

Witness Name: Julie Dyson
Statement No.: WITN2958001
Exhibits: Nil
Dated: 28th June, 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF JULIE DYSON

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 25th March, 2019.

I, Julie Dyson, will say as follows: -

Section 1. Introduction

1. My name is Julie Mary Dyson. My date of birth is GRO-C 1989. My address is known to the inquiry. I am a chartered accountant and I work in Glasgow as a Financial Analyst. I intend to speak about my mother, Eileen Patricia Dyson. In particular, my mother's illness and the treatment she received. I will also talk about the impact that my mother's illness has had on her and our family.

2. I would like to explain the difficulty I have of writing a statement of this nature. When my mother first spoke to me about the inquiry in late 2018, I told her that I would struggle to give evidence, because if anyone were to ask me how my mother's illness affects me, my knee-jerk reaction would be to say that it doesn't. I know that my main coping mechanism is to tell myself that 'everything is fine', and I tell myself this to the point that, on the surface, I believe it. I know that if I was to face into the reality of the lives that my family and I have lived, that the sheer weight of the injustice and the trauma would render me incapable of working or functioning at all in my day-to-day life.
3. We are a very close family. We spend a lot of time together, and we are all good friends as well as being a family. I have one brother, Keith Dyson. My mum is my closest friend, my dad and I go to the football together most weeks, and my brother and I are often told we are like twins.

Section 2. How Infected

4. My mother was infected with hepatitis C following the birth of my older brother before I was born. I know my mother had a traumatic birth with my brother and had to have a blood transfusion. The only details I know are from what my mother and father have told me. She gave birth to my brother, Keith, at Bellshill Maternity Hospital, Glasgow. During the birth of my brother, by way of caesarean section, she received a blood transfusion. The blood she received was contaminated and as a result she contracted hepatitis C
5. I don't know if my mother received any information or advice beforehand about the risk of being exposed to infection. I assume she wasn't because I understand it was an emergency delivery. I can't remember a time where I wasn't aware that my mum had Hepatitis C. I knew my mum had hepatitis C before I understood what that meant. My understanding when I was very young was that my mum didn't keep well, and I have only known my mother ill, but I never knew anything about the condition. I remember my mum and dad telling

Keith and I when we were around fourteen years old. However, we both said we already knew.

6. As a child my mum didn't tell me anything about Hepatitis C, so when I was young, I wasn't aware of the risks of contamination. As a teenager, once my mum had told me about the virus, she explained the risk of infection. I remember at this stage being confused how Keith and I had not contracted the virus, but she explained that it is not always passed on to a baby by the mother, and the only other time there is a direct risk is during breast-feeding. She said it was a blessing in disguise that she had been too sick to breastfeed us. As an adult I am now aware that a lot of our household rules as children were precautionary measures. I remember us all having different coloured towels so that we could tell them apart to use on family holidays, and mum would always find a different bathroom to use if we went on a holiday to a caravan.
7. I don't know if my mum was told anything about passing on the virus.

Section 3. Other Infections

8. My mother contracted hepatitis C as a result of being given contaminated blood. To my knowledge, she did not contract any other infections as a result of the blood transfusion.

Section 4. Consent

9. I know that my mum was given a lot of blood tests when I was young. I remember asking about this when I was around 11 years old, and her explaining to me that she thought the doctors were testing her too much. As a child, I had thought if a doctor wanted to do a test then it must be for a good reason. My mum explained to me you always are in control of your medical treatment and just because a doctor is learning something that that doesn't always mean it's

making you better. I often went with her for hospital appointments as a child and I'm aware she did have her bloods taken.

