

Witness Name: Lesley Jean Moore

Statement No. 1

Exhibits: None

Dated: 13<sup>TH</sup> June 2024

## UK COVID-19 INQUIRY

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### WITNESS STATEMENT OF LESLEY JEAN MOORE

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1. My full name is Lesley Jean Moore and my date of birth is the **Personal Data**  
I currently reside at **Personal Data**  
and I am currently a full time carer to my adopted son, **Personal Data**  
who was born on the **Personal Data** I have known him since he was 18  
months old and he came to me full time at three and a half years of age.
2. I make this statement at the request of the Covid-19 Public Inquiry Module 3 Legal  
Team and I confirm that this statement has been taken over the telephone by  
Shane Smith, a Solicitor of Slater & Gordon (UK) Limited who I understand is  
assisting Kim Harrison, a solicitor in the same organisation and who is the  
Recognised Legal Representative for Clinically Vulnerable Families (CVF) who are  
Core Participants within Module 3 of the Covid-19 Public Inquiry. The matters  
stated in the following paragraphs are true to the best of my knowledge,  
information and belief.
3. In order to understand my experience, it is first necessary to understand the  
complex health needs of my son, **PD** Due to complications at birth,  
**PD** has had complex cerebral palsy from birth. He has dystonic cerebral  
palsy on his left hand side which causes him to have involuntary movements and  
spasms. He also suffers from spastic cerebral palsy on his right hand side which

causes tightening of muscle tone which causes problems with his positioning and this has an impact on his breathing and general health. Due to him being 'nil by mouth' he has to be gastronomically fed which means that all his nutrition goes through his stomach peg, including medicines. From around the age of 17, he now also has obstructive sleep apnea and as a result wears a CPAP mask (continuous positive airway pressure) overnight that helps maintain his airways at night so that they don't collapse. He sleeps on his stomach on a specially designed sleep system which puts his hips at a 45 degree angle which enables his CPAP mask to remain on and it also inhibits his patterns of involuntary movements. If he was to sleep on his back, he would remove his mask due to his involuntary movements and have difficulties managing his secretions. It is also necessary, at day and night, to provide oral suction to clear secretions as he is unable to do this for himself and without intervention it could put him at serious risk of death. Therefore, he receives two forms of suction interventions: maintenance suction, which is a general and intermittent clearing of secretions produced and then emergency suction which is where he has lost control of his breathing and his airway is obstructed by thick secretions and he could die if there was no intervention. What further complicates **PD** situation is that he is non-verbal and very hard to read unless you know him and then you are able to understand his emotions and what his involuntary body movements are telling you. As you can see, even before the pandemic **PD** health issues render him extremely vulnerable and he is at a higher risk of a poorer outcome if he was to contract an illness and become unwell. It is paramount that I do all I can to keep him safe and as healthy as I can.

4. **PD** is highly dependent and has a lot of needs that require a substantial amount of continuous care and assistance. I live at home with **PD**, it is just the two of us, and at present to assist me I have two paid personal support workers (paid for through his Personal Health Budget) who provide assistance to **PD** roughly two to three nights per week for around 12 hours each shift. Although I provide the majority of care to **PD** they help tend to **PD** needs. Due to his complex health conditions, it takes around 9 to 12 months to train a personal support worker to a sufficient level where they understand **PD** his emotions, and his needs. It is always a requirement that there are two staff members present with **PD** at any one time and crucial that he is not left on his own, or with

only one personal support worker, especially if they do not understand him, with the exception of myself who is the only person able to provide 1:1 care. [ PD ] needs to be observed at all times. [ PD ] also attends a day centre four days a week.

