

Witness Name: John James Sullivan
Statement No: 1
Exhibits: 4
Dated: 26 June 2024

UK COVID-19 INQUIRY

WITNESS STATEMENT OF JOHN JAMES SULLIVAN

I, John James Sullivan, c/o Broudie Jackson Canter Solicitors, 3rd Floor Walker House, Exchange Flags, Liverpool, L2 3YL will say as follows:

Introduction

1. I am a member of the Covid-19 Bereaved Families for Justice UK ("CBFFJ UK") having joined the group following the death of my daughter Susan Tracey Sullivan. I am preparing this statement in the capacity of a bereaved father. I wanted to get involved with the Inquiry because everyone who died from or because of Covid-19 deserves a voice, and I wanted to find out once and for all what happened to Susan.
2. My daughter Susan was born on 17 November 1963. She was born with Down's Syndrome, and we were overjoyed to welcome our beautiful baby girl. She defied all the odds by being able to walk and talk despite what doctors said when she was born. Growing up, she was a lively, popular person and played table tennis and swam in the Special Olympics, winning bronze, silver, and gold at various times.
3. Susan attended day centres five days a week. There, she went to the shops, watched movies, and went out for day trips. Susan also frequently joined my wife Ida and me on holiday. Susan's favourite place was Spain, and she also travelled with us several times to Australia, America, and to the Caribbean on a cruise. She loved music and to dance, which is why she loved visiting Benidorm specifically. She went through a Grease phase and then an ABBA phase, and she would be the first up on stage or first one out on the dancefloor with me.
4. In 2018, she had a pacemaker fitted for preventative measures, but this did not majorly affect her. Overall, she was an extremely bubbly person. Susan was always laughing, and smiling and as she had an amazing level of empathy for others which is why she had many

friends both through the day centres and in the community. As a result, more than 200 people attended her memorial service in May 2022. Her friends who lived in Spain, Australia, New Zealand and Canada were able to participate via live-stream.

Susan's symptoms of Covid-19

5. When Covid-19 began to emerge, I was concerned about the lack of border control from countries with high infection prevalence and had concerns that the government was not doing enough. As I had cancer at that time, my wife Ida and I decided that the three of us (Susan, Ida and I) would start isolating from 13 March 2020 and Clifford would be extremely careful when leaving the house so he could still assist us. We stayed away from everyone as best we could. Our neighbours or our son Clifford would do our shopping. Clifford would spray everything (food items, the mail etc) with aerosol disinfectant before it came into the house from the porch. I had to be careful due to my cancer, and we were also worried about Susan going to hospital because of the rumours going around the disabled community that disabled people were not being treated properly.
6. Despite our efforts to isolate, Susan began showing Covid symptoms around 21 March 2020. I noticed that she was not her usual bubbly self: she seemed lethargic, like her battery was running low. Susan had a habit of rubbing her eyes due to the inflammation caused by Graves' Disease, I think that might be how she caught Covid.
7. We tried treating her at home with paracetamol, and despite also having a fever and a bit of a cough at times, things seemed to be looking up around the morning of 26 March 2020. Ida told me that she spoke to the neurologist that morning (during an appointment unrelated to Covid) and he said that it sounded like Susan may have caught Covid but was recovering from it.
8. However, during the night of 26 March into the early morning of 27 March 2020, Susan started to complain of an extremely bad stomach-ache. Ida woke me up very early in the morning and told me that she was worried as she had just read an article about a lady who had recently died with stomach pains which were apparently a symptom of Covid. I sat with Susan for a bit, and then at 4:50am, I told Clifford that we better call an ambulance because we were so worried.

Ambulance care

9. Susan kept saying to me, "Where are they? I'm waiting, Chief" (Susan used to call me 'Chief' and I used to call her 'Little Chief'). After about 3½ hours, Clifford called the ambulance service again for an update. Clifford said to us that the ambulance service needed to divert the ambulance to another patient. A bit later on, Ida phoned our local pharmacist and explained that we were waiting for an ambulance, but that Susan's stomach wasn't getting any better. From what Ida told me, the pharmacist was concerned and told us not to wait any longer and told us to take Susan to hospital ourselves. After roughly a six-hour wait, we had Susan downstairs putting her shoes on when the ambulance arrived.
10. I don't remember the ambulance crew wearing full PPE; I think they may have had facemasks on, but I don't remember if they had on aprons or gloves. The crew were quick in their assessment. I remember they took her pulse and put on an oxygen mask and then they had her out the door. At this point, Susan was in better spirits and was joking with Clifford about her glasses. I think she was relieved that the ambulance had arrived. She did not seem scared. Ida was able to ride in the ambulance with Susan to hospital. That was the last time I saw Susan. I gave her a kiss before she left and thought to myself, "She'll be back". We had good reason to trust the NHS. It never entered my mind that she would not make it back.

