

Witness Name: Alexander Robert Owen

Statement No.: WITN0971001

Exhibits: **WITN0971002**

Dated: 19TH MARCH 2020

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF ALEXANDER ROBERT OWEN

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 27 June 2019.

I, Alexander Robert Owen, will say as follows: -

Section 1. Introduction

1. My name is Alexander Robert Owen. My date of birth is GRO-C 1989 and my address is known to the Inquiry. I am affected by my Dad's infection with Hepatitis C by a blood transfusion.
2. I intend to speak about my Dad's infection with Hepatitis C. In particular, the nature of his illness, how the illness affected him, the treatment he received and the impact it had on him, myself and our family.
3. I originally thought that I wanted to remain anonymous in giving this statement, but I have now chosen to go ahead without anonymity.

Section 2. How Affected

4. My Father's full name was Robert Symington Leith. He was born on GRO-C 1956 and he passed on 12 September 2017, at the age of 61.
5. Dad was infected with Hepatitis C which he received as a result of a blood transfusion he was given after a serious motorbike accident in the late 1970's/early 1980's.
6. I am certain, based on his death certificate, that Dad passed away due to liver complications from Hepatitis C.
7. From the point of Dad's diagnosis with Hepatitis C onward, he had liver problems. These were cirrhosis and tumours of some sort on his liver.
8. There are 2 causes of death listed on his death certificate. One is sepsis and the other is Hepatic Encephalopathy, which I believe is liver related. A copy of the death certificate is labelled as Exhibit **WITN0971002**.
9. My relationship with my Dad was quite distant during some periods in his life, especially some of the periods where he was ill. I did care for my Dad during some of his illness.
10. In the end, I wasn't informed about his death until the next day, as I had fallen out with my step-siblings and there was a bitterness between us. We didn't have any contact at the time that dad died and today I don't have contact with them anymore. We are fairly distant.
11. Dad worked as a Fisherman for most of his life and he was based at Ayr Harbour and then moved to Troon Harbour. Growing up, I remember that he was away a lot of the time due to his work as a Fisherman. He would go to the North Sea out towards the islands, like Mallaig and Kintyre, and also Ireland. He did a lot of fishing in those days.

12. He would be away for a few weeks, then back at the weekend, then back to work again. It was a typical Fisherman's life.
13. Dad met my Mum, Julie Frost, who would become his second wife, in 1986 and they married in 1988. My Mum was married before she met my Dad and I have a half-brother who was from Mum's first marriage.
14. They were married for 7 years and they separated in 1994 when I was about 5 years old. It was a volatile marriage and my Dad was not the easiest person to get along with at that particular time in his life.
15. I once asked my Mother why she stayed with him for so long, given the volatile nature of their relationship, and she told me it was because she loved him. She knew he was volatile, but she said that when he was nice, he could be really nice.
16. I wasn't allowed to legally make the decision whether to see my Dad until I was 16 years old because, as I mentioned before, it was a volatile marriage GRO-C
17. The end to my parents' marriage was not good, but they had a good parental relationship with each other after that. My Mum is still shocked about Dad's death to this day. She is not broken hearted or anything like that. She is sad, shocked still, and I feel that she is more upset for him.
18. Dad met Kathleen, who would later become his last wife, in around 1996. Kathleen had 3 of her own daughters prior to meeting my Dad. Their relationship was a lot better than the one Dad had with my Mum, and he kind of seemed to settle down quite considerably with Kathleen.
19. Dad and Kathleen were together until Kathleen passed away in 2014. They were together for about 18 years. Dad was happily married to Kathleen and when she passed he was heartbroken, and that is how I ended up caring for him for a while.

