

# OPUS2

Scottish Covid-19 Inquiry

Day 47

May 14, 2024

Opus 2 - Official Court Reporters

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1 Tuesday, 14 May 2024  
2 (9.45 am)  
3 THE CHAIR: Good morning, Mr Stephen.  
4 MR STEPHEN: Good morning, my Lord. The first witness this  
5 morning is Michelle Morrison.  
6 MS MICHELLE MORRISON (called)  
7 THE CHAIR: Good morning, Ms Morrison.  
8 Right, when you're ready, Mr Stephen.  
9 MR STEPHEN: I'm obliged.  
10 Questions by MR STEPHEN  
11 MR STEPHEN: Could you confirm your full name, please?  
12 A. My name is Michelle Morrison.  
13 Q. Your age and contact details are already known to the  
14 Inquiry so I won't ask you for those. You've helpfully  
15 provided a detailed written statement already to the  
16 Inquiry and for the record that reference is  
17 SCI-WT0414-000001. Are you happy for that statement and  
18 the oral evidence you give today to form your evidence  
19 to the Inquiry?  
20 A. I am.  
21 Q. Are you happy for that to be recorded and published?  
22 A. Yes, I am.  
23 Q. Thank you. Everything you've said in your statement  
24 will be taken into account even if we don't cover it in  
25 oral evidence today.

1

1 A. Okay.  
2 Q. The last thing to mention, before I start asking you  
3 some more questions, is there is a restriction order in  
4 place, so please don't name any specific individuals  
5 when you're giving your evidence, whether it's a staff  
6 member or family member or whoever it happens to be.  
7 A. Okay.  
8 Q. I'd like to ask you first about your role in the  
9 organisation that you are representing today.  
10 I understand you are a national development director for  
11 PAMIS, Promoting a More Inclusive Society?  
12 A. That is correct, I am, and I've been in that role for  
13 the last year or so, and I was a family support service  
14 director with the organisation prior to that.  
15 Q. How long were you a family support service director for?  
16 A. I was in that role for about 18 years before becoming  
17 the national development director, and 22 years  
18 altogether.  
19 Q. What does that role as a family support service director  
20 involve?  
21 A. So there's quite significant levels of support that you  
22 give individual families who are caring for people with  
23 profound and multiple learning disabilities. That can  
24 range depending on the individual family's needs. So we  
25 have families who care for people who are very young

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1 right through to people who are older adults, so that  
2 covers lots of different ages and stages of needs. So  
3 it might be educational support, it might be with  
4 social work, it might be through the health sector, it  
5 might be about how people access inclusive lives, it  
6 might be about housing issues; a whole range of  
7 different types of support that families needed, and  
8 that was our role within family support.  
9 Q. Is there a typical family that you deal with or ...?  
10 A. No, there's a very large range of families, so despite  
11 the fact that we fall under the label of "profound and  
12 multiple learning disabilities" or "profound  
13 intellectual and multiple disabilities", whichever label  
14 you would like to use, actually there's quite a spectrum  
15 of people within that. So we have people who may well  
16 be wheelchair users, for example, full-time wheelchair  
17 users, who have very limited function, through to some  
18 people who have got a bit more grasp of using maybe one  
19 or two words of language, who maybe will be able to move  
20 around and whose function may be a little bit higher.  
21 So that also impacts on the type of support that we give  
22 each family because they're very different and diverse.  
23 Q. I think in terms of the support you offer, you talk  
24 about dealing with, I suppose, the serious stuff but  
25 I think you also try and have fun as well; is that fair

3

1 to say?  
2 A. Yeah, there's --- a really important part of the service  
3 is about how we try and not only manage some of the  
4 crisis situations that come up for families but also try  
5 to allow people to have a life as well, and one of the  
6 big things about our organisation is recognising what  
7 inclusive activities actually are because they are so  
8 limited for people in the general community.  
9 So it's about how we make storytelling, arts,  
10 crafts, being out in speedboats, whatever it is, and try  
11 and make families recognise that there are things out  
12 there that they can enjoy and have fun doing. So that  
13 was a really important part of our job, and allowing  
14 families to come together; and the support that that can  
15 offer as well, that peer support is really integral too.  
16 Q. I notice at paragraph 11 of your statement you talk  
17 about all the different age ranges of those that you're  
18 dealing with with PMLD, to use the shorthand, but  
19 I think you also continue to support families even when  
20 they lose a person who they have been caring for with  
21 PMLD; is that right?  
22 A. Yeah, absolutely. The caring role is so intense for our  
23 families, every minute of every day is devoted to the  
24 person that is being cared for, so when that person  
25 dies, there's a huge loss. There's a huge loss of

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1 identity in terms of how you fill your day, how you move  
 2 on and how you cope with that grief. Because lots of  
 3 services are specialist, you also lose contact with  
 4 those specialists as well, so not only does the person  
 5 die but all of the connections that you had related to  
 6 that person disappear as well. So it's really important  
 7 for us to recognise that loss and how to help families  
 8 to stay connected and stay connected to people that  
 9 understand as well. So we will quite often allow those  
 10 families to join us in various different activities that  
 11 we're holding, but over the last number of years we've  
 12 also tried to hold a memorial service as well, once  
 13 a year, just to allow those families to come together  
 14 and, again, that support that's there to share that  
 15 grief and loss as well.

16 Q. Thank you. I think I heard you say that you've been  
 17 working for PAMIS for 22 years; is that right?

18 A. Yeah.

19 Q. What was your professional background prior to joining  
 20 PAMIS? What were you doing before that?

21 A. I started off my professional career as an occupational  
 22 therapy assistant, working in a long-stay hospital, so  
 23 that was working alongside people who had a range of  
 24 different learning disabilities, and latterly in my time  
 25 there it became more focused on people with profound and

5

1 multiple learning disabilities. We had an increasing  
 2 number of those people who came to live in the hospital  
 3 in which I worked because there had been closures of  
 4 other long-stay hospitals.

5 From there I developed that passion of recognising  
 6 the joy that people with profound disabilities can bring  
 7 to life and had the great fortune to then work in  
 8 a learning disability service that was very specific to  
 9 profound disability. It was a day centre that was set  
 10 up by families who absolutely recognised the lack of  
 11 resources that were there for people with profound  
 12 disabilities. So it was very small, very  
 13 family-orientated, allowed me to build on those skills  
 14 of activity that I had developed within the long-stay  
 15 hospital, and support not just the individual with  
 16 profound disabilities but starting to recognise what the  
 17 issues impacting families as carers were as well, and  
 18 from there moved to PAMIS, so it just felt like a very  
 19 natural progression.

20 Q. It sounds it, yes.

21 I wanted to turn now to ask about postural care.  
 22 That's a key theme, I think, that emerges from your  
 23 written statement. At paragraph 18 you say that you're  
 24 one of the main people within PAMIS working on that  
 25 subject. I think, as you just said, perhaps that was

6

1 a natural fit, given your background in occupational  
 2 therapy, would you say?

3 A. Yeah, absolutely. Working in the long-stay hospital, we  
 4 were a part of — because I worked in the occupational  
 5 therapy department, we were very closely linked with the  
 6 other disciplines, so physiotherapists, speech and  
 7 language therapists and dietetics, and we regularly  
 8 would come together as a multi-disciplinary team,  
 9 especially for people who had more profound  
 10 disabilities, and look at some of the issues that were  
 11 affecting those individuals. When I then moved to work  
 12 in a day centre, it was in the same local area in which  
 13 those professionals within the long-stay hospital  
 14 worked, and as part of their community role they would  
 15 work with the people that I worked alongside in the day  
 16 centre.

17 So my whole working career has been very much around  
 18 how we support individuals with a profound disability to  
 19 maximise their functional capacity, and posture and  
 20 positioning play are a really important part of that.  
 21 So I think, when the opportunity came up within PAMIS  
 22 for us to host a workshop around posture and  
 23 positioning, it was something that I in particular felt  
 24 really interested in because of my background and it was  
 25 something that just made so much sense. But it's also

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1 something that we recognise is not intuitive, so it is  
 2 something that people need to learn. They're not  
 3 necessarily just going to understand that we need to  
 4 protect someone with a disability's posture and  
 5 positioning. We maybe think a little bit about how we  
 6 protect our own, but we don't necessarily think about  
 7 all of the implications that arise for people who have  
 8 a disability.

9 Q. Thank you. Yes, I noticed that in your statement at  
 10 paragraph 17 you mention PAMIS holding a first postural  
 11 care workshop I think as early as 2010/2011 with  
 12 families and every year thereafter, so a long-held  
 13 project or passion you might say?

14 A. Yeah, and it started off very much as several areas of  
 15 the organisation would hold a workshop with specialists  
 16 who came along to chat to families, but from that  
 17 families were then saying, "We want to know more about  
 18 this". So their relationship with physiotherapists and  
 19 occupational therapists up until that point would be  
 20 very much the therapist delivered the information or  
 21 support or intervention to the individual and families  
 22 wouldn't necessarily do much at home. But what we were  
 23 learning through these workshops was actually posture  
 24 and positioning is about a 24-hour picture, it's not  
 25 just about the half-hour or hour that the

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1 physiotherapist is actually in the school or in the day  
2 centre, and actually the implications of how they lie  
3 has a huge influence on how our body changes and  
4 distorts if we have a disability and that was something  
5 that families had never heard before. So they were  
6 really keen to do something to change that and help  
7 other families to have more information around posture  
8 and positioning.

