

Witness Name: Paul Malby
Statement No.: WITN3763001

Exhibits: WITN3763002

Dated: 20th March 2020

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF PAUL CHRISTOPHER MALBY

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 02 October 2019.

I, Paul Christopher Malby, will say as follows: -

Section 1. Introduction

1. My name is Paul Christopher Malby. My date of birth is GRO-C 1958 and my address is known to the Inquiry. I am a retired business rates surveyor and I live with my wife. I intend to speak about my mother's infection with what I believe was Hepatitis C. In particular, I will focus on the nature of her illness, how the illness affected her, the treatment she received and the impact it had on her and our family life.
2. I have a sister Sandra Malby (W3840) who will also be providing a statement to the Inquiry

3. I can confirm that I am not legally represented and that I have no objection to my statement being in the public domain. I am not seeking anonymity.

Section 2. How Infected

4. My mother Joyce Malby (maiden name Bennett) was born on GRO-C 1928 and died on GRO-C 1989. Her cause of death as listed on her death certificate are 1) Heart failure, 2) Hepatic Failure and 3) Auto-immune Hepatitis. I have provided the inquiry with a copy of her death certificate.
5. For the sake of clarity, my mother never drank nor smoked and she was very health conscious throughout her life. My mother practised yoga regularly, walked her dog twice daily and was very careful to maintain a healthy diet. For example, I remember that even as my mother would serve the family ox-tail at mealtime, she would opt for eating fish instead as she felt red meat was unhealthy. My mother never took drugs and she abhorred tattoos. She even refused to pierce her ears. My parents enjoyed a committed relationship for over 40 years of marriage and there was never a hint of any infidelity or extra-marital affairs by either party.
6. In September and then again in December of 2019 I emailed the Sheffield Health and Social Care Foundation NHS Trust for my mother's medical records but no reply has been forthcoming, therefore I base my evidence only on my most vivid recollections.
7. I recall that my mother did suffer two or three bouts of ill-health requiring medical intervention and blood transfusions administered in Sheffield. Between about 1970 and 1982 my mother required operations to correct problems with her gall bladder, her bladder and, later, throat cancer; all of which she was thankfully able to recover from for a time.

8. My father, Raymond Percy, worked as a NatWest Bank Manager and enjoyed the benefits of private health insurance which he was able to extend to my mother. As well as attending her General Practitioner's surgery in GRO-C where she was often seen by Dr Eilbeck and Dr Lumsden, my mother's operations were carried out at Cleremont Hospital in Sheffield.
9. I remember visiting my mother in hospital after her various operations and I know from seeing it myself that she was given numerous blood transfusions during this period. Furthermore, my father always kept me updated with news of my mother's treatment when she was hospitalised and I could not be there and I recall that included transfusions. His profession made him a very methodical man and I know of no reason to doubt his assertions regarding my mother's care.
10. My father told me that one of my mother's medical interventions in particular required a lot of blood to be transfused. I do not recall any of the family being given any warnings about the possible risks associated with blood transfusions. Again, my father would have mentioned any such conversations with doctors to me as he was always very conscientious about sharing all details of my mother's treatment with me.
11. A few years after these interventions were carried out, in or around 1987, I remember my mother started complaining of numerous symptoms that eventually plunged her into a state of severe ill-health. Initially I remember my mother feeling increasingly tired, lethargic and just being generally unwell. We also noticed that she began to bruise easily and a cut appeared on her leg but seemingly would not heal or clot. As these symptoms increased in frequency my mother's quality of life and well-being began to plummet. Having previously been very active, she was no longer able to walk the dog or participate in many of the activities that energised her and kept her healthy.

12. On a family trip to the Isle of Wight in 1988 her condition became impossible to ignore or rationalise away. She was constantly fatigued. At that time, my mother also began frequently complaining of itchiness and unexplained rashes all over her body; she became no longer able to resist her exhaustion as stoically as she had previously done. It was heart-breaking to see what was happening to her. The most apparent change was her jaundiced complexion, a palpable indication that her health was worsening.
13. My mother began to visit her GPs more frequently in an attempt to find a solution to her worsening condition. Different tests were carried out and medication tried but her proactivity was in vain and no specific diagnosis was forthcoming.
14. Her GPs had told her that it would be helpful for her to 'work through her tiredness and remain active' but by mid 1988 it was undeniable that something significant was wrong. My mother's jaundice even began to spread from her skin to her eyes. She was deteriorating at a rapid rate and was becoming unrecognisable from the healthy, active woman she had been even just a year previously.
15. Up until this time my mother had been cared for at home and was being treated there with steroids, as well as having her lungs regularly drained of fluid. These treatments failed to address the jaundice which continued to worsen. By this stage my mother was completely bed-ridden.
16. My mother's GPs began to suggest that she might be suffering from some sort of unspecified tropical disease but could offer no further information. They kept asking if she had been to certain sub-tropical countries and we kept insisting she had not.
17. My father became extremely concerned and insisted that my mother check herself into Hallamshire Hospital, which she did in or around September 1988.