20. While Kathleen and my Dad were married, my Mum allowed me to visit him on alternate weekends and on special occasions, such as Christmas and Birthdays. It was a civil arrangement, and Mum had the discretion to allow me to visit, but not to visit alone.
21. So, on the odd occasion, I would go and visit, and the relationship between me and Dad at that point was actually good, there were no issues. I had previously been scared of him sometimes, but this feeling had dissipated by this time. Dad was happy and he had a new family with Kathleen and his 3 step-daughters.
22. Dad was still working while he was together with Kathleen at this point. However, he was working as part of the on-board crew rather than as a Captain and this work would entail going out to Arran. They would fill up a large barge with timber and then tug it back to Troon where he worked.
23. Dad also took his skipper's ticket, which I guess is a Captain's qualification, in roughly around 2005-2006.
24. In the late 1970's or early 1980's, I can't remember exactly when, Dad was involved in a serious motorbike accident. I am pretty sure that the nature of the accident was that he had to swerve to avoid something, resulting in him breaking hard and then coming off the bike.
25. Dad sustained serious injuries from the accident. I remember him having a large horizontal scar across his stomach because of the surgery he had after the accident.
26. The accident happened before I was born and before he met my Mum, so I am confident it definitely would have happened before 1986, as that is when they met.
27. I believe that the accident happened in Ayr and that he was taken to Ayr Hospital, which is now called the University of Ayr Hospital. If it wasn't Ayr, it would have been the Crosshouse Hospital.

28. The serious injuries he sustained resulted in surgery. He had his spleen removed and lost a significant amount of blood as he had internal bleeding from the accident. He was therefore given a blood transfusion. I don't know how many units of blood he had, but I expect that he would have had a lot of blood because of the internal bleeding.
29. Sometime between the summer and autumn of 2009, Dad went on a holiday to Egypt. Before he went on the trip, he went to have some travel vaccinations from his GP. From what I've been told, apparently the vaccinations triggered off the whole Hepatitis thing.
30. After he returned from the holiday, he was feeling poorly and not quite himself. The Doctor put this down to the after effects of tiredness. He had also been losing weight. Dad wasn't a heavy man, and he wasn't slim either, he was just an average build. But it became noticeable to those who saw him all the time that he had lost a little bit of weight.
31. I can't say for certain how Dad's Hepatitis C diagnosis came about, but I am pretty sure that he went to his GP practice in 2009 after he returned from his holiday, and they would have run his bloods, and then diagnosed him that way. I don't know whether the blood test that they did was a general one or a specific test for Hepatitis C, but he would have explained some of his symptoms to the Doctor to make the order of such a test.
32. I think Dad got a call to come into the surgery for the test results. He asked why they couldn't just tell him the results over the phone, and they said no we prefer you to come into the surgery to talk to us.
33. Dad's GP was Lindsay Millar, who was located at Cathcart Street practice. It was Doctor Millar who made the Hepatitis C diagnosis. I remember talking about it with Kathleen and her telling me how impressed she was with how nice, polite and caring Doctor Millar was.
34. As far as I am aware, Dad had tattoos down his arms, I don't think he had any down his torso.

35. As far as I know, Dad was given adequate information to understand and manage the Hepatitis C infection.
36. I think he was also provided with adequate information about the risks of others being infected as a result of his infection. I know that Kathleen was tested for Hepatitis C and she was clear, and he was aware that if he had a cut or bleed then that would be something he would have to make sure didn't contaminate anyone else. He was given quite good information about lowering the risk of transmission, such as using gloves etc.
37. I remember that Dad's diagnosis with Hepatitis C and his treatment was going on during the period 2009-2010.
38. The treatment that he received was Interferon and some tablets. I think he took tablets, but I don't recall what he had. I don't know what Interferon is or what it entails, but I do know that it is the treatment that he received. Dad started the Interferon in around late 2009, early 2010.
39. For a few months between 2011 and 2012, I can't remember exactly when, I lost contact with Dad and my step-family because of the demands of my university life. I didn't speak to Dad or my step-family during that time and we were very distant.
40. In 2012, I was informed of the extent of Dad's decline when I bumped into Kathleen and one of my step-sisters. They told me that he had multiple tumours on the liver and that he was going for regular scans more than once a year to keep an eye on the size of the tumours. I believe Dad's liver problems were caused by the Hepatitis C infection or its treatment, I can't say which one.
41. After I was informed about Dad's state, I went around and visited him. I still only visited sparsely as I was busy with university and I was on university placements at the time.