9 So from that we actually then went on to try and get  
10 extra funding because, as a third sector organisation,  
11 funding is always tight so you need to apply for funding  
12 to do specialist pieces of work. So we were able to  
13 successfully get several years' worth of funding to  
14 support postural care education and growth within  
15 several different areas of PAMIS.

16 Alongside that, families played a really important  
17 part in helping to shape what that information looked  
18 like and how they could reach other families. So  
19 families were really engaged in creating a — we've got  
20 a postural care film, we have information that sits on  
21 our website, we've got our education delivery, and a lot  
22 of that wouldn't be possible without families'  
23 intervention. So it was something that grew an interest  
24 across the organisation as well.

25 Q. Thank you. We'll come back to that education and

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1 funding in a little while.

2 At paragraph 20 of your statement you highlight  
3 postural care as a key issue — a "huge issue" I think  
4 is the way you put it — for those with profound and  
5 multiple learning disabilities. Why is that risk of  
6 postural deterioration so significant for those with  
7 PMLD?  
8 A. When most of us move around, we move in quite  
9 symmetrical movement patterns and that allows our body  
10 to function relatively well. Many of us might recognise  
11 that if we sit, for example, for a long period of time  
12 in one position or if we use the same chair every day,  
13 we will sit in a particular way and that might create  
14 some aches and pains. For somebody with a profound and  
15 multiple learning disability, who doesn't have any or  
16 very much control over their own movement, they are  
17 relying on other people to help them move and change  
18 those positions in a way that we don't think about. We  
19 just get up and move around. But there are  
20 gravitational forces that will distort an individual's  
21 body if they don't stand, lie and sit well in those  
22 symmetrical positions.

23 I had the unfortunate, I suppose, position of  
24 working in the long-stay hospital to see the true  
25 distortion that can happen to people when the right

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1 supports are not put in place, so — and that wasn't  
2 because anybody wasn't — you know, was doing the wrong  
3 thing, but 30 years ago we didn't understand those  
4 biomechanical forces and gravitational forces that we  
5 now understand cause those distortions.

6 So somebody who has a profound disability, who isn't  
7 able to get up and move around, whose muscles are weaker  
8 than ours, are at severe risk to those gravitational and  
9 biomechanical forces, and what that then causes to  
10 happen is the body to distort quite significantly. But  
11 there are pieces of equipment and there are techniques  
12 and there's understanding that helps to stop and prevent  
13 all of that from happening.

14 And that distortion can lead to quite significant  
15 health and well-being implications as well. So if you  
16 start to lean over to one side, for example, you're  
17 going to compress your lungs. That will then impact on  
18 your ability to breathe and breathe well. So we do have  
19 quite a number of people who will use oxygen because of  
20 the compression that's been placed on their lungs.  
21 Quite often, because the body is distorting, you'll then  
22 have a movement of internal organs, which means then  
23 that it can be difficult for any surgical intervention  
24 to happen, so if you don't — so say your swallow has  
25 become compromised because of your positioning, you then

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1 can't eat or drink orally so then you need a tube to do  
2 that, but actually it then becomes difficult to know  
3 where your stomach is for that tube to be put in place.  
4 So there are lots of different implications that are  
5 related to the distortion that somebody's body can  
6 experience.

7 Q. Is that distortion potentially fatal if left unchecked?

8 A. So there's certainly statistics coming out or research  
9 coming out that I've looked at, both adults with  
10 a learning disability and children and young people with  
11 additional support needs, that state that the  
12 respiratory function is a high determinant of avoidable  
13 death. And whilst postural care alone will not  
14 necessarily stop that respiratory function issue, what  
15 it will do, if good postural care is put in place, is  
16 make it easier for somebody to breathe, make it less  
17 likely that somebody will have issues with their swallow  
18 and will prevent a chest infection or pneumonia. And  
19 it's the chest infection and pneumonia that are quite  
20 often the contributing factors to that respiratory  
21 function that causes death. So absolutely it could  
22 potentially contribute to be life-sustaining.

23 Q. I think you touched on this in one of your answers  
24 a moment ago, but outside the pandemic, how would you  
25 ordinarily manage or mitigate that risk of postural

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1 deterioration in someone with PMLD? What would you  
 2 require to manage that?  
 3 A. There would be lots of equipment, lots of knowledge and  
 4 lots of hands—on support. So in a 24—hour picture,  
 5 you're talking about every way that you sit, lie, stand  
 6 and move being monitored by somebody who supports you,  
 7 whether that's your family carer, whether that's your  
 8 physiotherapist, your occupational therapist, your  
 9 teacher, your classroom support, your day service  
 10 worker, your personal assistant. All of these people  
 11 will be key to helping make sure that every position  
 12 that you adopt during the day is maximised to allow you  
 13 to have best function and most protection from that  
 14 distortion.  
 15 Alongside those people and the hands—on knowledge,  
 16 you need bits of equipment as well. So it might be  
 17 things like ankle—foot orthotics, which are a splint  
 18 that help hold your foot in a certain position; it could  
 19 be a specialist wheelchair; it could be hand or leg  
 20 splints that try and minimise some of the contractors;  
 21 it could be thoracic support that's on your wheelchair.  
 22 So lots of different types of equipment will support  
 23 that as well, but you need the knowledge to understand  
 24 why you need the equipment, if that makes sense.  
 25 Q. It does. Thank you.

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1 I think at paragraph 30 you make the point,  
 2 don't you — the wider point — that postural care is  
 3 important not just for those with PMLD, it can apply to  
 4 other conditions as well?  
 5 A. Yes, so anybody that has a difficulty with their  
 6 movement that is — and the more significant that  
 7 difficulty with your movement, the more likely you will  
 8 start to experience some distortion and how your body  
 9 manages itself if the right supports aren't put in  
 10 place. So certainly some of the regressive conditions,  
 11 like motor neurone disease, multiple sclerosis, there is  
 12 a chance that you will start to develop some distortion  
 13 related to the lessening ability to move around. If you  
 14 live with cerebral palsy, you will be at risk. And  
 15 again, the more affected you are by your cerebral palsy,  
 16 the more at risk you are to your body distorting.  
 17 Historically, that has been thought of as being an  
 18 inevitability, that your body will change, but I think  
 19 increasingly interventions that have been provided,  
 20 primarily by physiotherapists and occupational  
 21 therapists, are highlighting the fact that actually we  
 22 can do something to slow down that regression. So  
 23 learning disability are quite far ahead in the field, if  
 24 you like, compared to some other organisations, in  
 25 understanding the issues that are related to that

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1 postural distortion, and that's why the postural care  
 2 strategy that was created in Scotland was such an  
 3 important document because it helped take what we were  
 4 learning within learning disability and look at other  
 5 people who were at risk, you know, like older people.  
 6 The more you are reduced to sitting and lying as well,  
 7 the more of an impact that distortion potentially has on  
 8 your body as well. So the creation of that strategy was  
 9 recognising that this was wider than just learning  
 10 disability and profound disability.  
 11 Q. Thank you. We'll come back to that strategy in  
 12 a second. At paragraph 6 of your statement you say that  
 13 in 2020 you yourself were in I think — a transitional  
 14 stage is the way you put it, moving away from directly  
 15 supporting families — you'd obviously been a family  
 16 support service director previously — to focus more on  
 17 protecting the body shape of those with PMLD. Why that  
 18 change at that time?  
 19 A. I think it was just a fortuitous time where we had been  
 20 building up the knowledge and resources we'd been  
 21 creating within the organisation. We were in a real  
 22 push and momentum. Our families were behind us. We had  
 23 very good support from a number of families across the  
 24 organisation who wanted to drive change across the  
 25 country. So what we were potentially seeing were

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1 pockets of really good work in some areas but not  
 2 consistently across the country.  
 3 So the funding that we were looking to apply from —  
 4 for and were successful with the Alliance, that one  
 5 day's worth of funding, was to try and reach some of the  
 6 areas that PAMIS didn't have a family support service so  
 7 that we could try and influence the knowledge growth for  
 8 those families and also work alongside the allied health  
 9 professionals in those areas to help create those really  
 10 positive relationships that support postural care.  
 11 Alongside that we had been building up and  
 12 networking our contacts of interest in postural care  
 13 across Scotland as well, and so we were starting to  
 14 connect with allied health professionals in third sector  
 15 organisations who were also really interested in  
 16 postural care and we were all coming together really to  
 17 try and change how we address that as a country and try  
 18 to create some standard and consistency in what people  
 19 were receiving, regardless of what led to your need for  
 20 that postural care support.  
 21 So the work with NHS, the specialist board, it came  
 22 around because they recognised the benefit in having  
 23 that consistent support across the country. So that  
 24 allowed us to start writing that strategy. So I think  
 25 it was just a very fortuitous position that was building

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1 on the momentum that we had been building across the  
2 organisation in relation to postural care.  
3 Q. Thank you, because at paragraph 7 of your statement  
4 I think you talk about those kind of two strands of  
5 funding; I think, as you say, on the one hand Health and  
6 Social Care Alliance in respect of education for  
7 families around postural care and moving and handling,  
8 which we'll come on to later, and secondly funding from  
9 NHS Education for Scotland to support the writing of the  
10 strategy that you mentioned.

11 I want to ask you now about that strategy. You've  
12 touched on it a little bit already. You say at  
13 paragraph 7 that you were the lead author of that  
14 postural care strategy for Scotland. Was that as part  
15 of a strategy group? And I would ask you, without  
16 naming any individuals, where were the members of that  
17 group drawn from?

