Witness Name: Susan Lyons
Statement No.: 1
Exhibits: SL/01 – SL/05
Dated: 19 May 2025

UK COVID-19 INQUIRY

WITNESS STATEMENT OF SUSAN LYONS

I, Susan Lyons, of Irrelevant & Sensitive, will say as follows:

1. I make this statement in response to the UK Covid-19 Inquiry's request for evidence pursuant to Rule 9 of the Inquiry Rules 2006. Within this statement, I have set out (1) my experience during the pandemic as the mother and carer of a disabled woman with complex needs, including learning disabilities and epilepsy, and (2) my observations of my daughter's experience in a specialist care home during the pandemic, including the impact of visiting restrictions, the quality of care provided, and the use of Do Not Attempt Cardio Pulmonary Resuscitation ('**DNACPR**') notices.

2. I have prepared this statement in liaison with solicitors at Leigh Day who represent Core Participants John's Campaign, Care Rights UK, and the Patients Association in Module 6 of the COVID-19 Inquiry. They asked me to address questions based on the Inquiry's Rule 9 requests via email. Except where I indicate to the contrary, I make this witness statement on the basis of facts and matters within my own knowledge. Where these facts and matters are within my own knowledge, they are true. Where the facts and matters in this witness statement are not within my own knowledge, they are true to the best of my information and belief.

Background: My daughter's care needs and care arrangements

3. My 31-year-old daughter, Sarah has learning disabilities and epilepsy. She was of relatively normal intelligence up to age 16, and most people thought she was "normal", although she had severe specific learning difficulties. She developed epilepsy at age 12. She was given an anti-epileptic drug and had no more seizures for 2 years. Then,

at 14 the epilepsy went out of control. She suffered massive cognitive deterioration during a 10-month period from age 16-17. She went from being like an immature 16-year-old, who could tell me what she had seen and heard all week at school, to being like a 2-year-old with dementia in that her communication (her ability to understand and express herself) and memory (her ability to remember and differentiate between different situations) are both now very poor. She cannot now remember what she had for her last meal, or the name of the care worker in the room with her, may confuse incidents in the past with incidents in the present and takes words literally whilst also struggling to understand or retain complex or longer sentences.

4. Sarah struggles significantly with communication, which is often confused and conflated with non-verbal intelligence. Her own speech is muddled, with mispronunciations, poor grammar and sequencing of syllables, words, sentences and paragraphs. She needs to be addressed with clear, simple, and short sentences and does not understand abstract language, puns, double meaning, colloquialisms, sarcasm or sayings. So, for example, if someone asks, 'do you want a top up?' regarding her drink, she will not understand this but if someone asks, 'do you want more?' she will. However, she does understand concepts if they are explained to her in the right way. Unfortunately, her communication difficulties often mean that people she interacts with assume she will not be able to understand concepts.

5. It was extremely challenging for us as a family to witness the deterioration in Sarah's condition. We all suffered grief over the loss of who Sarah was at 16, but there is no closure, because her body is still talking and walking about, with a different person inside it. We all look at her, and think what she would be like, if she had stayed the same – the most amazing person, we had ever met! Her twin sister suffered especially from the loss of her best friend, developing severe mental health problems which affect her to this day.

Conditions

6. Sarah has been diagnosed with the following conditions:
    a. a congenital abnormality in the right frontal lobe of her brain, causing specific learning difficulties, and later the epilepsy;
    b. Lennox Gastaut syndrome – a severe drug-resistant epilepsy, which causes up to 300 seizures a month, irritability, aggression and cognitive deterioration;

c. Hartnup disease – a metabolic disorder, leading to a protein deficiency, and for her, mainly neuro-psychiatric symptoms like depression, anxiety, ADHD, and emotional volatility;
d. Genetically high cholesterol with a risk of early heart attack; an underactive thyroid gland, causing weight gain and tiredness;
e. Osteopenia – (a precursor to osteoporosis), thinning of the bones, due to the anti-epileptic drugs and a family history of osteoporosis;
f. Language disorder – causing severe difficulties in understanding and expressing language;
g. Dyslexia;
h. Dyspraxia – poor motor planning, co-ordination and visual perception;
i. Profound memory problems which make it very difficult for her to retain new information;
j. A generalized anxiety disorder – Sarah had a marked history of emotional problems and psychotherapy from the age of four;
k. ADHD;
l. as well as iron and vitamin D deficiencies, which impact her existing conditions.

7. Sarah experiences all seizure types, but the worst are "drop attacks" – where she falls down, without any warning and suffers head/neck/back injuries, broken bones/teeth, etc. Her seizures are much worse during menstruation. She can have status epilepticus (seizures non-stop) and needs emergency medication, otherwise it can lead to brain damage and death within a few hours. She is in the highest risk group for Sudden Death in Epilepsy (SUDEP) – her breathing or heart could stop without warning at any time, especially at night.

Care arrangements and needs

8. As a result of her complex conditions, Sarah requires 1:1 care and lives in a care home. Circa 120-130 residents live on the care home's premises, but they don't all live in one big building. There are numerous houses/bungalows (I think between 15-20) on a big campus and approximately 6-8 residents live in each house. The campus has its own medical centre, shop, café, a swimming pool, sports hall, social centre, farm, therapy centre and an admin building. People living in other care home settings across town come to the campus to use some of the services as 'day services'. The people living on or drawing on services on campus range from teens to older people but the majority I have seen on the campus are younger / working age people.

9. Sarah lives in a house, where during Covid, there were three other young women on what they refer to as the “girls’ side”. There is a locked door to a separate section of the house, where three young men live. This is referred to as the “boys’ side”. The two parts of the house are self-contained with their own communal lounge, kitchen, dining room, office and enclosed garden. We only tend to deal with the care staff on the girls’ side of the house, the team leaders and the manager of the house (this is why I refer to the ‘house’ at various points in this statement); and the medical staff who work on the care home premises. Occasionally, we deal with the speech and language therapist or the positive behaviour support team.

