

Witness Name: Lucy Alexandra Larkham

Statement No: WITN0528001

Exhibits: 0

Dated: April 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF LUCY ALEXANDRA LARKHAM

I, Lucy Alexandra Larkham will say as follows:-

Section 1. Introduction

1. My name is Lucy Alexandra Larkham (nee Marsden). My address is GRO-C
GRO-C. My date of birth is GRO-C 1984. I live with my husband Steven with whom I have two children, GRO-C I work as a health and safety environmental team leader at a local power station.
2. I make this statement in relation to my Dad, William Trevor Marsden who was infected with Hepatitis C as a result of being given contaminated blood products. My Dad has given his own statement to the Inquiry. His witness number is WITN1372001.

Section 2. How infected

3. I refer to my Dad's statement regarding the background of how he was infected, the advice he was given prior to receiving blood products, consent and how he found out he was infected.

Section 3. Other Infections

4. In around 2010, my parents attended a meeting in England about vCJD. I don't know much about it, as my parents didn't talk to us about it. I know that he was told that if he had vCJD, he would have at most a year to live. I would rather not have known this as it caused me a lot of distress. I think it may have been better for my Dad if he hadn't been told this.

Section 4. Consent

5. Please refer to paragraph 3.

Section 5. Impact of the Infection

6. After my Dad was infected, although I cannot say exactly when that would have been, I saw my Dad go from being a fit and healthy farmer to being a man that could not get himself out of bed. He looked so ill that it frightened me. Suddenly he couldn't do anything for himself.
7. He used to dress and feed my siblings and I and take us to school in the mornings, but once he became unwell, he was barely able to feed himself.
8. My Dad's job on the farm required him to be physically active. As the Hepatitis C caused him fatigue, he could not farm to his full potential.
9. Mentally, my Dad preferred to keep things to himself and did not like talking about his condition with us, but I know that he was depressed and hugely disappointed that he could not maintain the farm.
10. I do not know what further medical complications or conditions have resulted from my father's Hepatitis C infection and I refer to his statement regarding this.

11. Details of my Dad's treatment and any difficulties he had accessing treatment will be best described by my Dad and I again refer to his statement regarding this. I remember he had two courses of treatments, one in the late 1990s and a second round of treatment in 2006. He was told that he had cleared his Hepatitis C infection in 2007.
12. When my Dad was undergoing the 2006 treatment I was finishing my degree at university. I remember that my family did not know if the treatment would stimulate the Hepatitis C and kill him faster or if it would improve his health.
13. I cannot say whether there are treatments which I consider ought to have been but were not made available to my Dad, as I do not know what was on offer.
14. The treatment almost wrecked my Dad and as a family, we had no support whilst he was undergoing the treatment. He slept in a room under the stairs everyday and there were times he could not get out of bed. Physically, he deteriorated. He was unable to run the farm whilst he was on the treatment. He could not feed himself and he even struggled to get in and out of the bath.
15. He was always freezing and would wrap himself in a duvet with socks on. If he went outside, he would wear at least three coats. When he was inside, he had to have the heating on day and night to keep him warm, he still does. Whenever he came to my house, he was also very cold, even with the heating on. He also suffered from countless fevers and experienced several fits.
16. My Dad had to have any dental work done at the hospital rather than with a normal community dentist. Even some medical professionals considered Hepatitis C to be a dirty thing.
17. Before my Dad's treatment, all the things we did as a family, we did on the farm, but that had to stop once my Dad became unwell as he was physically unable to participate in such activities.