18 A. Yeah, that was part of a group. It was the connections  
19 that we had been making within PAMIS for the couple of  
20 years preceding us coming together as a strategy group,  
21 and that was — it had people who had represented allied  
22 health professionals in particular across a number of  
23 different territorial boards in Scotland, primarily  
24 physiotherapists and occupational therapists who were  
25 sitting on that, and they covered a range of services,

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1 so children and young people's services, neurological  
2 development, learning disability.

3 We also had some third sector organisations and we  
4 had family carers, so it was quite a wide breadth of  
5 representation that sat on that strategy group, and  
6 I think at the time that we were a strategy group  
7 before, you know, the strategy itself was launched,  
8 there were maybe about 15 to 20 of us that were quite  
9 regular attenders to that group.

10 Q. You touched on this already to an extent, but what was  
11 the catalyst for this strategy being created?

12 A. I think the wave of families in PAMIS who were  
13 interested was a really dynamic push on changing things.  
14 I think that allowed us to have slightly different  
15 conversations across some of the territorial boards in  
16 which we were working and connecting, being able to say,  
17 you know, "Families are saying we need to do something  
18 different, families are suggesting that we need to  
19 listen to them so that we can change and grow and do  
20 something a little bit differently to how things have  
21 been done before".

22 So it was certainly a challenging period of time  
23 I think in trying to influence and inspire and persuade  
24 people to come together, but I think that was  
25 definitely — something that helped drive it forward was

18

1 the dogged determination that families within PAMIS had  
2 to make a difference and our responsibility then  
3 organisationally to try and make that happen, so to kind  
4 of keep pushing at doors and keep asking for people to  
5 become involved; and a willingness amongst practitioners  
6 to change as well and be a part of that kind of  
7 pioneering approach, I suppose; and how we did something  
8 differently because it was very much a co-produced piece  
9 of work, which is something that is quite unusual, yeah.

10 Q. And at paragraph 60 of your statement you say that the  
11 writing of that strategy was paused, I think, due to the  
12 pandemic. I think you talk about the NHS Education for  
13 Scotland having to focus on COVID-19 education. But you  
14 were asked instead, was it, to write educational  
15 resources at that time, while that was down tools on  
16 that, or what were you asked to write about at that  
17 time?

18 A. So there was a recognition that postural care could  
19 potentially support the respiratory function of people  
20 who had movement difficulty and particularly if they  
21 were experiencing symptoms of COVID-19, so thinking  
22 about people in care homes, for example, that  
23 NHS Education for Scotland had the ability to reach out  
24 and get information out to, they were really keen that  
25 we were able to create something quite specific that

19

1 talked about how we could potentially maximise that  
2 respiratory function in particular to help alleviate any  
3 of the issues that might come alongside COVID-19.

4 As much as I was saying postural care was  
5 something — it's something that's a huge part of our  
6 organisation, but we are still — the conversation  
7 around it is still very small in Scotland and so there  
8 are lots and lots of people who don't know about it, and  
9 I think this was one way that NHS Education for Scotland  
10 thought we could really capture some ideas around how we  
11 could potentially alleviate some of the suffering  
12 potentially that people would experience, yeah, and just  
13 try and do something that was a bit more proactive.

14 And I think some of the thoughts around how we  
15 breathe and how we would best manage if we had a chest  
16 infection might be slightly different if you're somebody  
17 who has a profound disability, for example. If you ask  
18 somebody with a profound disability to sit up and  
19 they're not supported, then they will entirely compress  
20 their lungs and therefore their respiratory function  
21 will decrease quite significantly, and actually that  
22 could be quite detrimental. So even just in some of the  
23 language around that information was thinking about,  
24 well, actually, is there — you know, what position is  
25 this person best in to maximise their oxygen levels and

20

1 maybe we need to be monitoring that. So it was a — it  
 2 felt like a — again, it felt like quite a privileged  
 3 position to be asked to put that forward on behalf of  
 4 the strategy group. So that was something that PAMIS  
 5 led on but the strategy group very much supported the  
 6 writing of that at that time.

7 Q. You go on to say, I think, that the strategy itself was  
 8 launched in the summer of 2021. Would the  
 9 Scottish Government have been aware of the formulation  
 10 of that strategy when it was going on?

11 A. Yeah. So Scottish Government were very influential in  
 12 the whole process of the strategy from the chief allied  
 13 health professional a good number of years ago, back  
 14 in — I think it was maybe 2017/2018. It was through  
 15 their support that the strategy progressed and was able  
 16 to become a document. So Scottish Government were very  
 17 much a part of that strategy group and the creation of  
 18 working together, co—productively, and listening to  
 19 those families' voices as part of that whole process.  
 20 So, yeah, they were very heavily involved.

21 Q. Thank you. I think at paragraph 62 you talk about the  
 22 real excitement in writing that document. What was it  
 23 you hoped to achieve with it being published?

24 A. I think we just wanted everybody to know that postural  
 25 care was really important to the health and well—being

21

1 of so many people. This document has the ability to  
 2 help practitioners best support individuals who have  
 3 a movement difficulty which can have huge impact on the  
 4 health and well—being of individuals. You know, I think  
 5 within our organisation at PAMIS, we're able to see  
 6 a number of families where either the child or young  
 7 person is less likely to experience distortion or hip  
 8 dislocation or some of those issues that were — that  
 9 would very much have been classically seen in people  
 10 with profound disabilities, and knowing that there was  
 11 that potential to influence practitioners to give them  
 12 a way of working that could include individuals and the  
 13 people who cared for them in their healthcare and  
 14 understanding of postural care.

15 I think one of the things that we talked about  
 16 earlier is that postural care is not intuitive. You  
 17 need to know what it is in order to help you best  
 18 understand how to maximise somebody's movement  
 19 throughout the day. And just knowing that we could  
 20 potentially capture that through the strategy, it felt  
 21 like such an influential position to be in, to change  
 22 the lives of a projected significant amount of people  
 23 across the country.

24 Q. And were you also looking perhaps for a consistency of  
 25 approach across Scotland as to how you look at that

22

1 issue?

2 A. Yeah, very much. The document itself is broken down  
 3 into three ambitions and one of those ambitions is very  
 4 much around how the person who has a movement difficulty  
 5 sits right at the heart of any decision around  
 6 interventions. So it was a very different way of  
 7 working to maybe how some of these services had been  
 8 delivered historically.

9 Q. Thank you. At paragraph 65 of your statement I think  
 10 you expressly mention the Scottish Postural Care Forum  
 11 as maybe a lasting legacy of that strategy, if I can put  
 12 it that way. What does that forum continue to do on the  
 13 subject of postural care?

14 A. So currently we are trying to oversee the implementation  
 15 of the 12 or 14 recommendations that sit within that  
 16 strategy. We have just recently launched six modules  
 17 that sit on NHS Education for Scotland's TURAS platform,  
 18 and that enables anybody across health and social care  
 19 to access those modules and build on their knowledge of  
 20 what postural care is all about.

21 We're currently working with a range of different  
 22 practitioners across Scotland to look at how measurement  
 23 is carried out of people who — particularly of people  
 24 who have a learning disability. Historically people who  
 25 are linked to a physiotherapist will be measured to

23

1 check and monitor any distortion that might be happening  
 2 with their bodies but there isn't really a standardised  
 3 way of doing that. Different services will do that in  
 4 different ways, so they're currently looking at how they  
 5 can make that a standardised approach.

6 We are always trying to look at ways that we can  
 7 increase the voice around the importance of postural  
 8 care, what it's about, why we would need to be  
 9 interested in it, and we're currently looking at  
 10 a Postural Awareness Day. So there's lots of different  
 11 things. I suppose everybody who sits on that forum  
 12 comes voluntarily. There's no extra — you know,  
 13 there's no cover in your post, back—fill cover, if you  
 14 like, to come, so everybody who comes volunteers to do  
 15 those extra things to help move postural care forward.

16 Q. Before I move on, the recommendations that you  
 17 mentioned, are those still to be fulfilled, partly  
 18 fulfilled?

19 A. Yeah, they're still to be fulfilled. There's a number  
 20 of them that we are probably well on our way to having  
 21 achieved, but I think it's fair to say that the impact  
 22 of COVID has slowed down a number of those  
 23 recommendations being put in place. There were  
 24 recommendations around equipment, for example, and we  
 25 know that that kind of has stalled quite significantly.

24

1 There was a recommendation about how we could work  
2 better with health and social care partnerships and  
3 territorial boards, but they're still in a state of flux  
4 really since the impact of COVID, and so that has become  
5 much more difficult to progress as well. So, yeah,  
6 there's definitely some of those recommendations that  
7 feel a little bit further away than they did when the  
8 document was being written.

9 Q. Thank you. I wanted to move on then to the impact of  
10 postural deterioration during the pandemic. At  
11 paragraph 82 of your statement, you say that around the  
12 end of 2021, I think, when some normality at least was  
13 coming back, PAMIS was starting to receive enquiries  
14 about postural-related issues and equipment. Who was  
15 getting in touch with you and what were the issues that  
16 they were raising at that time?

17 A. There were a range of different families getting in  
18 touch, from children and young people through adults,  
19 from people who were wheelchair users to people who had  
20 mobility. So there was a range of different issues  
21 cropping up for folk. I think maybe by the time we got  
22 to that normality kicking in, people or families were  
23 maybe less in that kind of panicked stage of trying to  
24 manage everything that had been going on during lockdown  
25 and maybe starting to look at things in a slightly

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1 different way to what they had done previously because,  
2 you know, our services were starting to open back up.