42. Up until her death in 2014, Kathleen cared for Dad considerably throughout his treatment.
43. After Kathleen passed away, I cared for him between from May to about October 2014.
44. Around October 2014, I unfortunately stopped talking to Dad completely and lost contact with him due to falling out with the family.
45. From October 2014, until his death in September 2017, I did not have any contact with Dad, but I was made aware by my cousin (who spoke to Dad) and my Uncle, that his health was significantly deteriorating.
46. I wasn't aware of the significance of Dad's deteriorating condition at the time because I had lost contact with him, and there was a distant relationship between myself and my step-siblings. I feel like it was all kept away from me by them, and if given the option, I would've liked to have spoken to him to make amends. I feel like my final goodbyes were stolen away from me. I wish I was able to tell him I loved him and to reassure him before he died.
47. On 12 September 2017, Dad passed away due to what I was told at the time was a fungal infection in the blood, which was impacting his liver and other conditions.

Section 3. Other Infections

48. As far as I am aware, Dad did not receive any other infection besides Hepatitis C as a result of being given the blood transfusion.

Section 4. Consent

49. As far as I am aware, I do not believe that he was treated or tested without his knowledge, consent, without being given adequate or full information, or for the purposes of research.

Section 5. Impact

Physical and Mental impact of Hepatitis C and the treatment

50. As far as I am aware, the Hepatitis C infection made Dad feel generally poorly. He was sick and he lost a lot of weight, however the infection did not make him lose as much weight as the Interferon treatment did. He also suffered liver damage because of the Hepatitis C.
51. The Interferon was also making him feel nauseous, generally lousy and interrupting his sleep. He became bed bound because of the treatment. He also experienced seizure like activity.
52. He also experienced an inability to socialise as he felt like he shouldn't be around people just in case he would infect them. He would still go to visit the people that he was close to, but he wouldn't go to the pub to socialise just in case he gave someone something.
53. When Dad commenced the Interferon treatment, he lost a significant amount of weight. He was very thin. He had lost a little bit of weight when he was initially ill, but when the treatment started the weight loss was significant, you could really see it.
54. He also became very depressed. He was very anxious about the whole thing and about being told that he had Hepatitis. The diagnosis was really hard for him to deal with, and it was also hard for him to deal with the treatment, its side-effects and the fact that he was not going to be able to work the way that he had been working, as there was a high risk of injury on the boats that he was working on. Dad was a typical man's man though, and he would never open up and cry in front of anyone.
55. The risk of injury at work, as well as him feeling generally poorly and nauseous all the time, meant that he was forced to stop working. The nauseous feeling also made him feel like he didn't want to go to work.

56. I don't know whether the general poorly, sick feeling that dad constantly had was due to the Hepatitis infection itself or the treatment.
57. I think it was a combination of the illness, and being forced to give up the job that he loved, and had done all his life, which caused the depression. His memory also wasn't great at times, and became worse over time.
58. The depression got worse throughout his treatment. Dad was referred to counselling at the time, not on the NHS, but a counselling company that was hired by the NHS. He had monthly follow-ups with the Psychologist and he was prescribed medication. As a man's man, he tended to put his feelings aside.
59. At one point, I can't say when, it would have been in around 2010/11, Dad stopped the Interferon, and he was given numerous medications. He subsequently put on a lot of weight. He went from major weight loss, to major weight gain.
60. He ballooned. It was unbelievable how much weight he gained. I would say that before he was ill he sat around the 15 stone mark, then when he lost weight due to the infection and the treatment he went down to about 10 stone. When he put on weight he went up to about 20 stone. He was very overweight, and he had never been like that in his life before. The weight gain in itself gave him struggles. He was much less mobile.
61. I don't know whether the weight gain was a side-effect of stopping the treatment.
62. Dad's seizure like activity was diagnosed as epilepsy.
63. As I mentioned before, throughout all of this time, Kathleen cared for my Dad up until her death in 2014. The Hepatitis changed a lot of Dad's life. He had to go onto state benefits and disability benefits because of the side-effects of the infection and its treatment.