18. My Dad has an interest in motorbikes, but he could no longer ride them. I try to keep his interest alive and often print articles off the internet to read to him. I also took him to motor sports events, but the last time we did that was in 2000.
19. When my Dad was at his worst, he couldn't walk. He had no energy or strength. His friends didn't visit us much and he would spend his time inside rather than going to see them. He could no longer accompany neighbouring farmers to unions and on trips. This must have been difficult for him. He took a lot of pride in participating in the local farming events.
20. My Dad had to sell plots of his land and his cattle when things became difficult for us financially. For my Dad, this was practically like losing a part of him. The farm and land have been in his family for 6 generations. I felt very sorry for my Dad when he lost his land and cattle. He lost so much and it did not have to be that way.
21. Since becoming unwell, my Dad's eating habits have changed considerably. He cannot eat large meals. Even today, he only eats small quantities of certain foods, such as fruit and vegetables.
22. Memory loss has been a massive issue for my Dad, which also makes things difficult for us. He is terrible with names and phone numbers and needs a lot of help remembering things. He also regularly forgets where he has left things and needs help finding them.
23. For as long as I can remember, my parents sheltered my siblings and I from my Dad's illness as much as they could. I found it hard to come to terms with how unwell my Dad was and that he had been given contaminated blood.
24. The situation with my Dad has undoubtedly had an impact on me whilst I was growing up and on my schooling. I became very concerned that we would lose our house and the farm, but more importantly that we would lose our Dad. If that had happened, I cannot imagine how difficult it would have been for my mother to cope financially.

25. From the age of 15, I became my father's carer. I helped him take medication, I dressed him, fed him and generally cared for him. I distinctly remember having to help him bathe, which was not something I expected to have to do whilst he was so young.

26. Before my Dad became unwell, we used to go on at least one family holiday a year, including skiing trips. However, once my Dad was unwell, he could no longer manage to travel and I imagine we also couldn't afford to go on such holidays. My siblings and I definitely missed going on family holidays.

27. Mentally, what has happened to my Dad still affects me today. Not a week goes by where I do not cry. I constantly think of how things could have been different for my family. I am terrified of losing my Dad. I visit him every weekend and whenever I can after work. I also call him twice a day to check that he is ok and eating.

28. As a family, we have hardly spoken about my father's health.

29. Some people associate Haemophilia with HIV and AIDS, which were both considered dirty. Due to the stigma my family are not open about my Dad's Haemophilia and Hepatitis C infection. Only two of my close friends know about my Dad's Haemophilia and Hepatitis C infection. Even my school teachers were unaware of the situation at home.

30. My husband knows about my Dad's Haemophilia and Hepatitis C. We have been together for almost twenty years. He also worries about my Dad.

31.

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32. My Dad is a great granddad to my children and not a day goes by that he will not call in to see my sons

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 even if for only five minutes.

33. My mother lost her job as a result of what happened to my Dad. She thoroughly enjoyed her career so I cannot imagine how difficult that must have been for her. She was and still is an incredibly hard working woman and somehow, she managed to keep everyone together through extremely difficult times.
34. It must have been very tiring for her as she had to care for both my Dad and my siblings and I. My mother managed to get us to school, buy us uniforms and put food on the table. When my siblings and I were growing up, we should have had happy family times, going on holidays and doing normal family things, but these things were taken away from us.
35. I see couples at work retiring at the age of fifty and going off to travel the world together, but my parents will never be able to do that.
36. My younger brother and sister, Samuel and Rachael were also stripped of their childhoods, although they will not remember as much as my older sister Nicola and I do. Other children their age were able to participate in after school clubs, but there was nobody available to take them to such clubs when they were at an age when they would have gone to them, as my Dad was unwell and my Mum was caring for my Dad and working. Nicola, my older sister is the most anxious of us all. She worries about hers and her husband's finances. Like me she calls our Dad twice a day.
37. When I had homework that I struggled with, I had no-one to ask for help as my Dad was ill and my Mum was caring for him. Trying to concentrate on exams was difficult when my mind was clouded with thoughts about losing the farm and how tight our finances were. I didn't attend even half of the lessons that my classmates did. When I did attend school, I wanted to get home as soon as possible, which meant that I was unable to participate in extra-curricular activities. Even if I had gone to clubs or sporting events, there was no one to drive me to them or pick me up. I was unable to socialise with friends after school and could not do what normal teenage girls were doing. I simply could not risk being away from home.