3 What they were starting to see was bits of equipment  
4 had maybe been outgrown or needed to be maintained or  
5 changed or had been overused and worn out and were no  
6 longer meeting the postural support needs. So if  
7 somebody can't use that alternative bit of equipment,  
8 that does have quite a big impact on how else you manage  
9 your life. You know, if somebody is a wheelchair user,  
10 you pretty much only have the ability to lie or to sit,  
11 so if your wheelchair, for example, is not supporting  
12 you as well as it could be, then you don't necessarily  
13 have another alternative to get out of the house.

14 So these pieces of equipment can be quite integral  
15 to the function of somebody with a profound disability.  
16 So we were starting to get enquiries about some of that  
17 equipment having failed or needing to be maintained or  
18 it having been outgrown. But there were also other  
19 issues cropping up where — so some people maybe who had  
20 been mobile gaining weight because they weren't moving  
21 around as much, they weren't at the services and the  
22 activities that they had been previously. That gaining  
23 weight then meant that it was more difficult for them to  
24 walk around the way they would have been able to  
25 previously and, if they were able to — I'm thinking of

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1 one young man in particular who was able to move around  
2 but he needed physical support to do that. He was then  
3 putting lots of extra weight on to his carer to be  
4 supported to walk around, so that had quite  
5 a significant impact on his postural deterioration as  
6 well because of his leg positioning.

7 There's also — several families reported having  
8 issues with tightening of muscles and I think, you know,  
9 if we all sat for quite long periods of time and maybe  
10 we didn't exercise and we tried to touch our toes, we'd  
11 probably feel that quite tight down the back of our  
12 legs. And we don't necessarily see any of those changes  
13 physically when we look at ourselves, but quite often  
14 when we look at people with profound disabilities, that  
15 muscle tightening happens quite quickly and is really  
16 noticeable when, for example, the person comes out of  
17 their wheelchair and lies either on their bed or on the  
18 floor because they're not able to stretch their legs  
19 out. So when you then try to stretch that leg, so say  
20 you're helping the person get dressed, that can be quite  
21 painful and cause a lot of discomfort, and if that  
22 tightening remains and isn't stretched, then that's when  
23 you're starting to lead down that path of distortion as  
24 well.

25 Q. When you were receiving these queries to PAMIS, were

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1 your family support service directors able to do  
2 anything about the issues that they were being told  
3 about?

4 A. It was becoming quite difficult to navigate the systems  
5 of support that had been there previously. Even where  
6 some services were coming back to normal, there were  
7 slightly different routes and processes that you had to  
8 go down to be able to contact people. So I think it's  
9 probably fair to say that family support found it  
10 difficult to navigate where to get support from  
11 professionals that maybe would have been involved  
12 previously.

13 What they were able to do was to direct families  
14 either to myself or other colleagues, who may be able to  
15 speak individually to families and talk about some  
16 movement activities that could be done to help alleviate  
17 some of that or, for me, for example, I might have had  
18 slightly different contacts with physios or been able to  
19 try and make ways forward in a way that family support  
20 service directors might not have had the same contacts.  
21 So there was lots of conversation around us amongst how  
22 we tried to get the best information to families to  
23 allow them to deal with the — what was happening.

24 I think unfortunately it's also fair to say that  
25 what happens with that deterioration is a huge level of

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1 guilt for families as well because they then start to  
 2 blame themselves for that deterioration happening.  
 3 I think especially at that time, when there were no  
 4 other interventions, there were no other people coming  
 5 in to support, families were having to try and manage  
 6 lots of different things that were going on and so there  
 7 was a lot of guilt around some of that distortion, and  
 8 that in itself can then make it — not necessarily  
 9 distortion but tightening — and that in itself can make  
 10 it difficult for you to look for help because you feel  
 11 that it's your fault that that's happened.

12 Q. Thank you. At paragraph 81 you mention the redeployment  
 13 of physiotherapists and occupational therapists.  
 14 Did you receive feedback about the impact, if any, that  
 15 that was having on those with PMLD?

16 A. Yeah, it was a really difficult period of time for  
 17 families. So I think they kind of felt abandoned, that  
 18 the usual person that they would pick up the phone to  
 19 wasn't there. I think things happened so quickly that  
 20 lots of those physios and occupational therapists that  
 21 families would have had a connection with didn't have  
 22 time to say, "This is where I now am" or "Here is where  
 23 to connect with me" or "Here is who you can get in touch  
 24 with because I'm not here". None of that was put in  
 25 place so it was really difficult for families to start

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1 to make some of those connections and contacts.  
 2 But what physios and OTs were trying really hard to  
 3 do, the people who were left — because I think in some  
 4 departments there was like one person left to kind of  
 5 man the department — so they were trying really hard to  
 6 let folk know that they were there, if they could offer  
 7 support. But that in itself is limited as well in what  
 8 they were actually able to do. Sometimes they weren't  
 9 working from their usual bases. So I think social media  
 10 played a part in trying to create some of that support  
 11 for families, but it was really difficult to get — it  
 12 was really difficult to get tailored and individual  
 13 information for families.

14 Q. Thank you. In your view, should these issues, postural  
 15 deterioration issues for those with PMLD or indeed  
 16 others, have been foreseen by the Scottish Government as  
 17 a result of the restrictions that were put in place as  
 18 a result of COVID?

19 A. I would love to say yes, it should have been. It should  
 20 have been. I mean, certainly it's something that our  
 21 organisation have been talking about for a long time.  
 22 It's something that's known across lots of AHPs, again,  
 23 physios and OTs in particular, because things like  
 24 school holidays — there are always deteriorations that  
 25 we see during a school holiday time, whether that's

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1 a long summer break or whether that's a fortnight at  
 2 Christmas. When people are out of their usual routines  
 3 of types of support that they receive in day centres or  
 4 schools, then you can start to see — you start to see  
 5 deterioration.

6 So I would love to say that they should have been  
 7 aware of that, but whether there were just so many other  
 8 conflicting things going on or things that seemed to  
 9 have a higher priority — and maybe postural care just  
 10 hasn't quite captured the importance that it should  
 11 have.

12 Q. Because, yes, at paragraph 105 of your statement I think  
 13 you say:

14 "I do not think I could say that the importance of  
 15 postural care would be understood if there was another  
 16 lockdown tomorrow."

17 Why do you hold that view?

18 A. I think even though it's something that, as an  
 19 organisation, we are incredibly passionate about, we  
 20 acknowledge that everybody that our organisation  
 21 supports is at risk of their body shape deteriorating  
 22 and that we have a number of carers who wholeheartedly  
 23 agree with us, we still haven't got that message out to  
 24 all of the families that we support and we still do see  
 25 some of those distortions and deteriorations happening

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1 even where families do know and understand. So I think  
 2 even within our organisation, we know that it's an  
 3 important message but we haven't reached everybody, and  
 4 even though I know that I'm involved heavily in the  
 5 strategic work that's happening across the country,  
 6 sometimes I think those practitioners that are involved  
 7 in that feel a bit like a lone voice within their  
 8 departments and their teams and their organisations.

9 And so I think it's just — even though we know it's  
 10 really important, I think it's not recognised. I think  
 11 everybody really needs to go through that educational  
 12 process to understand why posture changes and the impact  
 13 that that has on an individual to truly then start to  
 14 recognise the importance of postural care. And if you  
 15 don't go through that process, I think it's really  
 16 difficult for people to grasp. But it fundamentally  
 17 underlies almost every other issue that an individual,  
 18 certainly an individual with profound disabilities, will  
 19 experience. Whether it's a respiratory function,  
 20 whether it's the function of their arms or their legs or  
 21 their head control or the way that they eat and drink,  
 22 all of that fundamentally is supported by good posture  
 23 and positioning, but it's really difficult to get that  
 24 message across to people.

25 THE CHAIR: Perhaps that's why you're here today or at least

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1 one of the reasons why you're here today. You say it's  
 2 very important and you've presented a very persuasive  
 3 case why it is, presumably because you want us to think  
 4 that it is --  
 5 A. Yes.  
 6 THE CHAIR: -- that's not a criticism at all -- and to  
 7 possibly make recommendations; is that fair to say?  
 8 A. Yes, it definitely is.  
 9 THE CHAIR: Understood.  
 10 A. Thanks.  
 11 MR STEPHEN: I'm obliged.  
 12 Yes, if there was a lesson to be learned then -- and  
 13 we are obviously as an Inquiry interested in what  
 14 recommendations can be made. You mentioned education --  
 15 what would you suggest is the lesson or lessons to be  
 16 learned here? If postural care wasn't sufficiently  
 17 taken into account during the pandemic, what would you  
 18 suggest?  
 19 A. I think education is such a huge part of how we can make  
 20 change in relation to how people understand postural  
 21 care. We have a huge health and social care workforce  
 22 and lots of those people will come into contact with  
 23 somebody who has a profound disability. If you start to  
 24 understand how best to manage some of that, then you  
 25 will see a difference in the way that somebody is