Section 5. Impact

10. My mum's physical health was severely impacted. She was very weak. Walking any length of time was very difficult as she was so fatigued, and she would often have to go into bed to rest during the day. I remember when Keith and I were very young – before we were of school or nursery age – mum would make a tent from the bedsheets, by bending her knees so that the blankets raised up and she would let us crawl under the blankets and play games around the bed. She taught us how to make different foods when we were young, like scrambled eggs, so that we were able to help make food for her or for ourselves if she was too weak. She would look very pale, and we learned to recognise the signs of her illness and how severe it was that day by the colour of her skin, by checking if there was any yellow in the whites of her eyes, or by how strong or weak her voice sounded when she spoke.
11. I remember seeing pictures of my mum from before I was born, and the contrast was startling. She looked so fit and healthy. Her eyes were bright, and she looked carefree. I remember a conversation we had about exercising, where my mum told me when she used to be able to work, she would go to the gym with her friends after work in the evenings. She said she loved it. I remember being shocked and confused because I couldn't imagine or think of a time that I had ever seen her well enough to do physical exercise. Any time my mum tried to do some exercise she would be in severe pain for up to a week afterwards. The idea of her as a gym-goer was so incompatible with the reality of life that I knew.
12. There were often episodes where my mum's pain was completely unbearable. As a family we would jump to action stations when this happened. Keith and I would try to help by rubbing her back to soothe her. We would fetch wet cloths to try to keep her temperature down, and fresh basins and towels when she

was being sick. I would help her find a night dress to wear as even the pressure of her clothes against her body would make the pain worse. My mum couldn't take painkillers so would always just have to bear the pain. We would call an ambulance if she developed a fever, as we learned that the hospital wouldn't do anything unless she had an infection and would need strong antibiotics to help recover.

13. Mum had a Tens machine that she used when we were younger, but I remember she would say that there were levels the pain would reach that the machine wouldn't have any effect whatsoever. From what I remember, this was more often than not. I have lost count of the number of times that I have looked after my mum while she is in agony. We felt quite helpless in these situations but would do anything we could to find even the smallest bit of relief.
14. There was an instance in particular that I remember, when I was in my early-20s. My mum had been very unwell and had been being sick in the bathroom and grown so weak from pain and vomiting that she was unable to get up from the floor. We were concerned as she was falling in and out of consciousness, so we did not want her to lie down on the floor: primarily because of the choking risk, but also in respect to her dignity. She also wasn't able to sit upright as this made the pain worse. The only thing I could think to do was to sit behind her, leaning back myself to the angle that I knew would help, and then lift her up to lean on me, so that I could hold her when her own body couldn't. I am not sure how long we sat there but I remember both my arms went numb.
15. Growing up, my mum never let on that there was any impact to her mental health. I was never worried about her mental health as a child and had a very happy childhood. However, now that I am older, I realise the ways that she has had to consider all of her choices through the lens of this illness. Her diet was severely restricted, her clothes had to fit in a way that didn't press her on her abdomen where it would be painful, she had to consider the activities she could do alone, or with the family, so she would be reminded of her trauma at every meal, every day getting dressed, and in everything she did. I now understand

that there would not be one aspect of her whole life after becoming infected which would not be altered.

16. I know that my mum had friends before I was born, and I knew growing up that they had stopped spending time with her because she was unwell. As a child I grasped the concept that including a sick person requires empathy that they never had. As I got older, my understanding developed, and it became clear that the stigma surrounding the Hepatitis C was a contributing factor.
17. My mother never received any treatment for the infection until the Harvoni in 2015. She received antibiotics when her bile ducts were blocked and would only be treated for the acute symptoms, like the violent sickness or an infection when she was admitted to hospital or when a doctor would visit the house. When my mum was being treated in 2015, I remember her phoning me at work to tell me that the treatment was working. Due to the stigma that surrounds Hepatitis C, I hadn't told anyone at work that my mother was unwell or receiving any treatment. I remember going into a private meeting room and bursting into tears because I was so relieved that my mum could be well.
18. I know that my mother's dental treatment was affected as receiving a local anaesthetic would cause her to be unwell and often in hospital. Any dental treatment she did receive could only be done without local anaesthetic, so this meant that her treatment options were limited. I also used to try to go along to her routine nurse appointments when my mum had to have bloods taken, because the nurses treated her better when there was someone else in the room.
19. As a child growing up, I was made aware that my mum would struggle with physical household tasks, as she would become fatigued, and tasks like vacuuming would give her a lot of pain. Grocery shopping had the added stress of making sure the restricted diet my mum had to have was catered for. Keith and I had specific chores to do, but cleanliness and my mum's diet were the big focus in the household, and we were all conscious about not letting my mum get any germs or infections.