10. Sarah has very specific needs and we regularly have to advocate for her needs, which include:
    a. 1:1 care all her waking hours, and waking night staff, with video/audio/mattress monitoring, to detect seizures and falls at night.
    b. A combination of five of the latest anti-epileptic medications, and emergency medication to stop non-stop seizures.
    c. An onsite consultant neurologist to arrange drug changes as soon as possible, if required.
    d. An onsite medical centre with doctors and nurses 24/7 to deal with injuries, non-stop seizures, and SUDEP.
    e. All triggers for seizures need to be controlled to reduce the number of seizures. Triggers include hunger, heat, cold, pain, menstruation, boredom, inactivity and stress.
    f. Depo-Provera injections to suppress the menstrual cycle.
    g. A high protein, low fat diet, with plenty of iron, calcium and vitamin D.
    h. Medication including: Levothyroxine tablets, Iron tablets, Vitamin D tablets.
    i. Weight bearing exercise to strengthen her bones.
    j. An onsite team of speech and language therapists, occupational therapists, physiotherapists and a positive behaviour team (to give advice and training to her care staff on communication, functional living, injuries and challenging behaviour).
    k. A ‘total communication’[1] environment with visual support for her comprehension, such as signing, photos, symbols, facial expression, gestures, and plain, simple, and concrete language. Communication should be at the level it would be for 2-year-old.

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[1] The ‘total communication’ approach if about finding and using the right combination of communication methods for each person. See: Total communication - Sense

l. Emotional support such as someone to talk to about her problems.

11. Sarah requires significant, specialist and tailored support to meet her complex needs. It is therefore extremely important for someone who knows her well (like myself or my husband) to advocate for her to ensure there is awareness of what her complex needs are and how they can be met. Often the need for someone to advocate for her, because of limited communication is far more basic. To illustrate what I mean by this, I have provided a recent example of what can happen if I don't advocate for Sarah:

> Sarah had a drop attack at home at Christmas (2024) and fell to the floor. The hospital told us she had a fracture in a small bone in the pelvis and a chipped bone in her foot. The best treatment for both fractures was walking as much as possible, with the support of a walking boot. They sent a discharge summary to the GP. A week later, we took her to the fracture clinic. The orthopaedic specialist went through all the fractures with us – he could see no fracture in the pelvis or her foot; but there was fracture in her leg, just below the knee. The specialist said it would be too painful for Sarah to walk for 2 – 3 weeks.
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> I wrote to the house and the GP that day, telling them about the appointment. On her return to the house, Sarah had an appointment at the local fracture clinic, which nobody told us about until after the appointment. Two members of the care staff took her. The x-ray department x-rayed her pelvis and foot; and the consultant discussed the x-rays. The house sent me a report on the appointment. I pointed out to the house that the x-rays were done on the wrong bones, and that the consultant was not asked to consult about the fracture below the knee. The GP had to write to the consultant explaining all this and asking for another appointment to get the right advice. If I had been at the appointment, I would have raised these questions myself; but nobody thought to brief the care staff, that the fracture was below the knee – and apparently, none of them had noticed where her pain was, in their day to day care.

Living and care arrangements before the pandemic

12. From age 10 until her epilepsy got worse, Sarah was boarding in residential specialist speech and language schools during the week. She used to come home on weekends and school holidays.

13. After her epilepsy went out of control when she was 14 years old, Sarah moved between several different residential schools and there were some periods in which Sarah was out of school whilst we were looking for new, more appropriate placements. Several schools struggled to provide her with the specialist support she required. During the periods Sarah was not in school, she stayed with us at home.

14. We typically had to call 999 between 1 – 3 times a week for non-stop seizures, which led to Sarah being rushed to hospital. Sometimes she was admitted for drug changes. She also used to be admitted to hospital every month, on the first day of her period due to the high number of seizures that occurred, as a result of her menstruation. We also took her regularly to A&E for assessment and treatment of injuries from falling during seizures.

15. At 16, it became obvious that only specialist residential epilepsy schools and later specialist Further Education (FE) college, could cope with her epilepsy. Sarah left specialist epilepsy FE college at 22 but was still spending weekends and school holidays at home during this time.

16. In January 2016, she was referred to a new neurology specialist who told us for the first time, how to stop the seizures getting to the level of 150 in a day, by using 'emergency medication' 2 - 3 times a week. We have hardly ever had to call 999 for non-stop seizures since then, although we still have to call them sometimes for injuries from seizures.

17. Sarah moved into specialist epilepsy supported living in July 2016 but asked to leave after saying a staff member had hit her. She was then at home with us for 10 months (from November 2016 until September 2017), but we really struggled to cope with the lack of sleep (due to Sarah's seizures throughout the night) and the stress over the drop attacks and her medical care, especially as none of Social Services' respite Centres could cope with Sarah's epilepsy.

18. In September 2017 Sarah went to live in her current, specialist care home, with an onsite medical Centre and GP practice, where the medical staff can deal with her day to day medical needs and many of the emergencies, without having to call 999. We spoke to her on the phone regularly, and received weekly updates from the care staff, so that we could have conversations with her about what she had been doing, as she often struggled to remember this herself. We still gave advice regularly to the staff in the house on how to handle her, especially changes in her behaviour.

19. Sarah spent time at home with us at weekends, Christmas, Easter, birthdays and an annual summer holiday, because really, she still wanted to live at home with us and told us this. We made sure she saw the family and a school friend to maintain her relationship. We took her places she enjoys like restaurants, the cinema, the theatre, theme parks, and zoos to keep her active. We took her out shopping for her clothes, equipment and gifts. When she was at home, we still had to take her to A&E for broken bones, etc.

20. When she was staying at the house on the care home campus, she could do work experience at the farm, shop and dog parlour. She had trips out, takeaway every week, could use the sports facilities and go to the cafe for lunch and to the shops to buy herself treats. As set out further below, unfortunately this all stopped during Covid and Sarah was therefore much more unhappy and bored, when staying in the house on the care home premises.

Living and care arrangements when the pandemic started and during the first six months of the pandemic when care was provided at home

21. Sarah was home for her birthday, when the first lockdown was announced. We received a letter telling us that Sarah and other residents on home leave could not return to care home premises. Nobody had any idea how long the first lockdown was going to last or what would happen, so we did not know at this stage how long Sarah would be at home for. This was a shock, as I had to give up work as an accountant immediately to provide the 1:1 care Sarah needed[2] but I tried to still do the bookkeeping, VAT returns and partnership accounts when Sarah was asleep. Sarah ended up staying home with us for 6 months.