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1 supported, and the treatment or intervention or care  
 2 that you are trying to carry out, some of that will be  
 3 made so much easier and so much better if you understand  
 4 postural care.  
 5 Sadly we see situations where people have been in  
 6 a hospital situation and the team around the  
 7 individual -- you know, a couple of emergency  
 8 situations, the team around the individual have not  
 9 understood the importance of posture. Families have  
 10 tried really hard to convey the message and we've had  
 11 experiences where people have nearly died because  
 12 posture and positioning has not been carried out in  
 13 those emergency situations because those practitioners  
 14 are desperately trying to save that person's life but  
 15 they don't understand the implication of posture and  
 16 positioning in relation to their profound disability.  
 17 And that's something that we need to change. We need  
 18 people to understand that posture and positioning is  
 19 integral to so many people that we care for -- not just  
 20 people with profound disabilities but so many people  
 21 that we care for -- and I think that's something that  
 22 sits underneath all of this, is how do we better educate  
 23 our health and social care workforce.  
 24 Q. Before we move on, I was struck at paragraph 91 of your  
 25 statement -- you say that:

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1 "The damage done by COVID ... and [the] restrictions  
 2 in terms of postural care can partly be measured."  
 3 And I think in terms of data is what you're getting  
 4 at there. Could you please explain what you mean by  
 5 that, when you talk about how that might be measured,  
 6 looking back as to the impact that postural care had?  
 7 Because you talked about families feeding back to PAMIS  
 8 but this seems to be about data so what are you  
 9 referring to there?  
 10 A. Within children and young people's services, they have  
 11 a measuring system that's called the "Cerebral Palsy  
 12 Integrated Pathway System" or "CPIPS", and that sits  
 13 across Scotland. And the physiotherapists who are  
 14 working with children and young people who have  
 15 cerebral palsy or I think more recently who present as  
 16 though they have cerebral palsy will be measured to look  
 17 at something called their "hip migration". So for  
 18 children and young people who don't weight-bear -- so  
 19 a lot of those people are people who have profound  
 20 disabilities -- their hip joint will not form the way  
 21 ours does because we get up, we move around and that's  
 22 what creates our ball and socket joint. For people who  
 23 don't have the ability to get up and move around, they  
 24 will have a very flat socket, so it's very easy for  
 25 their hip to what's called "migrate" and dislocate out

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1 of that joint. And that's something that has been a big  
 2 issue in profound disability for a very long time.  
 3 This measuring system is something that keeps an eye  
 4 through x-ray on children and young people every six  
 5 months and looks at the position of that child or young  
 6 person's hip, and so it then flags up at a potentially  
 7 early stage to say there is an issue. And we don't want  
 8 it to worsen enough to get to the need for surgical  
 9 intervention, but what we do need to do is make sure  
 10 that the wheelchair is correct, that they've got a  
 11 lying(?) system for bed or various other bits of  
 12 equipment that might mitigate the issue of the hip  
 13 dislocating.  
 14 So that is a system that's been in place for --  
 15 I think maybe about five or six years that that system  
 16 has been in place, so it will have good pre-COVID data  
 17 but it will also start to produce data that happened  
 18 over the last -- or didn't happen over the last couple  
 19 of years because clinics weren't taking place, those  
 20 x-rays weren't happening. So there will be a gap in  
 21 time between pre-COVID measurements and post-COVID  
 22 measurements and so that data might well start to show  
 23 whether there have been changes or not during that  
 24 period of time.  
 25 Now, that data in itself is limited because it is

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1 only very specific children and young people who would  
2 be measured under it and it is only that hip — the hip  
3 location that is being measured, but it will give an  
4 idea of what has been happening for some people during  
5 that period of time.

6 Some therapists, physios in particular, do measure  
7 other parts of the body and there are some territorial  
8 boards who are already looking at chest measurements  
9 because that's something else that will distort and  
10 change shape as other forces come into play for people  
11 with profound disabilities. So some physiotherapists  
12 are already capturing that, but again it's not  
13 consistent across the country and that's why the forum  
14 is currently looking at trying to get a standardised  
15 assessment across the country, so that everybody is  
16 looking at the same type of data and that way we can  
17 then get a good picture of what's actually been  
18 happening. But there will be some pockets of data that  
19 will allow us to see the reality of what distortion has  
20 happened during that period of time. But certainly  
21 anecdotally, from physios and OTs as well as from  
22 families, we know that there have been deteriorations  
23 for individuals.

24 Q. Thank you. I want to move on now to the impact on  
25 family carers themselves. We've obviously talked about

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1 those being cared for but I want to focus now on carers.  
2 At paragraph 32 of your statement you say that:

3 "So many people do not understand what our family  
4 carers go through on a daily basis."

5 Again, at paragraph 53 you say that if you don't  
6 understand the complexity in caring for someone with  
7 profound disabilities you absolutely do not register —  
8 and I paraphrase here — how physically demanding all of  
9 that is. Are you able to give the Inquiry a flavour of  
10 what those demands are, even in ordinary times, prior to  
11 the pandemic, that are placed upon the families that you  
12 deal with?

13 A. Yeah, for lots of people with profound disabilities they  
14 are entirely reliant on a care-giver to manage every  
15 aspect of their life. So from the minute you wake up in  
16 the morning, you are potentially unable to alert anybody  
17 else to the fact that you're awake and that you want to  
18 get up out of bed. So families need to be aware of  
19 what's happening, and quite often they will sleep with  
20 baby monitors during the night to hear any vocalisation  
21 that might be happening, any seizure activity, any  
22 disturbance that's happening during the night, but also  
23 to alert them to the fact that the person has woken up  
24 in the morning.

25 Then what will often need to happen is that that

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1 individual will need to be hoisted up out of their bed  
2 or physically moved from their bed to an alternative  
3 position, so that will quite often be a wheelchair that  
4 the person will be transferred into. So in order to  
5 make that transfer, you need to put on a sling, you need  
6 to mobilise a hoist, you then need to attach the sling  
7 to the hoist, make that transfer, lower the person down  
8 into their wheelchair and then you can move around the  
9 house.

10 Depending on what's actually happening in the  
11 morning, you might also want that person to get dressed  
12 at that point and you might want them to go for a wash  
13 at that point. If you want that person to go for  
14 a wash, you will probably undress the person on the bed,  
15 depending on the hoisting system that you have. You may  
16 have a single track that's in your bedroom, which means  
17 you can be hoisted up out of your bed and into  
18 a wheelchair and then wheeled to your bathroom, where  
19 you then have to make another transfer to get into your  
20 bath, or you may have a mobile hoist that allows you to  
21 make that transfer from bed to bath. And you also need  
22 to be physically undressed to make that — you know, to  
23 get ready for the bath, but then you also need to be  
24 toweled and redressed once you come out of that bath.

25 Most people who have a profound disability will also

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1 wear incontinence pads, and that's something that needs  
2 to be changed several times a day. Depending on other  
3 issues that are related to the individual, whether it  
4 might be medication that they're on or seizure activity  
5 or digestive function, they may need that pad to be  
6 changed seven, eight, more, times a day. And that in  
7 itself is really physically demanding because you're  
8 then having to partially undress somebody. They are  
9 generally lying down at this point but you'll have to  
10 partially undress somebody. You then need the person to  
11 be able to stretch their legs wide apart so you can  
12 change that pad, so that can be — depending on how  
13 tight somebody is, that can be quite difficult just to  
14 manage that movement. You obviously then change the  
15 pad.

16 When it comes to eating and drinking, the majority  
17 of people will need to have something done to their diet  
18 in order to be able to manage it, so it might well be  
19 a blended diet or a mashed diet or a specifically  
20 prepared diet. So not only have you then had to make  
21 the breakfast or the lunch or the dinner, but then you  
22 also have to prepare it well for the individual.  
23 Sometimes you need to add something to it, so you might  
24 need to add a thickener or you might need to add an  
25 additive that allows it to have more calorie content

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1 because lots of people with profound disabilities are  
 2 underweight.  
 3 If you are supporting somebody who can't eat or  
 4 drink orally and they eat or drink through a tube, you  
 5 then have to go through a particular process of flushing  
 6 out the tube, preparing syringes, giving that feed. And  
 7 I've only touched on getting dressed, having a wash and  
 8 having something to eat and drink. So the demands that  
 9 are placed on somebody who cares for somebody with  
 10 a profound disability are really quite significant. It  
 11 can take half an hour to do one transfer; it can take  
 12 half an hour to get somebody dressed or undressed; it  
 13 can take over an hour for somebody to actually eat. So  
 14 these are quite intensive caring tasks.  
 15 A previous study that had been carried out suggests  
 16 that somebody who cares for somebody with a profound  
 17 disability spends between eight and ten hours delivering  
 18 just personal care tasks, like eating, drinking, getting  
 19 dressed. So, yeah, it's really quite intensive to care  
 20 for somebody.  
 21 Q. If it's that intensive during the ordinary course of  
 22 events, what were you hearing and seeing from families  
 23 as regards the impact of the pandemic on caring for  
 24 those with those needs?  
 25 A. Exhaustion and overwhelmed. It was an incredibly

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1 difficult time for families. Lots of people would be  
 2 supported. Whether it be by school staff, day centre  
 3 staff, home care workers coming in, personal assistants,  
 4 there would be --- at some point in the day somebody  
 5 would be coming in to give you a hand to some extent.  
 6 So that varied from family to family and could be quite  
 7 substantial support to minimal support, but I would  
 8 probably say all of our families had some level of  
 9 external support that came in to help.  
 10 So what you were then having was potentially that  
 11 eight-hour gap in the day where somebody would be at  
 12 school or be at a day service or be supported elsewhere  
 13 that you were then picking up all of the care that was  
 14 required during that time as well. So there were all of  
 15 those additional moves, transfers, positioning,  
 16 changing, pad changing, meals, that you weren't needing  
 17 to do generally. So families were exhausted, absolutely  
 18 exhausted.  
 19 And I think what carried people through initially  
 20 was, "This is 12 weeks, it's 12 weeks. Just let's get  
 21 to the end of 12 weeks. We can do this". And then  
 22 fatigue starts to set in because there's that --- it  
 23 becomes not knowing when it's going to end and how  
 24 do you keep going when you don't know when it's going to  
 25 end. So lots of our families would have not only the

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1 help that comes in on a daily basis or a week-to-week  
 2 basis but they would also have respite as well, so that  
 3 tended to be something that was overnight and it might  
 4 have been for more than one overnight at a time. And  
 5 that was the kind of break that allowed our families to  
 6 switch off and recharge, and that opportunity wasn't  
 7 there. So it was --- there was a real desperation and  
 8 exhaustion and overwhelm. It was --- yeah, it was really  
 9 significant.

