [S] was not just a brother to her, but also an unconditional friend with whom she could share anything. That is irreplaceable.

Impact on me

60. Following [S]'s death, I started a course in September 1993. I found that I had to try and fill every single hour with classes and events; to fill the day to keep myself distracted. It was that or I would go under. After reading the old diaries that I kept at the time, I realised that I had blanked out how awful that period was for me while [S] had been ill. I had put all of my feelings into a box to try and protect myself. The process of opening that box again, to discuss these events and prepare this witness statement for the Inquest, has been traumatising. The hardship and the secrecy surrounding [S]'s diagnosis has made me short and harsh with people complaining about minor things.
61. Throughout the whole time, I found that I had to just try and keep going to get on with things. During [S]'s illness I found a lump in my breast and went to the doctor, who strongly recommended that I got treatment privately, to get the issue sorted as quickly as possible; the family just could not cope with having that on top of [S]'s condition. The doctor was told about [S]'s HIV diagnosis and to prove that he was not scared he touched my skin, and said that he "was not at all bothered". I found this incredible.
62. I had to leave work when [S] became ill, in order to be able to look after him and this made me feel increasingly isolated. From May 1990 I greatly reduced my hours and finally left in 1991. Since his death I find that I can talk to friends a lot more about it, but at the time I could not in order to try and protect him. I did not tell many people about his HIV until after his death. It is still very difficult to explain the situation to strangers or new friends.
63. Helping out with GRO-B's children, my grandchildren, has been a life-saver but I cannot help but compare them to [S] and GRO-B at the same age. They look like them, with GRO-B's son reminding me of [S] and they have

Financial impact

64. Financially, S infection has also had a severe impact upon us. I gave up work and GRO-B was the sole provider to the family. I found myself buying extra food in order to try and tempt S to eat, which often went to waste. In addition to this we had to have the washing machine on constantly cleaning sheets etc, and the house had to be kept very warm to keep him warm. The bills began to mount up, as did the train tickets to London in order to get him to St Mary's.
65. Eventually it got to the point when S could not go on public transport, partly due to his wheelchair and we could not get a disabled badge in Westminster, for St Mary's, as it had its own system. He was too unwell for public transport. We began receiving parking fines and found ourselves having to dash out of St Mary's in order to confront traffic wardens before they could ticket us, or to put more money in the machine. I had to drive across Central London with a sick child, park the car and manoeuvre his wheelchair. It was deeply traumatic but we had no choice.

Section 6: Treatment, care and support

66. S was always treated with Factor VIII blood product for his haemophilia and never received home treatment, instead going into Lewisham or St Mary's to be treated there. Following his diagnosis with HIV he was given AZT tablets to be taken to try and slow the progress of the infection.
67. I was given some lessons on the ward as to how much and what drugs to administer for S when we were allowed to take him home, and also for his final months. I recall being told that I had to keep gloves on and to keep them sterile, and the drugs that I was using were so toxic that it could make me ill to touch them. GRO-B also learned how to put on the sterile gloves, and the routines, although I administered the drugs on my own.
68. We were given support from the two or three of visits to Helen House hospice, however they would not administer the drugs. One man from the hospice gave S a ride in his helicopter, which was something he had wanted to experience, despite there being driving snow, which was amazing.
69. Our GP was always very good to us. He would leave his number whenever he would go on holiday and even rang while away to check up on us, to make sure that everything was alright. He would also brief another GP at the surgery on the situation so that they could assist in his absence, if necessary.
70. I do recall one situation when the treatment we received was unsatisfactory. We had to take S to Guy's Hospital for a brain scan, however there was no trolley provided for him. We had to carry him through Guy's Hospital. Fortunately, he was so light by this stage that I could carry him myself. Almost everything S was suffering from at this point was undiagnosed apart from TB and Listeria and Shingles. The doctor simply told me "we don't know".

Obstacles to treatment

71. In terms of access to treatment, we did have some difficulties throughout the process. We felt that we could not counter Dr Whitmore's arguments for fear that the supply of Factor VIII would be affected, although we just assumed that S was given the best treatment possible. I know that my husband has never forgiven Dr Whitmore for telling us that all of S's treatment was British.
72. I always found it peculiar that when we attended St Mary's S was made to wait until the end of the day for his operation. It was explained to me that the St Mary's had to clean up thoroughly after S's operation, in order to limit the chance of cross-infection. They wanted to get everyone out of the way and clean up after S. I was very surprised by this, as surely they should be cleaning up thoroughly after every operation. S was at risk from other people's infections and illnesses as well and his weakened immune system exacerbated this. They should have deep cleaned before him.
73. I do recall that there was some difficulty in obtaining dental treatment for S because of his haemophilia. Normally S would be referred to Lewisham, however subsequent to his HIV diagnosis he was sent to King's College Hospital ("King's College"), as normal dentists would not accept him. Happily, we had no difficulty once the special booking had been made and GRO-B has even told me that she found going to King's College quite exciting as it was a specialist dental hospital. Apart from having to go to hospital for dental

Counselling

74. We were offered some counselling as a family, however after a few sessions, we decided that this was not particularly helpful. None of us were willing to talk about things in a room together and it was not successful. This was partly because S was present and none of us felt that we could talk openly about our feelings in front of him.
75. In addition to this, my daughter has said that some of the feelings and issues she would have wanted to talk about with a counsellor, were about the rest of the family. She did not think she could raise these in a family counselling session.
76. I can simply remember after he died, not wanting to talk about it at all. I only wanted S back and so I filled my days with courses and volunteering to try and keep busy. In retrospect, I accept that individual counselling possibly could have helped.
77. I know that GRO-B sees a counsellor and received some counselling at university. I believe she found it difficult to keep going to counselling but did appreciate the support that she had been receiving.
78. Lewisham provided us with a social worker called Clare, however she got married and moved to America and was never replaced after that, no one fully understood our family's situation and while we did receive some help from a pleasant nurse, we had no real back-up and support. GRO-B also had two or three counselling sessions via the McMillan nurse.

Section 7: Financial assistance

79. We did receive some financial support from the Macfarlane Trust. This was single lump-sum payment which I believe was to the sum of £15,000, or possibly £20,000.
80. I can recall that the forms to apply to the Macfarlane Trust for financial assistance were not easy or simple to fill out. My daughter GRO-B can remember us filling them out on holiday and that the process was very difficult. The fact that she can remember this despite not being involved in them indicates how tricky they must have been. Since this one-off payment I think we have received no further help from the Macfarlane Trust.
81. In addition to this, a social worker at St. Mary's once managed to secure us some money to assist with transporting S and whilst this was not much it did go some way towards paying for petrol and train fares.

Section 8: Other issues

82. The secrecy and stigma of S's illness has been incredibly difficult. Sometimes I would say that I had a son who died or at other times I would just say I have a daughter, but that feels wrong as if I am somehow denying him. A lot of my old friends now know what happened, although more casual acquaintances do not. I usually just say "it's a long story" if it comes up in the hope that people do not ask further. I had to cope with and go through so much at the time that I just boxed up all of the grief and feelings; this was how I coped.
83. S death has been incredibly difficult for us all. I lost both my parents and my son when I was still quite young and I feel that I have become quite a hard person as a result. My whole life has been affected by his death and if I get to 80 years old, on my birthday I feel I will still be looking around for him, as someone is missing.

Statement of Truth

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

Signed

GRO-B

Dated

14-11-20