22. Sarah typically had about 4 seizures a night at that time, mainly from 5 am onwards. There is a baby monitor in her bedroom, with a receiver in mine, so I could hear seizures and check on her. She was often awake crying to me until 1 am, saying that she didn't want to go back to the care home campus as the team leader wanted to kill her. She woke up at dawn in the summer, around 4 – 5 am. She would go downstairs to watch the news on the TV at full blast, which woke us up; or she would wake me up

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[2] I was working as a qualified accountant part time, for my husband and his partner in practice in Shoreditch. I worked 2-3 days per week, except when Sarah was home.

asking to go shopping, or put loud music on. Sarah normally spends at least half of the day asleep, so being awake half the night is no problem for her, but it impacted on my husband and me, and I often only slept between 1am and 4am during this period.

23. During the time Sarah spent at home, she repeatedly told us she did not want to go back to the care home because of an incident that had occurred there in the kitchen. Apparently, she had been helping cut up some vegetables for dinner. She said a new team leader came in and was waving the knife about. Sarah thought that the new team leader wanted to kill her with the knife. This was obviously a misunderstanding, due to her comprehension difficulties. She was in tears to me about it 3 – 4 times a week for the first 12 weeks she spent at home during the pandemic.

24. I had asked the care home for a 2-week supply of the medication Sarah needed before she came home, but they only sent me a 10-day supply. I had asked for the additional supply, because Sarah has sometimes had to stay home for longer than anticipated (for example, because she has needed to go to hospital after a seizure). On this occasion, we kept Sarah at home longer than planned originally, because of her aunt's death and we thought Sarah should go with us to the funeral for closure. However, lockdown was announced in that interim period. We decided not to attend the funeral, as we knew NR my husband was high risk due to his cardiovascular disease; and we already feared that if Sarah developed Covid, hospitals would refuse to treat her, on account of her learning disabilities, based on past experience. We decided to watch the funeral, being live streamed, at home instead. I didn't know that there would be a lockdown and so I assumed Sarah would be returning to her care home after the funeral.

25. When the lockdown was announced and we were told Sarah could not return to the care home campus, it was a big shock, and I panicked about how to make all the necessary arrangements for her care. I had to quickly get Sarah registered with our GP as a temporary patient, get another prescription from them for the medication she needed, arrange the Depo-Provera injection that was due, while suffering grief and shock over my sister-in-law's death.

26. Sarah is on the latest anti-epilepsy drugs, only available to tertiary centres. Most doctors, and responsible healthcare professionals (HCPs) have never heard of them. They are very expensive, and no pharmacy keeps them in stock. Sarah ran out of the medication she needed and there were at least 5-7 days on which I could not give her the correct medication she needed. The pharmacist could not get hold of one of the

drugs she needed for 10 days. If Sarah started having many seizures, then the emergency protocol was to give her clobazam, a benzodiazapine to break the cycle, before it accelerated to 150 seizures in a day. I gave her clobazam every day for those 5 - 7 days to try to suppress the rebound seizures she would have after a drug reduction – an abrupt one in this case. The only safe place to take someone like Sarah off one drug suddenly is hospital and we had to cope with it having happened for an extended period at home.

27. Sarah was not counted as Clinically Extremely Vulnerable (CEV), so we could not get priority supermarket deliveries. I often had to take her food shopping with me which was challenging given her care needs and the various restrictions in place (which she struggled to understand).

28. After 6 months at home, Sarah decided she wanted to go back to live in the care home. The Commissioning Care Group (CCG) paid for an independent advocate to obtain Sarah's views and a best interest meeting was held, at which it was agreed she should go back, as she wanted to. At the meeting Sarah saw the care home manager and said she wanted to go back. I believed she had no conception of the likely impact of the Covid care home guidance on her, but I made no attempt to talk her out of it, because I was worried my husband was going to have another heart attack, due to the stress; and we were living on 3 hours sleep a night as a result of the seizures. I was on my knees with exhaustion.

The impact of Sarah's condition and care needs on her family

29. My husband, my daughter's twin and I all suffered anxiety, depression, and post traumatic stress due to the trauma of watching the uncontrolled seizures, severe injuries, 999 calls, and A&E admissions to hospital. We all have to be hyper-vigilant. Several times all of us have witnessed a drop attack where Sarah hit her head or neck with such force that we believed she had broken her neck and was dead. It was a paralysing shock, but we had to call 999 and take action to try and save her. I cannot put into words the stress of not knowing when the next drop attack is going to happen and how it might affect Sarah. It has had a profound impact on all of us. My husband suffered two heart attacks - one in November / December 2017 and second in December 2019. He continues to have breathlessness, left arm pain and tightness in his chest when he experiences significant stress.

30. As set out below, the NHS and social/care services are too fragmented for people like Sarah. I have often had to run around between services, between the GP, pharmacist, consultant neurologist, epilepsy nurse and care provider to try and secure the specialist care that Sarah needs. I have suffered carer breakdown twice (in 2004 and in 2019) due to the stress of trying to deal with the NHS and Social Services, on top of her enormous care needs 24/7 at home. I ended up needing secondary mental health services myself due to the stress of this and my psychiatrist had to speak to the CCG twice, to impress on them the seriousness of the situation to get them to agree funding for a specialist care home.

31. During Covid, there was the additional stress of knowing that if we took Sarah to hospital, they might well refuse to treat her, because all the beds were full with Covid patients and she had learning disabilities. We were also worried Sarah might catch Covid in A&E, and could die from that, including because we felt that she was not likely to get hospital treatment for it. There was also the worry, if my husband and I both got Covid when she was home that we might be too ill to look after her. What would happen to her then? Nobody else in the family could cope with Sarah's complex care needs.

<u>My daughter's experience of care prior to the pandemic</u>

32. Even prior to the pandemic, in our experience during the November 2016 - September 2017 period in which Sarah was living at home, it was hard to get GP appointments, prescriptions and the Depo-Provera injections done on time. By way of example, the GPs refused for months to prescribe the formulation of the emergency medication Sarah needed, telling me it was no longer manufactured – even though it was the policy of the county council and local CCGs to prescribe that particular medication, as all agency carers were trained in its use. The Local Authority's epilepsy nurse had to write to the GP twice and point this out to them before they prescribed it. We also struggled with Sarah's medication being changed every time she came across a different consultant neurologist – they always thought they could make things better by changing the dosage, but this never worked and we ended up where we had started. Unfortunately, these are just a couple of a number of examples, and we often had to 'fight' for Sarah to get the right care, including the Depo-Provera injections she needed every 10 weeks on time.