10 When you think --- we've talked about the physical  
 11 demands, but even that moving and handling somebody, the  
 12 amount of times you need to bend and adjust and twiddle  
 13 with attachments and various different things that are  
 14 parts of equipment or wheelchairs or whatever else, it's  
 15 hugely physically demanding.

16 Q. Are there any specific examples that you were getting  
 17 from families about the physical impact upon them? For  
 18 example, at paragraph 33 you talk about the  
 19 musculoskeletal impact I think on carers. Were there  
 20 any specific physical --- I hesitate to use the word  
 21 "injuries", but at least impacts you were finding on  
 22 those caring for those with PMLD?

23 A. Yes, back, shoulder --- back and shoulder pain were two  
 24 very common complaints that families had. You know,  
 25 with the best will in the world, we would be trying

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1 really hard to encourage families to use equipment where  
 2 they had it to try and lessen that burden, but even the  
 3 demands of using that equipment --- you could be talking  
 4 about eight, nine, ten transfers a day, so even though  
 5 you are using the correct equipment, it's still really  
 6 physically demanding moving somebody to put on a sling,  
 7 adjusting somebody once they're in their wheelchair,  
 8 repeatedly throughout the day, regardless these are  
 9 really difficult manoeuvres. We have had a couple of  
 10 families where they have already had deterioration, one  
 11 in a hip joint, one in a knee joint, that was  
 12 exacerbated during the pandemic because of the amount of  
 13 physical movement that they were undertaking.  
 14 Q. Do you think the complexity of those demands, those  
 15 daily demands, was understood by the Scottish Government  
 16 in imposing these restrictions?  
 17 A. I don't think so. I think there was a recognition that  
 18 carers needed support and I think the carers policy team  
 19 in Scottish Government absolutely understood that there  
 20 were significant needs for carers and they were trying  
 21 really hard to get information out around vaccines and  
 22 various other things that were happening, but I think,  
 23 like I mentioned earlier, in terms of the spectrum of  
 24 learning disability and profound disability and just how  
 25 diverse even the profound disability community is, the

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1 caring community is diverse and people have — you know,  
2 people are carers even with relatively small tasks that  
3 they carry out.

4 So I don't think the intensity is necessarily  
5 recognised of somebody who has a profound disability or  
6 how potentially long and ongoing that is because quite  
7 often you're caring for your child. So many families  
8 will have been caring for a very long period of time and  
9 I don't think there's any of that recognition that  
10 actually you've been caring for your son or daughter for  
11 the last 30 years, you are getting older yourself, you  
12 are feeling a little bit more tired generally — I don't  
13 think there was necessarily any recognition that that  
14 was any different to anybody else who falls under the  
15 remit of being an unpaid carer, so I don't think that  
16 was recognised. I think carers were recognised but not  
17 our family carers as having a more intensive caring  
18 role.

19 Q. But presumably you think it should be better understood?

20 A. Yes, absolutely.

21 MR STEPHEN: Thank you. I wanted to move on now then just  
22 to the work of PAMIS during the pandemic. You've  
23 obviously helped those facing the burdens that you've  
24 spoken about earlier today. The Inquiry has heard a lot  
25 of evidence previously from various organisations about

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1 the pivot required from physical working to online and  
2 I don't think PAMIS is any exception to that.

3 In paragraph 35 you talk about the change from the  
4 delivery of in-person training to online training and  
5 having to upskill — I think is the word you use —  
6 family carers. What was involved in that task of  
7 upskilling and how straightforward or onerous was that  
8 task?

9 A. It was broken down into two different groups. We had  
10 family carers who were trainers and we had family carers  
11 who were delegates or participants of that education and  
12 both needed different sets of skills to be able to  
13 either attend or to deliver the education. The four  
14 family carers and the physiotherapists who were involved  
15 in delivering the education, they needed to change all  
16 of their materials and they were not able to do that  
17 themselves. So they would have previously gone out,  
18 delivered in-person training, maybe with a PowerPoint  
19 that somebody else had set up on a laptop and flip chart  
20 paper, and that's what they would have used.

21 And we — yeah, as an organisation, we needed to get  
22 all of that up online on to a Zoom platform and we had  
23 to change and record lots of material, so recording  
24 over — like voiceovers of presentations, recording  
25 families and the individual stories that they were

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1 telling, helping — it kind of seems odd now, going back  
2 to that point — but helping those who were presenting  
3 understand how to mute and unmute themselves, how to  
4 share the screen and how to — I suppose just that —  
5 you know, something that you don't get when you're  
6 delivering online — you get lots of feedback when  
7 you're in a room and you don't get that when you're  
8 delivering online, and just trying to manage that for  
9 those carers that were involved because so much of it is  
10 those side conversations or — just that general feeling  
11 of warmth or acceptance that's happening when you're  
12 sharing your stories.

13 One mum in particular talks about her son who died,  
14 directly related to the deterioration in his posture,  
15 and for her delivering that online was quite difficult.  
16 So there's lots of different ways we had to try and  
17 support those families that were involved in delivering  
18 the education. But even the families who came along as  
19 well, how to click on the link, where does that take  
20 them, the fact that they might be in a waiting lobby,  
21 what did that mean, once they actually came into the  
22 Zoom room, what could they touch or not touch.

23 Depending on what they were logging in with had an  
24 impact on how they actually came up on screen as well.  
25 So, for example, we had a family who logged in on

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1 a tablet and they were touching the screen but what they  
2 were doing was actually drawing on everybody else's  
3 screen; all of those things that we now probably can't  
4 imagine doing now.

5 So there was lots of work that we needed to do in  
6 two different ways, but lots of our families also didn't  
7 have a means to connect to that education either. So  
8 they either didn't have wifi or they didn't have  
9 a device, so other colleagues had been working with  
10 Connecting Scotland to try and fill that gap so that we  
11 were trying to — because we were mindful that, in  
12 delivering digitally, we were excluding people, so  
13 trying to be really mindful about how we tried to make  
14 it as equitable as possible for people to come along and  
15 join us.

16 Q. I was going to ask you about digital exclusion, if that  
17 was a concern —

18 A. Yeah.

19 Q. — but I think you've answered it. Do you think that  
20 gap was filled then, if that was a concern, to reach  
21 those families?

22 A. Yeah, I think the family support services directors not  
23 only were able to get devices and dongles that delivered  
24 wifi for folk but also were able to support people in  
25 their learning of how to use these devices as well, so

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1 that was a huge role that they took on too because, if  
 2 you're taking something like a tablet to somebody who  
 3 has never used one before — and I think it always  
 4 surprised me how, for want of a better expression, tech  
 5 savvy — I think that's the way I've written it in the  
 6 statement as well — some of our families actually were.  
 7 So these felt like really strange devices for a lot of  
 8 folk. So there was quite a lot of work that family  
 9 support service directors were doing to try and build up  
 10 families' expertise in using these. As an organisation,  
 11 we delivered lots of different things digitally and we  
 12 had lots of engagement from families, including lots of  
 13 those families who received equipment through  
 14 Connecting Scotland.

15 Q. Thank you. At paragraph 37 of your statement I saw you  
 16 talk about the utilisation of social media platforms  
 17 like Facebook to communicate those messages to families.  
 18 I was struck as you said you were editing or one was  
 19 editing those 30-minute videos down into digestible  
 20 small chunks. It's interesting, I think, because you've  
 21 talked about how demanding the role of carers can be and  
 22 the hours spent doing that. Was there a balance for  
 23 PAMIS to strike between trying to help those families  
 24 but also not overwhelming them at a time which I think  
 25 you said earlier was a very difficult one?

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1 A. Yeah, and I think I've already touched on the guilt that  
 2 families can feel, so there was definitely a fine  
 3 balance for us. Something that our families have very  
 4 clearly told us in the past is, "Please give us all the  
 5 information and then it's up to us to decide how we use  
 6 that information". So we were really mindful that we  
 7 wanted to make sure that we had all the information out  
 8 there but that it was shared in a way that we tried not  
 9 to put pressure on families to say, "You absolutely must  
 10 do this", but to highlight, "These are things that you  
 11 might see changing and this is what you might want to do  
 12 if you see that happening and if you're really  
 13 concerned, you know, try to get in touch with A, B  
 14 or C".

15 So there was very much a fine balance of trying to  
 16 make sure that the appropriate information and support  
 17 was there but also to recognise that families might  
 18 be — well, families were struggling. We knew that  
 19 families were — families were struggling just to meet  
 20 the day-to-day needs of the person that they were caring  
 21 for without us then putting any additional pressure on  
 22 them to fill that gap that services were no longer able  
 23 to fill.