5. Due to his poor health, it has always been a worry that he might contract a respiratory illness because this would put him at serious risk of worsened health and potentially death. The reason why him contracting a respiratory illness is so much of a concern is that when he coughs he cuts off his airway which stops him from breathing, which can lead to life threatening complications. It also increases his involuntary movements which make it very hard to manage his body and can cause him a lot of pain. The thought of [ PD ] catching a coughing disease or virus was worrying because he would be at a greater risk of a poorer outcome than most because of his vulnerabilities and he might even die.
6. In early 2020, I was watching the news and the scenes from around the world about this respiratory type virus that was affecting populations, causing widespread illness and that was resulting in a high number of deaths. I became fixated on watching the news and understanding what was happening because of my concerns over [ PD ] and how he would cope if he were to contract such an illness; I knew it would not be good for him.
7. Around the 9<sup>th</sup> or 10<sup>th</sup> March 2020, I was sat outside [ PD ] college (which he regularly attended for four days each week, with three days being funded by Education and one day by Social Care) listening to Michael Rosen, a well known children's author, who was talking on Radio 4 about Covid-19. He was explaining that when it came to Government's response to saving lives in the face of this killer virus, the elderly were not going to be prioritised and they would be ignored, and that they were effectively '*lambs to the slaughter*'. It made me think, and emphasised my feelings, that those who had complex health needs and who were clinically vulnerable were going to be treated in exactly the same way. They would not be prioritised because there was a lack of understanding by politicians of the difficulties faced by families like mine and also their lack of value of sons like mine.

8. Weighing up all the information and lack of information, and my knowledge of [ PD ] vulnerabilities, I made the decision myself to pull [ PD ] out of college, which I did on 11<sup>th</sup> March. I decided that the best place for him to be would be at home with me where I could control his environment and minimise the risk of him contracting this nasty illness. The way we had been treated before the pandemic by the Government gave me no hope that we would be high up on the list of priorities, since they had no understanding of the needs of those who had complex health needs and who would be the most vulnerable to the bad effects of Covid-19. They also did not understand what support would be needed to help keep someone like [ PD ] safe.
9. At the very start of the pandemic, before the national lockdown, I had made clear to his personal support workers' my concerns about Covid-19 and the risk to [ PD ] but neither seemed as concerned or as worried as myself about covid. For example, one of the workers had to rely on various family members to look after their child so that they were able to fulfill their contractual hours with [ PD ] This caused me concern because the child was frequently going between different households increasing the risk that they would contract Covid-19, which would be passed on to their parent who could then potentially bring Covid-19 into our household, and infect [ PD ] This worker was also working other shifts in a care home. The other worker was still shopping and being social and again this increased the likelihood that they would contract Covid-19 and pass it onto [ PD ] The risk became far too great, and it was not a chance I was prepared to take. There was a lack of decision from the Government on a lockdown despite Covid-19 having reached the UK. I would often watch the news in disbelief that no one in Government seemed to be taking this seriously. Therefore, I decided to tell both of the personal support workers not to come to work and so for the first 4 months of the pandemic I was the sole carer for [ PD ] tending to his every need day and night, and continued to pay the workers their wage.
10. I should not have been in such a position that I was having to think for myself and take decision on what was best for [ PD ] to keep him safe without any support and/or guidance from the Government. When the decision by the Government was made to lock down, I had already done so myself and had cut ourselves off from

the outside world, to keep [ PD ] safe. The days before I took [ PD ] out of college I had been out and bought food and supplies to last at least a month, which was very fortunate as we were late being put on the clinically vulnerable list.

11. In June 2020, I invited the personal support workers back when the weather improved but only on the basis that they and [ PD ] would sit in the garden and monitor him outside. I required them to wear masks if they needed to get close to [ PD ] for any intervention whatsoever. When the weather was poor they did not come into work. During the Autumn they worked indoors with windows open and FFP3 masks on. This continued until the December when we entered the second lock down and then I again told them not to visit and I was once again [ PD ] sole carer for 3 months.

12. In around summer 2020, the personal support workers went to the hospital to be fit tested for FFP3 masks and when they returned I realised that their masks had valves on them which meant they were breathing out *their* air and therefore not protecting [ PD ] the masks were only protecting them from contracting Covid-19 and not protecting [ PD ] from getting it from them, if they were infected. Concerned by this and given what I had read about masks I was forced to buy my own FFP3 masks without the valve and insist that they wore those instead so that it minimised the risk to [ PD ] from contracting Covid-19. I later relaxed on this and would also allow a FFP2 mask to be worn. However, this was a clear example of the Government failing to understand the risks and how to protect people like [ PD ] from falling ill with Covid-19. They did not understand the mitigations that they were putting in place and it was only because of my understanding, from reading a number of articles and the like, that I had some understanding of how what the nurses were being fitted with were offered little or no protection to [ PD ] This lack of understanding could have cost [ PD ] his life.