33. Whenever Sarah was hospitalised prior to living in her care home, I had to stay with her 24/7 in hospital to ensure she was monitored and her needs were met, including

because hospital staff often failed to meet Sarah's communication needs. We sometimes felt that Sarah's needs were not met because of her learning disabilities. For example, she broke her collarbone, and the orthopedic department refused to pin it, on the grounds she had learning disabilities and despite experiencing multiple head injuries she only received one CT scan.

34. We were the only people who noticed when Sarah's language deteriorated once she was living in her care home and asked the onsite speech therapist to assess her and give advice to the care staff. We also pushed for Sarah to be given psychotherapy/counselling in her care home, because she had had this for many years prior to moving there. She needs to talk about her emotional problems, to stop her spiralling down further into anxiety and confusion. We told her care home from day one that she needed someone to talk to, from outside the house. They never provided it - their clinical psychologist said she could not benefit from counselling. Unfortunately, Sarah has deteriorated significantly in her language and memory since living in the care home and we think that this may be at least in part because of the lack of therapy. We thought art therapy or play therapy should have been tried but the care home staff didn't listen to us, not even when Sarah's mental health and behaviour got significantly worse during Covid (as set out below).

My daughter's experience of care during the pandemic

35. I have set out a summary of my daughter's experience of being in a care home during the pandemic as a blog for John's Campaign[3], which I exhibit to this statement as **Exhibit SL/01 [INQ000612644]**. In summary, as set out further below, Sarah was a healthy young woman in her 20s, apart from her epilepsy, but she was imprisoned within four walls, with little opportunity for exercise or emotional support from us, her family, and we were prevented from assessing and providing valuable input into her care for 2 years. It felt to us like our daughter was being held hostage in her care home because the Government was sensitive to criticism over the seeding of care homes with Covid after having discharged elderly people into them at the beginning of the pandemic. We found this particularly frustrating in circumstances where Sarah's care home set-up is very different to what is often thought of as a 'traditional' care home where older people live together in a single building.

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[3] Would You Put Your Three-year-old Through This? | John's Campaign

<u>Infection, prevention and control (IPC) measures that were introduced to reduce the spread of Covid-19</u>

36. As set out above, Sarah's care home is a specialist care home in which residents live in houses or bungalows across a large campus, with approximately six residents per house / bungalow.

37. From the first lockdown onwards, the care home wrote letters to parents, about the precautions for Covid that were being taken. The restrictions and measures that applied during the time that Sarah was living there from November 2020 onwards included:
    a. The staff were given a uniform to wear, instead of their own clothes. They were expected to wear surgical masks on shift. As we were not able to visit the care home (except the Visitor's Centre), we don't know if PPE was used appropriately throughout the care home.
    b. All onsite communal activities, day services, and work experience were stopped. Residents could not mix with residents in other houses. All trips off campus were stopped and all trips onto campus for those drawing on day services were stopped.
    c. We (and other parents/relatives) could not go into our loved one's house on the care home campus until March 2022 (we were excluded from November 2020 until then). In the period of December 2020 until March 2022 we were only allowed into a room in the Visitor's Centre. We could meet Sarah outside if we were taking her home and from May 2021, if we were taking her out for the day.
    d. When Sarah was allowed to come home for a visit in June 2021, we were supposed to drive home, wearing masks, avoiding service stations, with the windows open – this was impractical on motorways due the road noise. We had to avoid having visitors to our house, and if they had to come, they were supposed to wear a mask and rooms should have been well ventilated. We were supposed to use outdoor spaces, avoiding public transport. Before her return, we had to arrange PCR tests for the family, a lateral flow test on the day of return, and then Sarah had to have three days of lateral flow tests, and a PCR test in isolation on day four after her return. Sarah had to isolate for 14 days on her return – see below.
    e. The campus had two houses consisting of four flats which were normally used for parents to stay in, while visiting their children. During Covid when parents were not allowed to visit, these four flats were used to isolate a resident for 14

days after home leave. If a resident went on home leave, they had to be isolated in one of these flats with their familiar care workers for 14 days on their return. This meant that Sarah could come home, when there was a slot for her to be isolated in one of the four flats for 14 days. Given the number of residents (c.120-130), there weren't many slots available, especially at Christmas.

f. If a resident got Covid, they were isolated in their room for 10 days, and the house was put into isolation for 28 days. The resident was only allowed out of their room to use the bathroom. The staff had to wear full PPE – mask, apron and gloves to deliver care in the resident's bedroom. The other residents could only go out of the house for exercise once a day, after the care staff had rung all the other houses to tell them not to let their residents out on the grounds.

g. If a care worker got Covid, they had to take the time off work. The relevant house was put into isolation for 28 days and the residents were only allowed out once a day for exercise, and the house had to ring all the others to notify them not to let their residents out at the same time[4].

h. Once lateral flow tests became available, the staff had to test weekly.

38. The care home made some adjustments to its practices based on the needs of its residents. For example, the residents were not expected to wear PPE, as all the residents had learning disabilities and would probably have pulled masks off because they didn't like them or struggled to understand why they were needed. However, there were no adjustments for staff PPE (as set out further below).

The impact of IPC measures

39. When our daughter returned to her care home in November 2020, she had to be isolated in a flat for 14 days with her regular care workers. She couldn't go for a walk in the open air. We were concerned about this because boredom and inactivity increase seizures, and Sarah needs weight bearing exercise to strengthen her bones which was far more difficult to do indoors. On our arrival at the care home one of the care workers told us how the night before she and her family had been to a pub or restaurant. We couldn't understand why our daughter had to be in isolation for 14 days,

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[4] The care workers in Sarah's house generally work on the girls' side of the house but there was sometimes crossover with the staff in the boys' side of the house. The care home also has 'bank staff' who sometimes fill in when there are staff shortages. I don't know how many houses they work on. The house manager manages two houses, so she mixed with the staff and residents of those houses.

while the staff were going out whenever they wanted and then interacting with residents.

40. After the first isolation in November 2020, Sarah returned to her residential house, where she could only socialise with the other three female residents in her house for two years. She was afraid of one of them, who had more severe learning disabilities than her – yet in the pandemic, she couldn't get away from her. She had seen this young woman attack the staff. Sarah therefore tended to stay in her bedroom on her own, she often had no social contact, except with the care staff working directly with her.

41. Throughout the pandemic Sarah was more withdrawn and ate less. This was concerning to us because Sarah is a person, who lives to eat. Hunger is the major trigger for her seizures. She became more verbally abusive to staff and occasionally showed physical aggression, like hitting or kicking them.