Accident and Emergency care

11. Due to my own health issues, I could not go to hospital with Susan. Ida has explained to me what happened when she was there. When they arrived, Susan was taken to the Emergency Department ('ED'), and Ida was told to stay in the family waiting room. It was a small room at this point, with someone else's family there. Ida wasn't waiting for too long when she heard two healthcare workers in the ED saying under the circumstances "the mother should be allowed in". Ida said that she realised at that point they were speaking about her. Ida was then led back to the ED to see Susan where a nurse had just finished taking her blood samples. Ida told Susan that she loved her, to which Susan replied, "love you too".
12. A doctor asked Ida if we had any plans in place for resuscitation. Ida said "no" but was confused by the question as we had not thought about it before as Susan has never been seriously ill. Ida asked the doctor for more information and after he explained what he meant, Ida said that we would want Susan to be resuscitated. At no point during Susan's

admission was Ida included in a discussion with a doctor about Susan's prognosis or treatment.

13. Ida went back into the family waiting room and was told by the healthcare staff to wait for a further update. The ED was getting busier, so she tried to stay seated out of the way in the family room while she waited. Luckily Ida wore her own PPE to the hospital including a mask and gloves – she was not asked to change into fresh PPE when she arrived.
14. By this time, Ida had been at the hospital for a few hours, so Clifford took her some food. Ida was given the phone number for the ED so she was able to call for updates from Clifford's car outside. Eventually the doctor was able speak to Ida with an update. She met him at the door of the ED and he told Ida that they were pleased with Susan so she was being sent to a ward. Ida asked, "not the intensive treatment unit?". The doctor replied, "no". When she asked the doctor, "that's good isn't it?", he did not reply. Ida was told to ring the ward later for an update. Ida didn't stay after that as there wasn't much she could do at that point.

Ward admission and care

15. Ida came home, and later that day she called the ward as advised and was told that there was no visiting allowed, and the hospital was shut down to all visitors. Ida and I had Clifford handle the majority of the phone calls from the hospital following that. Clifford was the first to know that Susan was being treated for Covid on the evening of 27 March and was the first to know that her outlook was starting to change.
16. The next morning (28 March 2020), a nurse telephoned us and told us that Susan was not tolerating her oxygen mask and kept taking it off. The nurse kindly took the phone to Susan so that we could speak to her. Both Ida and Clifford tried to speak with Susan over the phone to calm her and convince her to keep the mask on her face. Unfortunately, she was crying too hard by that point, and I did not get the chance to speak with Susan one last time. Looking back, I wonder how they were adjusting to Susan's communication style. She would not have understood questions they asked her and would not have had the ability to answer serious questions, especially without her family or other familiar people there to support her.

17. At around 2:10pm that day (28 March 2020), Clifford found out that Susan was in a critical condition. After much asking, he was allowed to visit Susan, Clifford is an electrician and had his own masks and gloves which he wore to the hospital. He said that the nurses did give him an apron and new gloves when he arrived. That afternoon, Susan passed away in her brother's arms.
18. She was aged 56. The cause of death on her death certificate was "Covid-19" and "Down's Syndrome".
19. I feel as though the hospital just gave her a bed to die in and did nothing to proactively treat her.
20. Susan's funeral was delayed due to Covid restrictions, and we had family that needed to travel over from Australia. Susan's body was cremated, and once travel restrictions ended, we arranged a memorial service for her. We knew people would want to attend a larger service – we had lived in the same house for 55 years and Susan was well loved in the local community. She would pop into people's houses for a cup of tea and in her younger days, helped Ida and I run the local Youth Club.