64. Kathleen had to help him to get about as his mobility was poor. She did all of the shopping and cooking. I think that Dad must have still done his own clothes shopping as the style of the clothes that he wore was very out there.
65. During the period 2010 to 2011, Dad's step-grandson [GRO-C] was born, and albeit that he was suffering from a lot at that point, his grandson was the joy of his day. He loved him.
66. Dad was an avid photographer and took photos of everything. When [GRO-C] was born, he took constant pictures of him. It was nice to see a bit of happiness then. Even though Dad was weak, sick and bed-ridden a lot of the time, he would always make a point of coming out to see [GRO-C] when he visited.
67. In 2011, I graduated from college. Dad made an effort to be there, even though he was feeling very poorly at the time. That made me feel good about myself. He was so proud and it was nice to have him there. I was really happy as I was a bit of a brat as a teenager.
68. As I have mentioned above, in 2012 I was informed that Dad's condition had greatly deteriorated. At this point, I had not spoken to him for a few months between 2011 and 2012. At the time, I was at university studying nursing and had become very distant with Dad because of the demands of university.
69. I had started my university practical placement in 2012 and on one of my lunch breaks I bumped into Kathleen and one of my step-sisters. As I mentioned before, they informed me that Dad had multiple tumours on the liver and that he was going for regular scans more than once a year to keep an eye on the sizes of those tumours. I firmly believe that the tumours were caused by the Hepatitis C infection or the treatment he received for it, I can't say exactly which one.
70. After I was informed about his state, I went around to visit him. As I mentioned before, my visits were sparse, because at the time I was very

busy with university. At the time, I was working 12 hour shifts at my university placement and then going home and doing assessments all night.

71. When I visited him, it was very evident to me that Dad, being someone who was not in touch with his emotions, was very depressed. He was very distant and wouldn't talk. He was not the person that I knew. Sometimes it looked as though he was sitting, daydreaming.

72. It was clear that a lot of things were taking their toll on him. The seizures were getting worse. He would have the seizures in bed which would wake up Kathleen, and she would have to give him some sort of medication to help.

73. The side-effects of the infection and the treatment were getting worse as time went on, even though they had already been bad in the past.

74. After visiting Dad in 2012, I then lost contact with him over 2012 and 2013 due to commitments with my university studies and placements.

75. As I had lost contact with Dad, I was informed through the grapevine that his illness was getting progressively worse and that he had developed a heart condition. He had a damaged heart. I believe that I was informed that this was related to the Interferon treatment.

76. He was also getting dementia like symptoms. For someone in his 50's, these were getting worse quite fast, to the extent that he would forget what he was doing, if he had taken his medication that day, or whether he had taken it on time, whereas when the memory loss first started it would only be little blips where he didn't know what he was talking about. However, it wasn't to the point where he forgot where he was and what time of year it was.

77. As I mentioned previously, in May 2014 Kathleen passed away. She had heart problems and was meant to get a stent put in, but she had put this off due to caring for my Dad.

78. Dad was heart-broken when Kathleen passed. He was lost as she had taken care of him for so long. It was almost as though he had forgotten how to take care of himself.
79. My contact with Dad started up again in May 2014, after Kathleen's death. I told Dad that I would now care for him. I cared for Dad from around May 2014 to October 2014.
80. There was an agreement at the time with the council for self-directed care. The way this would work was that money would go into a fund and I was paid a wage out of this for caring for Dad.
81. This arrangement was implemented and I would spend a minimum of 4 hours a day, 5 out of 7 days of the week, caring for Dad. My step-sisters would take over on the weekends.
82. I remember one time when I took Dad to a Psychologists appointment at the hospital. I am sure that we were talking about the Hepatitis, and how the treatment hadn't completely got rid of it, about Dad losing Kathleen and how he was depressed about this.
83. We also discussed Dad's memory loss and his heart condition. We talked briefly about managing his feelings of anxiety and depression toward all of this. Dad's medication was not altered to take account of the increased depression at this time, as he had to have a reduced dosage due to his liver not functioning properly.
84. A memory test was done where he had to remember certain things at the end of the appointment, and from what I recall, I don't think his memory was terrible at this point, it was just satisfactory.
85. I remember there were times when Dad would seem a bit confused. I remember times where I stayed the night at his house and he would come downstairs and talk to me. That was hard for me as I knew him as a very strong and resilient person, and it was almost like an awkwardness to have to reassure him that everything was ok.