42. Sarah is heavily reliant on visual input to support comprehension of spoken language – like facial expression. She found it difficult to hear the staff speaking through masks and could not read their facial expressions. She cried to me what hard work it was to understand the staff. As she was not getting the words reinforced every day for her memory, she forgot most of her vocabulary – her language fell off a cliff. She used to be able to say to us "What's for lunch?" After Covid, she could only say "The thingy, the thingy….?" We couldn't understand what she wanted to know. If we said to her after the pandemic "Let's go to the shops?" She said to us "What are shops?" If we talked to her about her sibling XXXX, she said to us "What is XXXX?". These were all things she used to know before the pandemic.

43. The staff ordered books off the internet for Sarah to read, to keep her occupied. Whilst this was in principle a kind gesture, I had to point out that the books they ordered were way above her reading age – they needed to buy books with plenty of pictures, not dense text. This was then done but my intervention was needed to ensure that Sarah could access the activity that they had provided for her.

44. When the house had to go into isolation for 28 days, if a staff member or resident got Covid, it was in Sarah's care plan that she could only go out for exercise to play football. She was allowed out once a day for exercise but in her case, she was only allowed out, if she wanted to play football. She couldn't just go for a walk, if she wanted to. There was no regard for the impact of boredom and inactivity on seizures. I suspect it

was a way of them rationing her exercise, as it was a faff for them to ring round all the other houses every day, to tell them to keep their residents in to allow for walks across the campus to be taken, but I don't know why Sarah was only allowed out to play football during the isolation periods.

45. In January and February 2022, the care home asked for two meetings with us to talk about how the IPC arrangements in place affected her mental health and behaviour, which had progressively gotten worse. We don't know what they expected us to do – the Covid guidance was not of our making, and we didn't agree with it. We couldn't have moved her to another care home, closer to home, as they were not accepting new residents (either because they might bring Covid in or because of staff shortages) or were too expensive (we checked). They asked us to have Sarah home more – we have had her home about 30% of the time since then to date.

Visiting restrictions, limited communication and their impact

46. As set out above, Sarah was at home until 2 November 2020, so we were not affected by visiting restrictions that applied in her care home until then. When Sarah moved back into the care home, from December 2020 the arrangements were as follows: visits into care home premises were allowed with a slot booking, for a limited period and on completion of a test (this only became available in December when lateral flow tests were widely available). Visits out were allowed with a booking and with 14 days' isolation on return regardless of the length or nature of the visit. If a resident's house was in isolation (because a resident or staff member had tested positive) no visiting was allowed for any of the house's residents during the 28 days of isolation. (Although, when this happened to Sarah once, I complained and they did allow us to see her, behind the Perspex screen in the Visitors Centre.) As houses were in any event not allowed to mix, other houses were not affected and families visiting residents in other houses could still visit them in the Visitors Centre, as long as they had a negative test.

47. In order to visit, visitors had to book an hour and a half slot for visiting and do a lateral flow test for Covid on arrival at the Visitors Centre. The first half an hour was spent doing the test, doing a questionnaire about symptoms, waiting for the results and putting on PPE. If the visitor tested positive, they wouldn't be allowed to see their loved one. If they were negative, they had to wear full PPE and sit for an hour behind a Perspex screen talking to their loved one, who was accompanied by a care worker.

There was no regard for privacy. I felt that this breached our rights to private family life and couldn't understand why this was necessary.

48. Nobody could explain to Sarah why she had to stay behind a Perspex screen. She struggled not being able to see our faces and therefore facial expressions, behind masks. She uses facial expressions as visual support to what people were saying, e.g. to assess whether they were telling her a joke or telling her off. She struggled to understand the words through a mask. We were not as relaxed a member of staff present, as we would have been on our own with her and we felt that Sarah didn't feel able to tell us about any complaints she had about staff.

49. In order to visit Sarah, we had to do a long drive (3.5 hours each way on a good day, over 5 hours on a day with heavy traffic). We knew that if we tested positive on arrival, we wouldn't be allowed to see her; she would be devastated, and we faced a long drive home. In order to try and minimize the risk of this happening, we didn't go out among people at all during the two weeks before we went to see her. I took this matter up with John's Campaign in May 2021, as it seemed the Covid guidance was written as if all families lived 5 minutes away from their relative's care home; when in fact working age disabled people (like our daughter) often live in a specialist care home hours away from home. Eventually the guidance was changed so that Covid tests could be done at home before families set off.

50. If we wanted to visit Sarah, we'd ask when the Visitors' Centre was free – the first free slot was often after approximately two weeks. We could only book another slot, after the visit. Given the length of our drive, we could only book slots from noon onwards (to give us time to get there – I could not get up at 5 - 6 am; and be able to drive safely on the motorways late at night on the way back, due to delays). My husband had to take time off work, and we would spend the entire day travelling in order to spend one hour with Sarah.

51. Sarah was so shy during the first half an hour of each visit that we were often unable to speak to her for a big part of our visiting slot. Then, when it was time to leave, she'd scream, "Don't leave me!" Sometimes she ran to our car screaming. The staff told us, she cried for two days after a visit. One time, in March 2021, I couldn't visit because I was having the Covid vaccine, and knew if I had a temperature, they would turn me away. My husband therefore went on his own. The staff told us after my husband's visit that Sarah was crying inconsolably, saying she was missing both of us and wanted

to go home. They asked us to have her home – we had never been keen to put her through 14 days isolation in a flat on her return, but we agreed.

52. The first slot they had for isolation for 14 days on her return was in June 2021 – so she still had to wait another 3 months to see us normally (i.e. without the PPE / behind the screen). They also asked us to book another monthly slot for a visit on April 1st. Thankfully, the government changed its guidance in the meantime, and we were able to take her out for the day from May 2021.

53. The visiting restrictions meant Sarah had only four one-hour visits with us from November 2020 until May 2021.

54. Sarah did not have to self-isolate after we took her out for the day from May 2021 onwards, but we had to fill out a form about where we were going to take her and with whom. We had to promise to keep her outdoors, except to use toilets indoors. We couldn't do any 'risky' activities, i.e. activities that involved close contact with other people, or we would have to tell them on her return. We had to take a picnic, in order to avoid restaurants / cafes. We had to do a test at the care home before we could take her out. I suspect but don't know Sarah was also tested on her return. This did not apply to what they considered 'high risk visits' like to a hospital. She would have had to do 14 days' isolation, if we had had to take her to hospital or any other setting deemed to be 'high risk'. We and Sarah had had two Covid vaccinations by this time.