24 I think it's also fair to say that the family  
 25 support service directors were ready to manage some of

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1 that overwhelming guilt that families were experiencing  
 2 and sharing as well and recognition that — our  
 3 anticipation that that's what would happen. So it was  
 4 that bit about how we tried to work organisationally to  
 5 say, "This is what we're going to do but this is what it  
 6 might create so let's be ready for that".

7 Q. Thank you. I think you talk about the running of online  
 8 education sessions in your statement on postural care,  
 9 which we've covered today, but also on moving and  
 10 handling, which you've mentioned in passing but I wanted  
 11 to ask you about now.

12 You talk at paragraph 51 of your statement about an  
 13 emotional link, I think, or barrier to the use of  
 14 equipment by family carers, which I found very  
 15 interesting. What do you mean by that when you're  
 16 talking about that in your statement?

17 A. Quite often when somebody with a profound disability is  
 18 born and that recognition that there is a disability  
 19 there, whether it's at the time of birth or whether it's  
 20 very close after birth, what can go alongside that is,  
 21 "Take your child home and love them because they might  
 22 not survive for very long", so there is a want and  
 23 desire to comfort and hold. And every milestone that  
 24 that child reaches, whilst it's a celebration that  
 25 they're here and they're alive, there is also a change

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1 in equipment that comes alongside that as well, that  
 2 reinforces the fact that your child is different and  
 3 your child has differing needs. And that becomes really  
 4 difficult for families to accept, you know, that move  
 5 from a buggy to a wheelchair; that recognition that you  
 6 can no longer physically lift and carry but that you now  
 7 need a piece of equipment to do that for you.

8 So it's very difficult to break some of those habits  
 9 and connections because the equipment is — the  
 10 equipment is a reminder, but it's a barrier to that  
 11 contact as well. So that is something that can be  
 12 really difficult for our families to overcome and start  
 13 to embrace; something that they potentially know will  
 14 make a difference to their own health and well-being but  
 15 there are so many other things that they need to work  
 16 through in order to get to that point.

17 Q. Thank you. And finally at paragraphs 56 and 57 of your  
 18 statement you highlight that there were perhaps also  
 19 some upsides to the running of these education sessions  
 20 online, albeit they were a substitute to how you would  
 21 have done things previously. Could you elaborate on  
 22 what those were please?

23 A. I think one of the things that we realised was that  
 24 families actually enjoyed connecting with each other  
 25 across area, so when we were delivering things in person

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1 they would have been specific to Glasgow or Lanarkshire  
 2 or Tayside or whichever area we were holding them in,  
 3 and so families would only ever really know people that  
 4 lived in those areas.  
 5 For the first time, we were holding various  
 6 different sessions and so people across wherever — I'm  
 7 going to say in Scotland but we had people in Wales and  
 8 Ireland joining us as well in some of the postural care  
 9 sessions that we were delivering, and that was really  
 10 good for families to start connecting with people in  
 11 different geographical areas. It was actually something  
 12 that we probably hadn't necessarily appreciated  
 13 organisationally, around the benefit of hearing how  
 14 things work in different areas, things that might be  
 15 better or could be changed or how parents could  
 16 potentially influence some of what was happening, but  
 17 also just that — the connection that we could have with  
 18 families who weren't — so like in the Western Isles, we  
 19 had a family who came from the Western Isles and logged  
 20 in, who were able to deliver education to Shetland, to  
 21 places that we would not have been able to reach before  
 22 the days of recognising the benefit of a Zoom platform.  
 23 So that definitely opened up opportunities for us  
 24 and now, even though lots of things are back in person,  
 25 there are still quite a few things that we run digitally

1 as well because families have really enjoyed that aspect  
 2 of connecting with other people, or the opportunities  
 3 that didn't exist for folk because of their geographic  
 4 location previously.  
 5 Q. Thank you. I don't have anything else to ask you  
 6 really, so was there anything that you think we perhaps  
 7 haven't covered or could be a lesson learned or any  
 8 reflection that we haven't addressed that you'd like to  
 9 say now.  
 10 A. I think probably the value of people with profound  
 11 disabilities. I think they have not been recognised at  
 12 all during this whole process as individuals, as the joy  
 13 that they can bring, and I think very quickly people  
 14 have placed judgments on the quality of their life and  
 15 that's something that our families have had to fight for  
 16 a really long time but drove a huge amount of fear  
 17 during COVID. So I think that real recognition and  
 18 value of who individuals with profound disabilities are.  
 19 But also just that — to go alongside that, how  
 20 fabulous our family carers are in having come through  
 21 this whole process. And even though services are still  
 22 not the way they were previously, still that love for  
 23 the person that they care for is driving them to keep  
 24 going and, you know, just to celebrate that, that even  
 25 though things have been incredibly difficult, to

1 celebrate the achievement and the strength that they've  
 2 been able to show so many others of us through that  
 3 process.  
 4 MR STEPHEN: Thank you very much.  
 5 THE CHAIR: Yes, thank you, Ms Morrison. I'm very grateful.  
 6 11.15.  
 7 MR STEPHEN: Thank you, my Lord.  
 8 (10.53 am)  
 9 (A short break)  
 10 (11.14 am)  
 11 THE CHAIR: Now, good morning again.  
 12 MR STEPHEN: Good morning, my Lord. The next witness is  
 13 Wendy Scott—Crawford, who is appearing remotely.  
 14 MS WENDY SCOTT—CRAWFORD (called)  
 15 (Evidence given by videolink)  
 16 THE CHAIR: Yes, good morning, Ms Scott—Crawford.  
 17 A. Good morning?  
 18 THE CHAIR: You can hear me all right?  
 19 A. I can, thank you.  
 20 THE CHAIR: Probably more importantly you can hear  
 21 Mr Stephen, I take it?  
 22 A. Yes.  
 23 THE CHAIR: Good. Thank you. On you go, Mr Stephen.  
 24 MR STEPHEN: I'm obliged, my Lord.  
 25 Questions by MR STEPHEN

1 MR STEPHEN: Could you confirm your full name please?  
 2 A. It's Wendy Scott—Crawford.  
 3 Q. Your age and contact details are known to the Inquiry,  
 4 so I won't ask you for those. You have provided  
 5 a written statement already and for the record the  
 6 Inquiry reference number for that is SCI—WT0114—000001.  
 7 Are you happy for that written statement and the oral  
 8 evidence you give today to constitute your evidence to  
 9 the Inquiry?  
 10 A. Yes.  
 11 Q. And are you happy for that evidence to be recorded and  
 12 published?  
 13 A. Yes.  
 14 Q. Thank you. Everything you've said in that written  
 15 statement will be taken into account even if we don't  
 16 touch on it in your oral evidence today.  
 17 A. Yes.  
 18 Q. Just a reminder, there is a restriction order in place,  
 19 so please do not name any individuals and that includes  
 20 your daughter —  
 21 A. Yes.  
 22 Q. — and other family members; all right? Thank you.  
 23 A. Yes.  
 24 Q. You're here today to give evidence about one of your  
 25 daughters. Can I start by asking how old is your

1 daughter?  
 2 A. She's 21.  
 3 Q. And prior to your daughter being born, I understand that  
 4 you worked full-time but you gave that up to be  
 5 a full-time carer for your daughter.  
 6 A. I did, yes.  
 7 Q. Now, your daughter has a condition called "normal  
 8 pressure hydrocephalus"; is that right?  
 9 A. Yes.  
 10 Q. And what is that, in high-level terms?  
 11 A. It's enlarged ventricles within the brain. It's also  
 12 known as a "ventrochlomedia". It's where normally  
 13 children or young people are given a shunt, but in the  
 14 womb [redacted]'s brain mass didn't develop so she just  
 15 had like two big balloons in the centre of her brain.  
 16 Q. When did that condition come to light?  
 17 A. Pre-birth.  
 18 Q. What was the prognosis you were given when your daughter  
 19 was born?  
 20 A. Either she wouldn't survive the birth or she would maybe  
 21 just live to about two years old.  
 22 Q. What have been your daughter's care needs as a result of  
 23 that condition?  
 24 A. Quite intensive. [redacted] is non-verbal, she has  
 25 learning difficulties, she's got limited mobility, she's

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1 doubly incontinent, she has epilepsy, she's  
 2 anaphylactic, she has several other allergies which are  
 3 not anaphylactic but obviously need to be taken into  
 4 account, so her care is 24/7 care. She can never be  
 5 left alone and she just --- she needs somebody to help  
 6 her have a life.  
 7 Q. Is that what you enable her to do? You provide that  
 8 24-hour care that you were talking about?  
 9 A. I do, yes.  
 10 Q. You said it's 24 hours. What is your daughter's sleep  
 11 pattern like, for example?  
 12 A. She will --- well, we did an EEG because she's up and  
 13 down, up and down, all night and they wanted to do a EEG  
 14 for her epilepsy, and it turned out they discovered that  
 15 she sleeps solid for one hour when she's put to bed and  
 16 then she cat-naps the rest of the night for a maximum of  
 17 like 15 minutes, so she ---  
 18 Q. Sorry, I'm going to have to stop you there. I'm being  
 19 told there was a breach earlier on.  
 20 A. Oh, right.  
 21 Q. I think it must have just been a mention of your  
 22 daughter's name, so if you just bear with us, thank you.  
 23 (11.18 am)  
 24 (A short break)  
 25 (11.22 am)