20. As a child growing up, I remember TV reports about people who had contracted viruses from blood transfusions, and I remember how furious and upset my parents were when anything about this was on TV. I was confident that this was what had happened to mum because I never saw them as angry or upset about anything else than the way they would react to these television reports. My parents were always so lovely and gentle that I knew that it must be affecting us directly. It felt very tense because I knew they thought Keith and I were too young to be frank with, so I felt guilty for knowing this secret that I knew I wasn't supposed to know about. When my mum sat me and Keith down when we were teenagers and told us herself, I remember her being very quiet and very serious and nervous.

21. Holidays when I was a child were almost always last-minute because we could never book anything in advance in case mum was too sick to go. We went on lots of camping holidays. Some of the first holidays I went on as a baby were camping in Lourdes. It was lovely going somewhere peaceful where there were other families like us who looked after each other. There were a few summers where nothing was booked, and I'd come home from the last day of school and mum and dad would tell me to pack a bag and we'd go away. Other times we'd have to wait a little while into the school holidays before we could go anywhere. Sometimes we wouldn't be able to go away at all.

22. I remember on holiday my mum would always go to bed early and Keith and my dad and I would stay up late and play card games. I remember an incident when we were on holiday when I was 8 years old. We were staying in a hotel room, and Mum wasn't well, and she was being sick in the bathroom. My dad was trying to look after her, but my brother, who was 9 at the time, was upset by our mum being so ill and was sick on his bed too. My dad was frantically trying to take care of us all, and I remember it being really distressing.

23. In 2006, when I was 16 years old, I remember during the summer, my mum took severely ill on holiday. My dad had to drive through the night without stopping to get her home. This always sticks in my mind as it was the first time

my dad had tried a caffeinated energy drink. And I remember being worried after that happened that my mum might die far from home.

24. At school it was a secret that my mum was as sick as she was. My mum never told us about the infection because she didn't want other children bullying us. The most anyone knew was that my "mum didn't keep well". I knew that mum being sick was a private family topic and that I shouldn't talk about it outside of the house.

25. I never had big groups of friends, but I would have one or two close friends and we would play outside with them or I would go over to their house. I didn't often have friends over, or to stay over for sleepovers. My friends would ask me what was wrong with my mum and I would always dodge the question. Once or twice when I was in my early teens and my friends pressed me on the topic and I said that she had a lot of different conditions and that it was quite complicated. I remember one occasion when I was 13 years old and I was on the phone to my best friend. She was telling me I should come to her house and I told her I couldn't because I'd need to ask my mum and she was in bed resting. My friend kept telling me that it was fine, any time her mum was asleep she would just go wake her up and I should do the same. But I knew how rare it was when my mum could get enough relief from her pain that she was able to fall asleep. It's the first time I remember so clearly the feeling of being isolated from my peers over something I knew I'd never be able to explain. It wasn't that I couldn't see my friends, it was the clear understanding at that moment that the family was alone in this.

26. In 2005, when I was fourteen years old, my mum told my brother and I that she was infected with Hepatitis C, and the circumstances surrounding her infection. Her health had been really deteriorating and it was becoming impossible to shelter us from the extent of her ill health. It was at this point that I really grasped that someone was at fault for her illness and was incredibly angry that someone could let this happen without any repercussions. I know that I felt this anger very acutely up until the news that my mum got her cure. This was in 2016,

when I was 26 years old. Any contact with doctors or hospitals just made me angry, and still as far as possible I avoid going to the doctor.

27. In 2007, as I was preparing to go to university, my mother's health deteriorated drastically. I remember her coming home from hospital one day and telling us that the doctors had said they couldn't do any more. My mum had been told she wasn't going to live much longer. Mum wrote to the university on our behalf and explained her condition and asked that Keith and I could be given places in student accommodation, even though we lived too close to the university to qualify for a place. Her reasoning was that she didn't want us to have to see her suffering. She wanted us to have a normal university experience. The University approved this and Keith and I both moved out when I was 17 and Keith was 19.

28. My years at university were incredibly difficult. When I look back, I can see that I was clearly suffering from depression and was traumatised from years of my mum being ill, and the news that she would likely die from her illness. From first year I struggled socialising with my peers, even the other students that I lived with. I had always been a straight-A student, but I struggled to engage myself in lectures and in first year I failed some of my exams. I remember seeing my mum the same day; she had recently started taking a new drug called Ursofalk, and this meant that her diet didn't need to be as restricted. It was so bittersweet because I was devastated that I had failed exams for the first time, but I was overjoyed because my mum could eat brown bread without any pain.