18. By December of 1988 my mother's jaundice was strikingly bad and her lungs continued to fill with fluid. She had difficulty breathing at times. Notwithstanding, the doctors at the hospital continued to reassure us, suggesting that once the right balance of medicines was found a recovery would be inevitable.

19. When visiting my mother in hospital during this period I had difficulty recognising her as the steroids had caused her to swell up significantly. I could really see the difference in her as I was travelling back and forth from my home in the South East. During one visit I happened to read her medical chart and was surprised and horrified to discover that, not only had she been placed on morphine, but that her dose had been recently increased. This came as a complete shock to me and was a defining moment in realising the gravity of my mother's situation, in the absence of clear information being provided by her treating clinicians or nurses.

20. The doctors remained clueless about the underlying cause of her affliction. They would variously suggest that the problem might be with her organs or would revert to the theory that she had contracted a tropical disease. Mum was subjected to a battery of blood tests throughout this time but no identifiable pathology emerged.

21. I continued to witness my mother's deterioration. It was very painful to see her so swollen with a yellow complexion and with yellowed eyes. She also began hallucinating from the morphine. At times of partial lucidity, mum would plead to be told what was wrong with her. I felt so helpless – we all did. She repeatedly stated that that she did not want to die nor miss the birth of her 2nd grandchild, which my wife was imminently expecting. What do you say to reassure someone you love, knowing that the doctors do not have any idea what is wrong or how to remedy it?

22. After Christmas of 1988, possibly as late as February of 1989, I remember a doctor mentioning that he thought the cause of my mother's

illness might be a condition named auto-immune hepatitis. It wasn't a condition that I was aware of and I heard no further mention of this diagnosis until I read it on my mother's death certificate following her death on GRO-C 1989. (See Exhibit WITN3763002 – Death Certificate certified by P Skinner)

23. I was informed of my mother's death by my father who called me to let me know. No post-mortem was conducted on my mother and she was cremated in accordance with her wishes.

Section 3. Other Infections

24. As far as I am aware my mother was not infected with any condition, other than the Hepatitis that killed her. However, having not seen her medical records, I am unable to say so conclusively, especially in light of my emergent lack of trust for the medical profession and the doctors that treated her.

Section 4. Consent

25. I am unable to comment on whether my mother gave consent for all the testing that was done on her as, to the extent that consent was properly attained, it would have been provided by my father who trusted medical professionals implicitly. However, again I have no recollection of him discussing issues such as a request for consent with me at any stage and I am sure that it is something he would have mentioned.

Section 5. Impact

26. The events I have described have brought our entire family a great deal of anguish. Not least that of witnessing my father, Raymond Percy, cope with the premature loss of his life partner and great love of over 40 years.

27. After my mother's death my father appeared completely lost. As well as coping with his considerable grief, he also suffered due to his inability to face the challenges of looking after himself and addressing the demands of running a household. He was a product of his time who left the running of the household to the wife whilst he was the breadwinner; tasks that my mother had undertaken seemingly effortlessly, but only seemingly so. It is no coincidence that, without my mother's prompting to take his medication and encouragement to adhere to a healthy lifestyle, upon her death my father's type 2 diabetes soon progressed into type 1. Furthermore, he soon developed high blood pressure and angina; both proved to be of great detriment to his health.

28. All this is to say nothing of the deep and palpable loneliness that engulfed my father following the tragic events of GRO-C 1989. Prior to that day I had never witnessed my father crying. In the days weeks and months that followed, my father would often call me and try to incentivise me to visit. The numerous offers of financial contributions to the petrol expenses inherent in me visiting were his very practical way of imploring not to be left alone with his thoughts and sadness.

29. Following his retirement my father and mother had been used to spending the bulk of their time together, often gardening and enjoying the comforts of their home that they had built together, without seeking outside influence. They were at their happiest in each other's company. In the wake of her death my father lost not only his wife but his best friend and the opportunity to enjoy a peaceable retirement.

30. After his retirement, my father set up an accounting firm from home but he often stated that he was unable to take on any further clients due to his dwindling energy and enthusiasm.

31. My father Raymond died after a heart attack in 2004. Between 1989 and 2004 he was unable to recapture the same spark or happiness that characterised his enthusiastic approach to his life, family and work.