55. We had to follow this process until November 2021. From then onwards, we could do lateral flow tests at home before we set off, and send the care home photos of the test results. They stopped requiring parents to do lateral flow tests before going to the care home in September 2022, unless symptomatic.

56. It's my belief that human beings are social animals and need physical contact with each other, as part of emotional support. As a result of her conditions, Sarah is never going to be able to maintain a meaningful relationship outside our family, and really, we are the only people who can give her a hug and the emotional support she needs. It was heartbreaking that for 6 months we could only see Sarah behind a Perspex screen or on a computer screen (as set out below) – we couldn't ever give her a hug, even if she was crying her eyes out to us. Sarah and I have always had an incredibly close relationship. I missed seeing her regularly – it was like a knife twisting in my heart.

Essential care givers

57. When the Covid guidance introduced the idea of essential care givers, I asked the manager of Sarah's house, if I could become an essential caregiver for her and set out my justifications for that –that Sarah needed emotional support from me, in view of her history of marked emotional problems. I never got a reply from her and did not pursue the issue further as I worried that this would impact Sarah's care at the house.

58. I found the fact that access was still significantly restricted into 2022 very frustrating when many people had had two Covid vaccines / were testing, especially because I felt that I could provide valuable input into Sarah's care and could provide her with important emotional support.

Alternative arrangements made to stay in contact

59. As we couldn't see Sarah much, we set up Skype and spoke to her with assistance from care home staff 3 times a week. The care staff stayed in the room with Sarah throughout the conversation. The calls took place in a small computer room and we could hear the staff typing notes during the calls. Sarah persistently asked us when she could see us. We were informed by care staff that she left the calls upset and deflated. We felt that the calls did not meet Sarah's needs for emotional support and worried that they were harmful to her mental health.

60. Sometimes we could see Sarah laughing and joking with the care staff at the beginning of calls, then as soon as I went on phone/Skype with her, she used to burst into tears – she often didn't tell the care staff if she was in pain or somebody had upset her. She saved it all up for me. In my opinion, it was about levels of trust - she knew she could trust us, and we had always done our best to sort out her problems for her (although we didn't always succeed).

61. We felt uncomfortable about the fact that all of our calls with Sarah were listened to. We considered that it did not give our family necessary privacy and made it very difficult for us to try and establish closeness with Sarah. It has always been very important to us to maintain a close relationship with Sarah, to ensure she feels able to be open with us, and we felt that having monitored calls instead of proper in-person contact, including privacy, was severing our close relationship with our daughter.

62. In February 2021, I started sending Sarah custom-made postcards with one of our photographs to cheer her up – I could use emojis and symbols to improve her comprehension, although the staff probably read them to her as well. I used to send one about midway between visits. She was very proud of them, and used to show them to us on Skype, waving them around in front of us for several minutes! When we were able to access her room after the Pandemic, we found out that she used to prop them up around her bedroom.

Access to appropriate care and quality of care during the pandemic

63. It was difficult for us to monitor Sarah's care and whether / how it had changed as a result of the IPC measures in place as we weren't allowed into her house for 2 years. We were given weekly updates about what activities she had been doing, her diet, and which staff member had been looking after her. However, in the weekly updates during the pandemic the updates sometimes stated "shared" for the carer looking after Sarah which I assumed meant that she was not getting 1:1 care due to staff shortages.

64. The care home used to do annual reviews of Sarah's care plan with us from 2017 - 2019. They didn't do an annual review in 2020 or 2021, so I didn't see the care plans in place for those years - they just told me one time, when I was visiting, that her care plan allowed her out to play football (as set out above). The next annual review of the care plan was January 2022, where the focus was on her mental health and my husband and I were involved.

65. I realised when I saw Sarah's blood test results in 2021 that she had very high cholesterol. I raised her diet with the house manager on various occasions in 2021. When I brought it up again in January 2022 at the annual care review meeting, the house manager's response was along the lines of 'you have raised it many times'. I therefore asked the GP to refer Sarah to a specialist clinic, where she was diagnosed with genetically high cholesterol. They recommended she have a low fat diet. I saw from the weekly updates that Sarah was getting high fat food. I raised this with the house manager, who took no notice. I commissioned an independent dietitian to analyse Sarah's diet in the care home and at home in March 2022 and received a report in May 2022. She told me Sarah's diet in the care home was totally inappropriate for someone with high cholesterol. She produced a 20 plus page report of her dietary recommendations for Sarah but the reports and advice subsequently given continued to be ignored by the house. We continued to raise this throughout 2022-2024.

66. Later in 2022, Sarah was diagnosed with Hartup disease, as she had been part of a major genetics research project. She was referred to the metabolic unit at a hospital. They recommended a high protein, low fat diet for Sarah with plenty of iron, calcium and vitamin D. The house took no notice and refused to seek advice from either the local dietitian service or hospital on what steps to take. In 2024, the Independent Care Board required the care home to get advice from a hospital and analyse Sarah's nutritional intake daily, but this only led to temporary change. There was another annual review of the care plan in January 2025, including Sarah's diet, with us, the Independent Care Board (ICB), the dietitian at the hospital, and various people from the care home. Sarah's nutrition and the plan in this regard has finally been adhered to since that meeting but it took a very long time. I was repeatedly encouraged (including by the ICB) to make a complaint against the care home regarding their failure to address the concerns relating to Sarah's diet, but I was worried that this would lead to the care home kicking Sarah out.

67. We also found out later that Sarah was not being supported by the care home to use an Augmentative and Alternative Communication Aid (AAC) (this was software on Sarah's I-Pad). I understand that this was in part because the care home's speech and language therapist went on maternity leave. It was later assessed by the ICB that the care home should have obtained an independent speech and language therapist's assessment of another AAC, suitable for Sarah.

68. When we got copies of Sarah's care records in 2024, there was a section on "safeguarding". I noticed one of the entries was that Sarah had been left in her incontinence pants for 16 hours – Sarah wears them, because she is incontinent during seizures. This must have been very unpleasant and degrading for her. I believe this was due to the staff shortages, as per the paragraph below.