29. I remember one day at university seeing a sign on a public toilet for a helpline number, like Breathing Space or Samaritans. I was not suicidal, but I called because the advert said that they would speak to you if you needed to talk or to get something off of your chest. When I called, I explained that I was at university and I was worrying about my mum all the time as she was so sick and had been in and out of hospital. The lady on the phone said that if the hospital had sent my mum home then that must mean that she's okay. I remember again feeling so isolated and I felt there was no support. I felt like I was patronising this woman if I had to explain that people are sometimes sent

home from hospital if the hospital won't help any more, so I told her she was right, and I was being silly, and I hung up the phone.

30. I remember when I was in 2nd year, in 2008-09, that my mum and dad would tell me after the fact if my mum had been in hospital, because they knew it was too much for me. I was glad of this because I wasn't coping well, and knew I couldn't handle bad news, but I started to get scared every time I visited my parents because I assumed something would be going wrong and that I hadn't been told. When I would get off the train and walk home, I would always hold my breath as I turned the corner to our street because I was bracing myself for an ambulance being there. When I was in my 3rd year at university in 2009-10 I was juggling the heavy workload of my degree as well as my job, and my mum's health was still continuously worsening. I remember speaking to other students on my course about how I was feeling about university, and it struck me that they seemed genuinely concerned about me. The way that they reacted made me consider how much the trauma had taken its toll on me.

31. In my fourth year at university, in 2010-11, I remember my dad not being well and having to postpone exams. He was run ragged looking after my mum and the four of us were really struggling individually. My dad [GRO-C] [GRO-C] the day before one of my exams. I submitted an extenuating circumstance claim and opted to take the resit as my first attempt. In 2011 in my final semester, I had become really run-down and developed a severe chest infection which gave me pleurisy. I had to ask for an extension to my dissertation deadline. The university refused the extension and said the only way I could be awarded my degree would be to graduate in the following year, so I chose to do this.

32. I know that the strain of looking after the family has affected my father's health. I have seen the physical impact that it has on him: [GRO-C] [GRO-C], despite being a really healthy person. He has also submitted a statement to the inquiry.

33. I know Keith's mental health was badly affected. I am very close to my brother and we have spoken about this. He has also submitted a statement to the inquiry.

Section 6. Treatment care support

34. I remember my mum telling me she was offered a place with a support group for people with chronic pain, but this was in a hospital next to a mortuary and it was too upsetting to attend under those circumstances. I don't know if my mum or the family were offered any other counselling services. I was never offered any counselling or psychological support at all.

Section 7. Financial Assistance

35. I remember there being funds given to help with a heating allowance, and I also remember my mum telling me there was going to be a fund that she could apply to and that some money was awarded, but I don't know the amounts. I don't know if my mum was offered any other financial support. I assume she was not as, speaking as a chartered accountant, it's very obvious to me that my mother and father are both very financially knowledgeable and manage their finances well, so I know that they would have used any resources available to help the family.

Section 8. Other issues

36. Finally, I would like to note the impact at present, through the process of writing my witness statement and attending the hearings relating to the Infected Blood Inquiry. I needed to take a day off work to accompany my mum to the oral hearings in Edinburgh for the Inquiry. These fell at a busy period in my work when there is normally a restriction on taking days leave. I knew that my senior manager would be understanding if I explained the importance of this day, but

I never slept for two days prior to asking for this because I have never shared any of the circumstances surrounding my mum's ill health to an employer. We are a private family, and I also worried that mentioning the topic of the inquiry would create problems for me at my workplace, due to the stigma surrounding the virus. While I have been in the process of reviewing my witness statement, I find I am emotionally compromised at work. Most days I have to take one or two short breaks away from my desk because my hands start to tremble, and breathing is difficult. No one at my work is aware of this so I just offer to make cups of tea for the team so that I can have a moment's privacy to gather myself. Some days I have found it difficult to walk to work. The five-minute walk from the train station to the office has taken me ten or fifteen minutes because I feel like my legs are too heavy to move. It's as though I need to convince my brain to let me put myself out in the world because every part of me wants to retreat to the safety of home. I hope that this description offers a window into the scale of the trauma which I have carried for my entire life.

37. I do not wish to remain anonymous in this Inquiry.

Statement of Truth

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

Signed GRO-C _____

Dated 09/10/19 _____