13. There was a lack of understanding in the community of the impact of Covid-19 on those like [ PD ] For example, on one occasion I found two personal support workers sat in my house with [ PD ] without masks despite my insistence that they wore them when around him. It was concerning because you had to rely on honesty and the staff for seeing Covid-19 for what it was rather than what the Government and media were saying that it was. They did not appear to appreciate

the risks or how they were exposing [ PD ] to a serious risk of poor health, or worse. There was inconsistent messaging about how you could pass on Covid-19 or how you might contract it and this in part may be responsible for the lack of understanding shown by the staff. I had a covid guidelines list for staff which I updated when necessary, which included things like open the outside doors every 30 minutes to provide fresh air throughout the ground floor, eating their meals one at a time, and only by the open back door or on the balcony outside, weather permitting.

14. During the pandemic hospital visiting restrictions and nosocomial infections were deeply worrying for me and the constant concern of not being allowed to accompany [ PD ] into hospital, as his primary care giver who knows and understands his needs like no other, if he were admitted to hospital, was a constant worry and concern. His unique needs and his actual physical moving and handling required detailed knowledge and constant attention, which simply would not be adequately provided for in my absence. Therefore, I would choose to care for him at home with the permission of the doctors, if the need arose.
15. My main concern was that if he was within a healthcare setting where it was full of people who had Covid-19, that he would contract the virus and it would make him seriously ill and the concern being that he would not come out the healthcare setting alive. This was not a risk I was prepared to take and I had no confidence that [ PD ] would be kept safe in a healthcare setting because there was a lack of understanding of how Covid-19 was spread, what protections were needed to stop you from getting it and how at risk someone like [ PD ] was, this was a massive worry for me, so much so that I would have been incredibly reluctant for [ PD ] to go into hospital.
16. One of my concerns around healthcare settings stems initially from the initial messaging and belief was that covid was passed on only by touching things when it was obvious that it could also be passed on by breathing out and breathing in, it wasn't rocket science. I was a strong believer in the mask theory. My concern was that it wasn't being taken seriously enough and as a result I was reluctant to allow [ PD ] to attend any healthcare setting, in order to keep him safe and help him survive through the pandemic. I became that concerned that we may need to leave

the house that I managed to persuade wheelchair services to authorise and fund a medical physics worker from the hospital to come to us and help us design a special wheelchair mask that enclosed [ PD ] whole head like a transparent space mask so that if [ PD ] did have to go anywhere, for health/physical reasons, he could put it on and it would, in theory, keep him safe. Though thankfully we never needed to put that to the test because we now know that Covid-19 can be passed through the air and that particular mask wouldn't have helped in the way that we were being told it could. However, it was left to me to think of those types of protections and to be proactive in developing them to help keep [ PD ] safe.

17. Early on in the pandemic the ventilation team at our hospital that [ PD ] was under had requested the return of any spare CPAP machines or feed pumps. Given [ PD ] reliance on these life sustaining machines, and our past experiences with equipment failure, the request felt like a direct threat to his safety. In the end I believed that without a spare it would put [ PD ] at a greater risk of health complications and so I decided that the only way to help ensure his survival should his primary device fail was to ensure that I kept a spare CPAP machine and did not respond to the request. I did not have confidence in the system and if I had returned the spare CPAP machine but then needed it again I did not believe I would have got it back. This demonstrates a lack of resourcing and an understanding of the needs of people like [ PD ] and the practical issues that we face.
18. Around July 2020, I remember discussing with a group of parents who were in a similar position to me, a letter that I had received which suggested a DNACPR be put in place for [ PD ] This experience was particularly harrowing. I do not recall the exact contents of the letter, nor do I still have a copy of it, but I recall that the letter implied that in a critical situation, life saving measures might not have been taken for [ PD ] which is something I vehemently opposed. It had been suggested elsewhere that such a decision might be made for him without consent and this caused me a lot of concern and fueled my reluctance to have [ PD ] admitted to any healthcare setting should the need arise.
19. It felt like the state were imposing the DNACPR on [ PD ] because he was a burden and it would be easier to let him die than to save his life. The idea that his