69. When we reviewed the care records for the pandemic in 2024, it became clear to us that Sarah faced significant neglect during the pandemic. There were shifts when no carer was allocated to look after her, even though her condition puts her at high risk of death from seizures. On one occasion, a member of the care staff recorded having heard her crying in her room, beside her vomit after being left alone. We only found out about this in 2024, from the safeguarding concerns, in the care records. Staff had expressed concerns about Sarah not having an allocated worker for particular shifts. Sarah would not have known to change her incontinence pants, how to do personal hygiene and possibly get dressed, without prompting. Her 1:1 carer was responsible

for ensuring she received and ate her meals, so she would have gone hungry without their presence. This is particularly concerning in circumstances where hunger is a major trigger for her seizures. The response from the house manager was that Sarah should always have an allocated worker, and she should not have been left on her own for long periods, due to her mental health. However, it happened more than once.

70. I also felt that there was insufficient communication about Sarah's medical care during the pandemic. On one occasion we found out belatedly about a scan that occurred after they found an abdominal mass, although this had cleared by the time of the scan. We were also not allowed to attend meetings with the consultant neurologist until January 2022, even though this could have been arranged virtually and were excluded from certain best interest meetings concerning treatment for Sarah's epilepsy, despite the fact nobody understood her condition and complex treatment history as well as we did. I complained over the telephone to the onsite doctor, and eventually, we were given further information, but information had to be demanded, it was not readily shared.

Communication and issues raised with the care home

71. The house used to transmit their messages via email to parents but in my view didn't consider what it would be like for parents to receive the messages. So, for example, we'd get a vague and meaningless email saying the house was going into isolation. As it was an email, there was no opportunity to ask why – did residents and staff have Covid? Did Sarah have Covid? We and her twin sister were very worried. I had to send emails asking for clarification which the care home then responded to.

72. We researched PPE and bought FFP2 masks throughout the pandemic. We considered that FFP3 masks offered the best protection but due to the shortages in provision of masks, we thought it was best for us not to push for FFP3 masks; we felt we should leave the limited supply for medical / care professionals, who were in close contact with Covid patients and at greater risk of catching Covid. I brought up the use of FFP2 masks versus the surgical masks the staff were using with the registered manager[5]. The registered manager just said they had considered it. The staff only ever wore surgical masks, throughout the whole pandemic. One of the team leaders caught

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[5] I only brought up the use of FFP2 masks with the registered manager, as I knew if every care home in the country tried to obtain FFP3s, that could impact on medical professionals trying to obtain them, for themselves.

Covid after sharing a car home with a colleague after work. I can only assume they were not wearing masks; but even if they did wear masks, they were likely surgical masks.

73. When the Covid guidance was changed to allow staff working on their own with a person with learning disabilities and communication difficulties not to wear masks, I asked the registered manager, if our daughter's care workers could take their masks off in her room. She told me that they could not have our daughter breathing Covid over the other residents in the house and that it would not be possible for them to remove masks.

74. When Sarah caught Covid in April 2022, she thought it was a cold, and the staff let her believe that. She was isolated in her bedroom for 10 days. She was in tears to me, about 8 days later, because she felt so tired. I told her she hadn't had a cold, she had Covid. The advice is with people with language disorders "Don't lie to them, because they won't trust you, if you do!" We don't lie to Sarah and she trusts us. In our experience the staff at the house overestimate Sarah's ability to understand language but underestimate her non-verbal intelligence. Sarah understands concepts if they are explained to her in a simple and straightforward way. I complained to them that they had lied to Sarah about having Covid. They said they had asked my husband, and he said it was alright. However, he does not have the understanding of Sarah or her language disorder that I do, so it was a shame that they hadn't asked me.

75. When a resident in Sarah's house with more severe learning disabilities caught Covid, the staff told us they could not isolate her in her bedroom for 10 days because she displayed challenging behaviour, so they had cordoned off parts of the communal rooms for her. I thought this was ludicrous for an airborne virus and felt it was unfair that Sarah had been required to self-isolate, but this resident was not being required to do the same. I felt that the approach put Sarah at risk and also failed to recognise the impact self-isolation had on her.

76. I tried to raise my concerns about this with the care home. Other specialist care homes repurposed their old, disused houses for Covid positive residents so I suggested that the Covid-positive resident use such a dwelling so that others could have access to the communal rooms, like the kitchen, dining room and lounges. I asked the registered manager if they could do the same as the other specialist care homes, because there were disused houses on site. She told me "Oh we couldn't do that, with our young

people!" I think she meant that circumstances at other care homes were different. However, in my view their client group was exactly the same as the other specialist care homes – I knew because I had visited all of them, and Sarah had lived in 2 of them at school!

77. In April 2022 Sarah told us she objected to the lateral flow tests done at the care home. We knew this was likely, as we had a hard job to do them on her – and she will do more for us, than she will for other people. I sought the advice on Mencap, who considered it was assault, if people with learning disabilities were making it plain, they didn't consent. I didn't end up following this up with the care home as Sarah then had a bad fall during a seizure in May 2022, broke several bones and we were preoccupied with her recovery.

My experience of DNACPR notices

78. In March 2020, I received a letter from the GP surgery asking us to confirm our preferences in relation to a DNACPR for my daughter (see **Exhibit SL/02 [INQ000612649]**). No discussions were had with me or my daughter prior to this. When Sarah first saw Covid reported on the television, she had asked me what Covid was. I explained it was like flu, but some people died from it. She burst into tears, saying "I don't want to die, and I don't want you to die!" I took this to mean that she did not consent to a DNACPR. We were concerned that a DNACPR might be applied by doctors without us knowing after hearing reports about this on the news.

79. The first time I received the letter from the GP practice, if I recall correctly, I wrote back stating that we didn't agree with a DNACPR being applied to Sarah until she had a terminal diagnosis – then we were prepared to discuss it.

80. Despite this, the next year, the GP practice sent us another form about a DNACPR (see **Exhibit SL/03 [INQ000612650]**). I was shocked and horrified about this. The form also asked us, if Sarah became ill, did we want her to stay at the care home "for comfort care" or did we want her to be taken to hospital for treatment? While the care home had oxygen for use during seizures or SUDEP, I doubted they had enough to deliver oxygen 24/7 to a Covid patient if necessary. We didn't want Sarah dying due to lack of oxygen. As far as I know care homes are not trained in palliative care, and we were concerned about the suggestion that Sarah should receive such care there. I was extremely concerned that potentially inadequate care was being suggested and

considered this to breach Sarah's rights, including her right to life under the Human Rights Act 1998. My family and I were understandably very upset, particularly because we were not sent any similar request for any other member of our family. My husband for instance was in a high risk group and over 60. Nobody tried to discuss a DNACPR with him. We were very concerned that the suggestions had been made because of Sarah's learning disability; and that any DNACPR would stand as a proxy for "no treatment for anything".