86. I am usually the type of person that reassures people, but with him it was different as it made me feel like I was useless, and I was angry as he had changed from a man that I knew to someone I didn't recognise at all because of illness. It all seemed to happen all at the same time.
87. I remember Dad's confused times very vividly, as I am a heavy sleeper and I would wake up when he came downstairs to talk to me. It was a very dark, morbid feeling for me. Dad would come down and wake me up as he was struggling to sleep and couldn't stop thinking about Kathleen (this would continue until the end of his life). His concentration was not good. He would forget why he had come downstairs and would then say "its ok I will leave you now, go to bed, I'm alright".
88. Between June and October 2014, I was caring for Dad on a daily basis. I was helping with the simple things. I would take him on outings to get out of the house as his mobility was affected. He walked with a walking stick and had a mobility scooter. Getting him out of the house was important for his independence. He attended his Cardiologist and psychological appointments. I would not go in for the Cardiologist appointments, I would just sit in the waiting room. These were at Ayr Hospital.
89. I did much of what Kathleen had done, such as cooking Dad's meals and making sure his medications were taken at the right time. I don't know what his medications were, they were just in a blister pack that showed the week and the time that they needed to be taken. The medications were for liver disease, depression, pain management and heart problems. There was also a beta-blocker.
90. Dad took a water tablet for his heart. I remember being told to watch how much fluid he consumed with this tablet. He took another tablet to help him sleep at night, which was also related to his mental health. I think it was some kind of anti-psychotic, as I think he was experiencing some kind of psychosis. I know that a side-effect of antipsychotic medication is to balloon and gain lots of weight.

91. I would also manage Dad's medical appointments. They would all be placed on the fridge in order and each one would be ticked off once we had attended it. Sometimes he would still forget them, and sometimes he couldn't be bothered going as he was too sore, depressed and couldn't be bothered socialising.
92. I unfortunately lost contact with Dad after October 2014, as I had a falling out with my step-sisters. They were interfering, and said that I wasn't doing a good enough job caring for him. I told them that since they thought I wasn't doing a good job, and since they lived in the same town as Dad, while I lived an hour away, then they should do it.
93. Dad got angry at me for this, and it caused a huge falling out between us all. I decided at that moment to cut ties with them and stopped talking to Dad. It was very hard for me but I had to do it for me. I was driving myself into the ground taking care of him, it was demanding to say the least. I can't imagine what Kathleen went through.
94. In September 2014, I also lost my Cousin to suicide. That was another pressure I was facing and also why I think it may have been perceived that I wasn't doing a good enough job. I was struggling hugely with the loss of my Cousin who I was very close with.
95. The pressures of the loss of my Cousin, the loss of Kathleen, and Dad's illness seriously impacted my life. I felt very depressed, and I felt that I was losing everyone around me, and if I wasn't losing everyone then they were all ill. At the time my Mother was also suffering from a medical condition.
96. As mentioned before, from October 2014 until Dad's death in September 2017, I did not have any contact with him, but I was made aware through a Cousin that he was getting significantly worse.
97. He wasn't socialising or going out anymore, the dementia symptoms were getting worse (he would forget food in the fridge and would forget to turn off the gas), his mobility was greatly decreased, and at that point

the tumours on his liver had grown. I believe that as a result of the damage from Hepatitis C, and the associated treatment and the tumours, his ability to fight off any infection and illness was significantly reduced and as such resulted in his admission to University Hospital Ayr at the end of August/beginning of September 2017.

98. I was informed that when Dad was in hospital before he died he was hallucinating, which I believe was a side- effect of the infection.

Impact on family members

99. As I have mentioned already, I spent a lot of time caring for Dad, which eventually led to a falling out with my step-siblings, as they criticised the way that I was caring for him. It caused a huge family break up and we are now very distant.

100. I also experienced depression because of Dad's illness, and trying to juggle his care, my Cousin's suicide and Kathleen's death. As I mentioned before, Kathleen died from a heart condition which she put off treatment for, as she was caring for Dad so much. It is a sad thing to admit and accept, but unfortunately, caring for Dad killed Kathleen.