32. My maternal grandmother, Edith Bennett, also died earlier than expected and shortly after the death of her own daughter. I remember her attending my mother's funeral and stating at the time that she should have died instead of her. She was heart-broken and really lost the will to carry on without her daughter in her life.
33. No parent should have to witness the death of their own child, and in my experience at least, no parent survives for long after having done so.
34. My grief for my mother was delayed by two years mostly I think due to the dual distractions of work and looking after my children. However, about two years after her death, during one of many visits home to my father, I awoke in the middle of the night following a terrible dream and became inconsolable and unable to stop sobbing. My wife ushered me into the bathroom in order to avoid my father seeing me in that state and thereby being reminded of his own grief and desperation.
35. Although my father stayed in the household that he shared with my mother for only two years after her death, I always found it extremely difficult to visit him there due to the memories of the warmth and love that she had imparted within that place. It was the family home but for me, a constant reminder of the still painful loss we experienced. My wife and I would often stay in a nearby hotel because the strength of the memories was so overwhelming that the house felt practically uninhabitable.
36. The impact on me was exacerbated by the failure of the doctors to manage our expectations. The shock of my mother's death could have been somewhat mitigated by being given some indication that it was imminent. I feel that I was given false hope which made the eventual loss even harder to bear. Had I expected or been told that her passing was likely to occur I would have had the opportunity to say goodbye. They were so insistent, almost to the end, that the right medicine would be found to cure her. When I travelled home just prior to her passing it never

occurred to me that I would not see her alive again – I had no reason to think it due to what I had been told.

37. To this day I feel robbed of my chance to be there for her passing. I am still haunted by feelings of guilt due to my absence at the time of her passing and cannot escape the suspicion that this could have easily been avoided had my mother's clinicians and nurses communicated better with us rather than feeding us unrealistic reassurances. Instead, I have been left with images of my mother suffering and begging for her life not to end.

38. If my mother did indeed die from an infection with Hepatitis C through a blood transfusion then that cause should be listed on her death certificate. As it is, relatives and friends have been asking me whether her Auto-Immune Hepatitis was in any way contributed to by drinking. In this way my mother's legacy and memory may have been besmirched in the minds of those who have been given cause to doubt the fact that she was not a drinker.

39. My mother's death has also meant that she was robbed of the chance to be present for the birth and life of her second grandchild who was born shortly after her demise. I know she would have loved him dearly and contributed to his growth. I have another child who was very young at the time of her passing and in the aftermath of her death it was very painful to have to explain that granny was no longer there to offer them love and care.

Section 6. Treatment/Care/Support

40. I do not believe my mother received any treatment for her condition as, without a definitive diagnosis, it was impossible to tailor any effective solutions to her health problems.

41. It was of great disappointment to me that there was no successful treatment for my mother's condition. As far as I can tell, the only

treatment administered were the steroids and their only effect was to make my mother's body swell and become unrecognisable. I think it safe to say that this treatment was ineffective to say the least. I do not know why no treatment was administered once the doctors formed the theory that my mother's problems might be related to Auto-Immune Hepatitis. This would have been around December 1988 – February 1989 and I do not know what the state of medical advancement was at that time, nor whether any effective treatment was available.

42. Neither my father, nor any other members of my family, were offered any form of psychological or bereavement counselling. I do not believe such provisions were made at the time as that type of pastoral care was not part of the culture at the time.

Section 7. Financial Assistance

43. No claim for financial assistance has been made in respect of my mother's infection and death. The lack of a conclusive diagnosis, as well as our lack of proof of any contributing medical negligence, has certainly contributed to this fact.

Section 8. Other Issues

44. The mystery surrounding the underlying cause of my mother's has certainly taken its toll on our family emotionally. I still wish to see her medical records to understand whether there is any evidence that it was caused by infected blood, and whether the doctors could have done anything further to safeguard her life and ensure her continued presence in our lives.

45. I believe that she displayed many of the symptoms of Hepatitis C and I know that she had the transfusions in the tainted blood years. However, I am not sure what first drew me towards the Hepatitis C conclusion.

46. I have been asked if I was ever informed that there was a problem with my mother's liver specifically or heard my father talk of such. The answer is no, although I am aware that Hepatic failure is shown as one of the causes of death on her death certificate. I did get an explanation of Auto-Immune Hepatitis from one of the doctors who simply said that it attacks the healthy cells in some of the body's organs.

47. My mother's death at a relatively early age was a devastating event for our family which still has consequences to this day. There is no sense of closure and not a day passes when the feelings of loss are not in some way present. I believe that my mother's death was contributory in part to my father's early demise and can't help thinking of what might have been. Any kind of answer would mean so much to all of us.

48. I have had the 'Use of my Statement' form explained to me and have signed it on the basis that it will be submitted at the same time as my signed statement.

Statement of Truth

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

Signed

GRO-C

Dated

20th March

2020