Serious incident investigation

21. I obtained Susan's medical records and was horrified to discover the statement which said: *"ITU declined in view of Down's Syndrome and cardiac co-morbidities"* JS1/INQ000483292.
22. Due to my health, I was unable to make an official complaint until 08 March 2023, but I did do an article for the Guardian online which was published on 10 July 2022 [JS2/INQ000188822]. I wanted to get the message out about what happened to my daughter, and I suspect that may have gotten the hospital's attention. On 3 August 2022, the Head of Quality Governance at the hospital wrote to me saying that the Trust would carry out a serious incident investigation into Susan's care and treatment [JS3/INQ000483294].
23. The investigation was undertaken by people who never met Susan and the Serious Incident Investigation report ('the report') is full of and contradictions. For example, the report states that, *"the patient was discussed with the intensive care unit but considered*

not suitable for admission" and the report goes on to say that *"The investigating team have been unable to find any documented evidence of an ITU review taking place and can conclude that the patient was not reviewed face-to-face by ITU staff"* [JS4/INQ000483295].

24. The report picks up on the note that I had previously seen. It was made by a medical registrar who wrote Susan had been, *"declined ITU admission due to cardiac co-morbidities and Down's Syndrome"*. According to ITU consultants interviewed as part of the Trust's internal investigation, *"neither the presence of a cardiac pacemaker or Down's Syndrome are considered exclusion criteria for ITU review or possible admission"* [JS4/INQ000483295].
25. The report noted that the first consultant-led ward round took place on 28 March 2020, some 20 hours after Susan's admission, and that *"there is no documentation to suggest a consultant was aware of the patient on the 27 March 2020 or reviewed the case that day"*. [JS4/INQ000483295] During those 20 hours, her condition deteriorated rapidly, and I consider there were missed opportunities to treat her.
26. The report and medical notes say that oxygen was benefitting Susan, but I think that her difficulty in keep the mask on was based on fear of her surroundings and because she did not have a family member there to encourage her to keep the oxygen mask on. Similarly, the Trust made no effort to allow family to visit the hospital to help Susan (apart from to say goodbye when she was in her final few hours).
27. Susan was given no information in an accessible format for her to understand the importance of keeping the mask on. I learned later in the serious investigation report that hospital did not have any evidence to suggest the Trust's Learning Disability Team were involved in Susan's care. [JS4/INQ000483295]. A specialist learning disability nurse could have suggested ways of introducing the mask to Susan to allay her fears and improve her tolerance to the mask. Having family with her or better communication that was accessible to Susan might have made all the difference.
28. Providing information in an accessible format for Susan, allowing us to visit and to support her, or allowing a specialist learning disability nurse to visit would all have been "reasonable adjustments" under to the Equality Act 2010. I feel the Trust breached its duties under the Act and committed disability-based discrimination. If the Trust had not discriminated against Susan, doctors might have provided different treatments that may have prevented her

death, or at least the treatments that they offered, such as oxygen therapy, would have been more successful and may have improved her chances of survival.

29. I want it to be known that I am not against the NHS, and the NHS has been very good with my own health issues. However, during this vital period, NHS staff were obviously fire-fighting and no consultant was able to attend on Susan. It seems clear from the Trust's report that because Susan was denied a place in ITU she was denied treatment on an equal basis with others. It is clear from the Trust's own documentation that Susan was denied an ITU bed because of her disability.

Long-term impact of the pandemic

30. I spent 56 years supporting and encouraging my daughter, only to lose her very sadly during the Covid-19 pandemic. The impact of Susan's death and the delay in the Trust's investigation and the Covid-19 Inquiry have worsened my health as my cancer symptoms are triggered by stress. We have not been offered any bereavement counselling.

31. My wife Ida has not recovered from the experience of losing Susan. We have not been able to return to Benidorm since losing Susan, we used to go about twice a year, but have not yet been able to bring ourselves to go back there without her.

32. I have gone through the investigation into Susan's death alone, to prevent Ida or Clifford from further distress. Providing this statement to the Covid inquiry has allowed me to give Susan and her disabled peers a voice: that has been my motivation.

Statement of Truth:

I believe that the facts stated in this witness statement are true. I understand that proceedings may be brought against anyone who makes, or causes to be made, a false statement in a document verified by a statement of truth without an honest belief of its truth.

Signed:

Personal Data

Dated:

26th June 2024