101. Toward the later part of her life she was prescribed Diazepam to help calm her as she was very stressed out. I know this because I saw a recent prescription in Dad's medicine box made out to Kathleen for this medication.

102. It was a struggle for Kathleen, as I believe she was working as a manager in the care sector for people with learning difficulties, and she was balancing managing staff and looking after Dad. That would have been very tiring. Albeit she was constantly on the go, she made a wonderful mother to her three daughters, a loving grandmother to her grandchildren and a committed and compassionate wife to my dad, whom she remained with in sickness and in health.

103. Dad's death was a great challenge for my step-sisters as they had lost their Dad when they were young, and then into their 20's they had lost their Mother. So, they have had to deal with a fair amount of grief in their life.

Financial Impact

104. As I mentioned before, Dad had to stop working because of the infection, the side-effects of the treatment, and the risk of injury that his job posed.

105. This meant that he received benefits. I believe that a lot of the depression Dad experienced was because he was forced to stop working.

Stigma

106. Dad only told his family and closest friends about the infection. He knew that his friends would see the physical changes to him as a result of the infection and treatment, but he wouldn't divulge what it was that led to the physical changes. He wasn't one for telling people what it was, and if he was asked he wouldn't have told them.

Section 6. Treatment/Care/Support

107. I can't say for certain if Dad faced any difficulty or obstacles in obtaining treatment, care and support in consequence of being infected with Hepatitis C.

108. I am aware that he received psychological support for the infection. I believe the counselling provided was somewhat adequate. I was not given any psychological support upon Dad's diagnosis; I believe this was due to the fact that I was not involved directly in the care and support he received at the time of diagnosis.

109. However, after his death, I find it hard to comprehend that I've lost the man that was always so strong and resilient throughout his life, to something that came from receiving medical care due to a period of vulnerability all those years ago.

Section 7. Financial Assistance

110. I am aware that Dad received some sort of compensation pay-out, but I can't say for certain whether it was for the Hepatitis C infection or an employment related issue.

111. I suspect that it was due to the infection, and I am more certain that it was for the infection rather than a work-related issue, but I am going with my gut instinct on that. I know that the payment was in the thousands of pounds.

112. I am not aware what trust or scheme Dad received the payment from (if he did receive it from a trust or scheme), just that it was in the thousands of pounds.

113. I know that he used some of the pay-out for a holiday, and some of it for a renovation of his bathroom, as he needed to change the bathroom due to his being unwell; for example, he had to get a walk-in shower in the place of his bath because of his mobility issues.

Section 8. Other Issues

114. I have been fortunate enough to never have required a blood transfusion myself. Opinion wise, I am appalled that the transmission of infected blood has occurred in the first place. When placing your complete trust in the medical profession at such a vulnerable point in your life, you expect that they (the NHS) would do their utmost to ensure something like this would never occur.

115. It may not have been an intentional act on their part, however, being placed in such a position of trust and respect, as well as holding the knowledge and understanding of what blood borne infections are, one would expect that an enhanced duty of care would be undertaken before allowing blood to be stored for the purposes of transfusion.
116. This has been allowed to happen through a lack of screening, and from what I understand, blood was imported and used in people, and it is quite worrying to have that happen.
117. I have a great deal of sympathy for the public that have not only been infected, but affected too, and for those who have lost their lives, or had them significantly changed. My heart goes out to them because, albeit I had a somewhat distant experience, I still suffer the after effects of how cruel this illness can be. But those close to home with relatives, friends, etcetera, I can only imagine how much pain and anguish they have been put through, which is saddening in its entirety.
118. From my personal point of view, I feel like this infection Dad had seriously limited his life in his last years. It seriously impacted him and to see him go from someone strong and independent, who would never go to a Doctor, even if he was told to, to someone who was constantly going to appointments and a shell of what he used to be, was sad.
119. It is a stark reminder of how fragile life is. I continually contemplate how I have been robbed of time with Dad as well as my Dad's life being significantly reduced. There are so many if's, and's or but's, when you think what life might have been, and what could've been a happy family, due to something caused by a serious lack of care and due diligence.

Statement of Truth

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

Signed

GRO-C

Dated

19TH MARCH 2020