81. I sought advice from Mencap, who took the matter up with NHS England ('NHSE') (see **Exhibit SL/04 [INQ000612651]**). The Parliamentary Human Rights Committee held a meeting in July 2022 and Mencap brought this issue up[6]. Mencap told me, the Learning Disabilities Team for the North West had a meeting with the GP practice to agree on more acceptable wording in future letters. Mencap also told me that I could just ignore the letters about DNACPR in future.

82. NHSE eventually sent out a letter in March 2023 to medical professionals and practices regarding the use of DNACPR for people with learning disabilities and/or autism (see **Exhibit SL/05 [INQ000612652]**). I didn't hear any more about it.

83. I would like to see recommendations made that in future for people with learning disabilities, the senior clinician involved with the patient should have the discussion with the patient at their level (with Easy Read, symbols or whatever visual support they need, if necessary) and with their family when they have a terminal diagnosis, as part of end of life care planning – and not before!

The pandemic's long-term impact on my daughter and our family

84. I believe the treatment, the social isolation, lack of meaningful activities and close contact with us for years had a long-lasting impact on Sarah's mental health. She was extremely unhappy during the pandemic in the care home – frequently on Skype in tears to us; and to the staff (as they reported to us in the meetings in January and February 2022). She became far more verbally and physically abusive to the care staff and us. We looked at other care homes for her in 2021 and 2022, nearer to home – but could not find one which could meet her needs; and had a place for her. The ICB later asked the care home why it had not obtained a mental health assessment of her

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[6] INQ000499428, see paragraphs 32-36

during the pandemic and its aftermath – the care home had mental health nurses onsite. The ICB had a number of conversations with the care home about Sarah's mental health. A mental health assessment of Sarah was done belatedly in April 2024. We all wondered why it had not been done during the pandemic, when the care home was having meetings with us in January and February 2022, about Sarah's mental health and behaviour.

85. Sarah’s language and social skills deteriorated massively in my opinion, due to not getting reinforcement of her vocabulary, through hearing the words every day, and lack of social interaction. As set out above, she went for 2 years or more without an AAC to help her communicate her wants and needs.

86. After spending 2 years indoors, Sarah didn’t want to go out as much as she had pre-pandemic – we and the house find it very difficult to get her to go out now to do activities. In fact, she gets quite verbally abusive, if we press it. Her fitness went downhill – she is puffing and panting during leisurely walks with us. The most she could walk after the Pandemic was about 1 mile. This will impact on the number of her seizures, and therefore speed up the cognitive deterioration, and the potential osteoporosis.

87. Sarah had always been continent, except during seizures. She mainly wants to stay in her room in the care home now and won’t even use the toilet there. She prefers to use her continence pants instead. Every time, she comes home now, we have to prompt her every 2 hours to try to use the toilet – after a few days, she recognizes the signals and will use the toilet without prompting. We take her back fully continent; and next time she comes home, we have to start all over again.

88. Pre-pandemic, Sarah would rather have stuck pins in her eyes than miss a meal. The only time she ever missed a meal, was when she was too sick to eat – about once every 10 years! During 2021, she started refusing the odd meal, but by 2022 she frequently only had two meals a day at the care home, which is particularly concerning because hunger is the main trigger for her seizures. At home, she has three meals a day, the vast majority of the time. In 2024, she had on average seven seizures a day at the care home, and two at home – I believe the main cause of this is hunger!

Conclusion

89. One consultant neurologist told us in Sarah's teens, that we were the best people in the world to get her the help she needs. We knew if we took Sarah to hospital with Covid, the doctors might well have refused to treat her, saying she had learning disabilities; but we would have argued for her life as hard as we could. I was always worried that a care worker would probably have just accepted whatever the doctors said without question. My concerns about the lack of proper engagement with Sarah's needs and the need for us to advocate for her were confirmed by the information that was revealed by her care records after the pandemic and even in more recent examples (like the example referred to regarding the fracture in her leg at paragraph 11).

90. Sarah always was a special person to us, and even now, after significant deterioration, she is still witty and perceptive. For us, with regard to Sarah, the pandemic was hell – we saw her, operating at about the level of a 2-year-old (in terms of her behaviour and ability to cope), prevented from having meaningful contact with her family; denied access to activities all other "normal" young people her age could do, like going out to the pub, restaurants, cinemas, ten pin bowling, etc; struggling to hear what people around her were saying (except us at home), and struggling to express herself.

91. It seemed like nobody except us was looking at the big picture. Sarah's risk of dying from SUDEP was 1 in 50. By way of comparison, according to the Q Covid risk calculator, after the first vaccination, her risk of dying from Covid was about 1 in 16,000. After two vaccinations, it was 1 in about 21,000. The IPC measures and impact of the pandemic on staffing levels and care quality put her at even greater risk of cognitive deterioration, mental health problems, challenging behaviour and dying from the epilepsy, due to measures supposedly put in place to protect her, but which in fact made her epilepsy worse, over what was for her just an exhausting cold. I have never knowingly had Covid, so the precautions, we took at home to protect Sarah might have worked, without causing her the suffering. Had she lived at home throughout the pandemic, she would not have qualified for CEV status (she didn't when she was living with us), so why this obsession with protecting her in the care home without any regard to the circumstances and her specific needs?

92. I would like the government to take on board as a result of this Inquiry, that young people in good health with learning disabilities generally are not units of flesh and blood

to be warehoused within four walls to protect them from a virus. People are social animals and need emotional support from their families and friends. The restrictions that were applied were inhumane and failed to consider the impact they had. Modern thinking focuses on "person centred care" and yet young people with learning disabilities were treated with blanket policies designed for older care home residents, with no regard to their physical, emotional and mental health, or anything their families said.

93. The rights under the Human Rights Act 1998, including the right to life, apply just as much to people with learning disabilities, and yet during the pandemic, the rates of death among the disabled were higher than the "normal population" and while some of this was probably due to underlying health conditions, I can't help but think that some of this was due to the tacit attitude that people with learning disabilities were second class citizens, and NHS resources were wasted on them. My daughter has a very hard life. I don't know how she copes with it – but she loves life, and her life is just as important to her, as it is to "normal people"!

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: 05/19/2025