life was less valuable due to his health conditions was both heartbreaking and infuriating for me. Though I no longer have the correspondence I did not respond and at no point consented for there to be a DNACPR in place. At no point did I have any discussion with a clinician or Doctor responsible for [ PD ] care about his health, his health complexities and why it would be beneficial for there to be a DNACPR in place. I was also not given a reason as to why that needed to be put in place at this time, given how much [ PD ] would need to rely upon the hospital in his moment of need if he became so unwell with Covid-19, it was clear that they would just give up on him and without any consideration had decided that his vulnerabilities meant that he was not capable of being saved. I did not respond and was shocked that this was being dealt with by way of letter sent to me at home without warning; this was very upsetting. I felt that if [ PD ] turned up at hospital as one of four people needing a bed on an Intensive Care Unit, and there were only three beds, he wouldn't be the one chosen to get one.

20. Fairly early on in the pandemic, I had to proactively chase for [ PD ] clinically extremely vulnerable' status from the local GP. It was being communicated by Government that those who were clinically extremely vulnerable were required to shield and that precaution needed to be taken to keep those people safe, so much so that we were not allowed to leave our homes. This meant that we needed help with everyday tasks such as shopping and picking up prescriptions. However, we did not receive any letter and I had to chase this because we needed assistance and would not be provided with this assistance until his status was confirmed. It was like we were being told that we were so at risk that we couldn't leave our homes but then the administration delayed us being recognised as a clinically extremely vulnerable household so there was a period of time in which we had no assistance with shopping delivery slots, for example, to ensure that we were able to receive food and drink to help us survive through shielding considering that unlike others we were required to shield for longer and adhere to stricter rules. It seemed to take some time for the practical impact of shielding to take effect and the Government should have foreseen this and taken action to avoid this because it caused me anxiety and frustration.

21. I was doing everything to cut down our chances of contracting covid. Even when we were out of shielding and able to leave our home, we were not leaving the



house. We were not going to the cinema or going out like we usually would have, despite the Government telling us it was safe to do so. They didn't appreciate that those of us who were clinically vulnerable were still at risk, Covid-19 had not gone away and at a time when they were relaxing precautions they were doing nothing to reassure us that people like [PD] were safe.

22. In summer 2021, we had an additional personal support worker who stayed overnight in a tent in our back garden, one night a week so that he could provide two days support to [PD]. He was staying over in a tent to help minimise the risk of transmission to [PD]. He wasn't using public transport at the time and I was requiring him, and other staff to lateral flow test before they came into the house. I also made it a requirement that they had to open the windows and doors every 30 minutes and I had an air monitor to help monitor [PD] environment.
23. I was doing all I could to stop the virus getting in because my concern was if Covid-19 did get in and [PD] fell unwell with it that he would have a much poorer outcome because of his health conditions but also because it had seemed the Government had written him off and would not do all they could to save him. Furthermore, because of the DNACPR letter, I had reduced confidence in healthcare settings and that further compounded the reason why I did not want [PD] going into hospital.
24. I was determined to see him survive through the pandemic, despite no assistance from the Government. It felt, at times, like there was only me who understood [PD] and the risks to him and only me who was doing all I could to keep him safe. Then to further compound that worry, I had anxiety thinking that if he did become unwell no one would save him.
25. As a consequence of stopping taking [PD] to his college, he did not attend for a period of 18 months. He could have continued a little longer but because he was so vulnerable it wasn't worth the risk. Because he is so high risk, I wanted to keep him as safe as I could and felt that I had no alternative but to keep him at home. When he was eventually able to go back, after he had his first vaccination in February 2021, he was unable to because the support staff at the college had been allocated to other people with needs which meant [PD] would be unable to

receive the one to one care and attention from a support worker. [ PD ] is officially 1:1 but there needs to be a second person in the same room who knows and understands [ PD ] to support him adequately. This was down to a lack of resourcing.