38. As I have mentioned, I was finishing university in 2006. Due to my Dad's health, I hardly attended university as I had to stay at home and care for him. I also had to help maintain the farm. My university was in the centre of Belfast, which was a considerable distance from my home, so I was always worried if I was at school that something would happen to my Dad and I would not make it home in time to help him. The situation at home impacted on my performance in my exams and I don't think I did as well as I would have done if my Dad had not been unwell.
39. My university experience was also affected, as I was still caring for my Dad when I was at university. I didn't join any societies; I simply attended my lectures and immediately returned home afterwards. Looking back, it was not the university life I had envisaged. I achieved a 2.1 degree in Chemistry, but I feel I could have done better. I was constantly worrying and was always up late at night, but it shouldn't have been that way. I still think of myself as my Dad's carer today.
40. My mother had to work full time to provide for my siblings and I. There were four of us and I cannot imagine how difficult that must have been for her. Additionally, some of the farmland and all of the cattle had to be sold to help my family financially, which created further financial difficulties as we suffered a significant loss of income.
41. My Dad was born and bred a farmer and he could not read or write. Getting another job was impossible for him as all he knew was farming. He was not eligible for benefits, so once he became unwell he didn't have any income. Some of the land that was sold could have been mine and my sisters to farm today. The farm held a lot of sentimental value for us as it had been in our family for generations. It still upsets my Dad to discuss it, but he knows that he will never be able to herd cows again.
42. When I'm at work, I'm constantly rushing home to see him my Dad and spend time with him. I am lucky that I live near to my parents and have a local job. Every day that our Dad is alive is a blessing.

43. We are lucky that our Dad survived, but I cannot help but wonder what could have been if we still had the farm up the road. My sister would have loved to take over the farm. Our lives could have been completely different. We cannot change those things now, but at the very least we deserve justice and closure.

Section 6. Treatment/care/support

44. I do not know how difficult it was for my Dad to get onto the clinical trial of treatment in the 1990s, but he certainly received no support during it.

45. In our darkest times, we received no support from anyone. As my teachers didn't know about my situation, this was even harder for me. Nowadays, there is much better support for families and children of those who are unwell. When my Dad was unwell, there was no such thing. We could not talk to anybody about it because of the stigma, and we had to keep our emotions bottled up.

46. I now attend the Haemophilia clinic GRO-C every six months and get a lot of support, which is a massive change from how things used to be.

47. I have been to my GP to discuss my anxiety and I have used a helpline which is offered through my work a couple of times. No matter who I speak to, it is difficult to explain what I have been through. No counselling or psychological support has ever been offered to me as a result of my Dad's infection.

48. During the 1990s there were no active networks or support groups. Without campaigns on social media, our family was left to fend for itself. I recently attended a haemophilia weekend and met a woman with two sons like me. Her Dad had died from being given infected blood. We bonded over the similarity in our lives and keep in touch today. Things like that may have helped us when times were darkest.

Section 7. Financial Assistance

49. I therefore refer to my Dad's statement regarding any financial assistance he may have received. I have not received any financial assistance due to my Dad's Hepatitis C infection.

50. My Dad is now sixty and I do not know how long he has left, but whatever his life expectancy is, I believe that he deserves a better quality of life than he currently has. My parents do not qualify for benefits and my mother stopped paying into a pension when she stopped working. I want my Dad to enjoy his remaining years in the way he had hoped to, before he was infected with Hepatitis C.

Section 8. Other Issues

51. I do not understand how nobody has been held accountable for authorising the importation and use of contaminated blood products in the UK on patients.

52. I don't feel that those infected by contaminated blood and their families in Northern Ireland get as much information or support as those on the mainland. We feel isolated from the activities of the Inquiry and from the Haemophilia Society and other campaign groups. Articles and information are regularly shared on social media, but my Dad has no access to those platforms and I do not imagine that he is the only one considering that many people who were infected are from an older generation. It would be useful for such things to be made more accessible for those who are unable to use technology.

Anonymity

53. I do not wish to be anonymous and I would like to give oral evidence to the Inquiry.

Statement of Truth

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

Signed... GRO-C

Dated... 9/4/2019