26. [ PD ] eventually went back to his college in September 2021, so he did not attend for around 18 months. Since he was unable to attend he received none of his usual physio, no speech and language therapy sessions and no occupational therapy that he was entitled to and in need of, during that period and I had to do the best I could. This was not thought about by the Government i.e how someone with complex needs would still continue to receive such care during a pandemic and if they were to receive it, how it could be done safely given his status as clinically extremely vulnerable.
27. As a result of the pandemic, there was no real physical change in [ PD ] The college had sent home some programmes for him to do and that coupled with my own experience in dealing with those with complex learning difficulties and health issues, I was able to assist him the best I could to keep him mobile and moving, managing his postural and health needs, his communication skills and learning.
28. Crisis hit when the wheelchair that [ PD ] uses to get around broke within the first few weeks of lockdown. I contacted the wheelchair services through the hospital and they came out to the house and repaired the wheelchair in the garden outside and then disinfected the wheelchair and left it outside for a period time before I then took it in the house. This was a positive experience because it showed that care was being taken to provide services to [ PD ] by staff who understood the risks to him and were taking all steps that they could to minimise the risk of transmission of Covid-19 to him, I really appreciated that.
29. In terms of [ PD ] mental health he was struggling with being inside all the time. When we were required to shield and in the period before that when I had kept [ PD ] at home because I felt I had to, it was difficult for him because he liked getting out and seeing other people and being around others. This helped lift his spirits and so it was a very difficult time for him mentally. Little support was given by the Government to help combat this. In more recent times he has enjoyed

getting back to college then moving on to his day centre and around others, but it has taken years to get to the point where we feel comfortable and able to do this, though some activities we still have not. We are not going anywhere indoors unless absolutely necessary for his health because the risk to him still remains high.

30. In relation to my own physical health, the pandemic made it really hard because of the additional support I had to provide to [ PD ] We stopped going to see my horse in case I brought Covid-19 home or in case [ PD ] touched anything which may have been touched by someone who had Covid-19. It was physically demanding and draining because there were periods when I was not receiving the same support from the personal support workers because I feared the risk of them bringing Covid-19 into the house, so I had to do everything myself pretty much 24 hours a day 7 days a week on my own, and that was tough. This was a difficult period made worse by the lack of understanding by politicians who didn't seem to have an idea of what the impact on vulnerable people was by making them shield to extent that we had to, especially when rules were relaxed for others, and the fact that we were being expected to provide care for those who we supported without additional support from the Government made this harder.
31. My mental health really struggled during that period. I was angry that I was being left to struggle without support and paranoid by the misinformation that was being communicated and apparent lack of understanding of the virus and how it was transmitted, and how to keep someone like [ PD ] safe. There appeared to be a reluctance by some to take Covid-19 seriously, which further compounded the need for me to stay at home with [ PD ] to keep us both safe. When we were able to leave the house, I didn't even want to drive with the windows down because of the images I was seeing from the devastation which was being caused particularly to those who were vulnerable. I felt that Covid-19 was able to rage without any protection for the vulnerable. It was almost as if we were so low down on the list of priorities that if the virus got us, nobody would care and we would be left to die because that was a cheaper and easier alternative to trying to save someone like [ PD ] and to keep the most vulnerable and at risk people safe. I remember with disgust it being reported in the news that former Prime Minister Boris Johnson saying that he would rather see '*bodies pile high*' than put the country into a third lockdown.

32. Overall I would describe my experience during the pandemic as being a negative one. The pandemic really brought home how vulnerable we are with a Government who has no understanding or who has shown no willingness to understand those who are clinically vulnerable and those who have complex needs, in particular when it comes to the impact of the decisions that they made on people like [ PD ] Added to what is already a hard life because a lack of services, support and funding when we really needed to count on the Government they were not there for us. It really brought out in glorious technicolor that [ PD ] costs too much money to the state and people like him are seen as a hindrance. He is nothing more than a wheelchair and we were made to feel like we had no support to get through an incredibly difficult and challenging period in our lives.
33. I want to share my lived experience with this Public Inquiry so that it is understood how difficult it was for a clinically extremely vulnerable household like mine to survive with little support and little understanding by the Government on the impact of their policies and guidance on people like [ PD ] They were saying that they were aiming to keep those most clinically vulnerable safe but then no thought was given as to how practically we would be kept safe and what the practical impact of their decisions meant for the clinically extremely vulnerable households.
34. I hope that if there is any learning from this it is that those who are clinically extremely vulnerable and those that have complex health needs are prioritised by the Government and healthcare services as a top priority and recognised as a group of people that need to be protected and supported more so than those without a clinical vulnerability, through such a difficult health crisis.

**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:** 13/06/2024