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1 THE CHAIR: Sorry about the delay but these little mistakes  
 2 happen. They don't need to be worried about. I hope it  
 3 didn't disrupt you too much. On you go, Mr Stephen.  
 4 MR STEPHEN: Thank you, my Lord.  
 5 I think I was just asking you --- in relation to the  
 6 24/7 care that you provide for your daughter, I was  
 7 asking I think about her sleep pattern.  
 8 A. Yes. There was a test done --- she's basically up and  
 9 down all night. She sleeps for one hour solid when put  
 10 to bed and then she cat-naps for 15 minutes. Part of  
 11 her condition --- I forgot to mention she's autistic ---  
 12 is that she doesn't like the covers squint, so she'll  
 13 get very distressed, very agitated and you could be up  
 14 several times a night either changing her --- obviously  
 15 she's incontinent --- making sure her covers are straight  
 16 or --- well, it's just several times a night, so you're  
 17 up and down all night basically.  
 18 Q. Given your daughter's range of needs and what you've  
 19 described as the routine through the night, what impact  
 20 or pressure does that place on you as her carer?  
 21 A. It's become the norm. Life is quite foggy. You're  
 22 tired all the time. You just go through life --- like  
 23 I say, "foggy" is the best way to describe it. Your  
 24 whole life is just making sure that her needs are met  
 25 and, sometimes, if you've had a particularly bad night,

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1 you have to pick and choose your --- what's going to take  
 2 priority and what isn't going to take priority through  
 3 the day. Your world becomes very small. It's just  
 4 living tired.  
 5 Q. Thank you. I asked you earlier about your daughter's  
 6 care needs. How would you describe your daughter's  
 7 mobility, physical mobility? How is that?  
 8 A. She has very limited mobility. She has what they call  
 9 "right hemiplegia", which is a right-sided weakness.  
 10 When she has seizures, it's very similar to somebody  
 11 that's had a stroke, so you have to go back and do hand  
 12 over hand, help her with her feeding, put her back into  
 13 her wheelchair. She requires a lot of physio to get  
 14 back out of the wheelchair, a lot of support. It's like  
 15 three steps forward, two steps back with her care.  
 16 She's also got a visual impairment which impacts --- when  
 17 you have got her up, then she can't see obstacles,  
 18 tables, kerbs, just things --- she would fall over them  
 19 and injure herself quite badly.  
 20 Q. This is what you talk about at paragraph 19 of your  
 21 statement, about your daughter having no --- I think it's  
 22 3D vision or depth perception; is that right?  
 23 A. Yes. So it's quite common with hydrocephalus.  
 24 Q. How does your daughter communicate? You said earlier  
 25 that your daughter was non-verbal ---

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1 A. Yes.  
 2 Q. — so how does she communicate?  
 3 A. Pointing, gestures, facial expressions. She's very  
 4 expressionable. We've been using a form of sign  
 5 language called "Makaton", which is a basic sign  
 6 language. She uses pictures, music sometimes. If she's  
 7 wanting to get something across or talk about somebody,  
 8 she will find a particular song with a verse in it,  
 9 which took me a long time to work out that's what she  
 10 was actually doing. Yeah, so she gets her point across  
 11 but you have to know her to know exactly what she's  
 12 wanting. You have to be able to read her facial  
 13 expressions more than anything.  
 14 Q. And as her mother you of course understand the signs;  
 15 you can do that?  
 16 A. Yes, I just take a look at her and I know what's coming.  
 17 Q. Thank you. I wanted to ask about your daughter's  
 18 personality, certainly before the pandemic to start  
 19 with. How would you describe her?  
 20 A. I would describe her as very sociable, very happy, very  
 21 giggly, very — she was just a joy to be around. She  
 22 was kept busy at her school and she loved it. She loved  
 23 going to school, she loved being around the other staff,  
 24 she loved her peers. Bubbly and happy is just a really  
 25 good way to describe how she was before.

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1 Q. Were there any particular activities or interests that  
 2 she held? I think I heard you mention music earlier on.  
 3 Was that one or anything else?  
 4 A. She loves music, she loves drumming, she loves art.  
 5 She's got — she used to have access to a trike, like  
 6 a special needs trike; trampolining, again that was  
 7 provided when she was at school. Yeah, just — she just  
 8 enjoyed — she enjoyed how she perceived things.  
 9 Q. Thank you.  
 10 A. You know, the drawing and the art was a big thing as  
 11 well, but music is a huge thing in her life.  
 12 Q. You mentioned school and I was going to turn to that,  
 13 how that was before the pandemic, and your daughter's  
 14 education. How often did your daughter attend school  
 15 before the pandemic?  
 16 A. She used to go five days a week, with transport. They  
 17 would pick her up, take her to school and then bring her  
 18 home again.  
 19 Q. What were the activities — the routine that was offered  
 20 when she was attending school?  
 21 A. It was a very strict routine, obviously — she likes  
 22 routine. They had, like I said the trampolining; they  
 23 had the art; they had drumming classes; they had  
 24 a hydrotherapy pool; they have a cinema room; they used  
 25 to have theatre groups coming in and doing little shows

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1 for them; they'd have the bagpipe group coming in and  
 2 playing for them; they had her up walking around the  
 3 building quite a lot, which was really good for her;  
 4 they had her out on her trike; they had a physio; they  
 5 had a speech and language therapist. She used to come  
 6 home quite exhausted.  
 7 Q. Yes, because I saw in I think paragraph 28 of your  
 8 statement you refer to all the professionals being —  
 9 "under one roof" was the way that you put it. So she  
 10 was receiving speech and language therapy,  
 11 physiotherapy, occupational — that was all there in one  
 12 place?  
 13 A. Yes, all under the school roof. They all worked  
 14 together as a team for that — for each individual.  
 15 They made a care plan package, they were able to get to  
 16 know my daughter and the others and they were able to do  
 17 a programme for them that suited each individual child.  
 18 Q. Because I noticed at paragraph 22 of your statement,  
 19 when you talk about the school, you talk about your  
 20 daughter being there with full allied healthcare input.  
 21 What was that input? Is that what we're talking about,  
 22 the rest of those professionals that were there to  
 23 support her?  
 24 A. Yes, yeah. The whole allied team all work within the  
 25 school, so they're all employed by the school. So, you

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1 know, when these children are doing physiotherapy or  
 2 they're doing speech and language, it's made in a way  
 3 that the allied health team would come in and say,  
 4 "Right, this is the programme that we need for this  
 5 individual, this is what we need them to do, this is  
 6 what we need them to achieve and this is how we're going  
 7 to do it", and they would oversee it, but the actual —  
 8 like the staff of the classroom would actually  
 9 physically do what was on the programme.  
 10 But, like I say, they were all under one roof so it  
 11 was easy to just phone the school and say, "Look, I've  
 12 got an issue with this" or "I think I need help with  
 13 this", "What are we doing with this or what are we doing  
 14 with that?", and they made it fun. You know, it wasn't  
 15 just like going to the gym or — well, some people like  
 16 that — but, you know, the trampolining, for instance,  
 17 and out on the trike, that's all part of physiotherapy  
 18 and that was overseen by the professional  
 19 physiotherapist within school.  
 20 Q. I think the word you use in your statement — I think  
 21 you said it was like an extended family. It was more  
 22 than just a school. Would that be — was that right?  
 23 A. Definitely. Your life becomes quite isolated anyway  
 24 before, not to as extreme as it has been — but your  
 25 life becomes all about making sure that this — my

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1 daughter and others are given a good quality of life ,  
 2 and part of that is --- you know, the school is there for  
 3 a support. It's the first port of call that you go for  
 4 anything, you know, any issues, because they're the  
 5 professionals . You know, the speech and language,  
 6 it's --- you go to them and you ask them about this or  
 7 you go to the physiotherapist and you ask them about  
 8 that, and they do become such a big part of your life.  
 9 It's not like just dropping your child off at school and  
 10 going in on parents' evening. It's across the whole  
 11 board of every need of your child .

12 Q. You said earlier in your evidence and you say it again  
 13 at paragraph 26 of your statement about how happy your  
 14 daughter was at that school. I think you also say that  
 15 it was beneficial for you to enable you to spend, you  
 16 know, time --- I suppose respite perhaps and time with  
 17 your other children also?

18 A. Yes, definitely . You know, when you're at home, you  
 19 can't even nip --- you know, like most people, if you're  
 20 home, you can nip to a shop, if you forgot something at  
 21 the shop, or just nip back out and get it or go do  
 22 this --- with someone like my daughter, who is very  
 23 rigid, you can't do that. You can't --- like once you're  
 24 home, you're home and you're in. So if you want to do  
 25 something, it's a lot of careful planning. It's very

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1 difficult to go to a lot of places, particularly with  
 2 her allergies . So it gave me an opportunity to do that.  
 3 I had the opportunity to maybe meet up with a friend  
 4 that I hadn't seen for a long time. I was given the  
 5 opportunity to spend some time with my grandchild,  
 6 which, you know, I don't get a lot of. Yeah, it just  
 7 gives you that sort of --- a bit of breathing space.

8 Q. Thank you. That takes us then I suppose to lockdown by  
 9 contrast perhaps. At paragraph 62 of your statement you  
 10 say that during lockdown children got to do online  
 11 education, but the SEN, by which I think you mean  
 12 special educational needs, kids didn't get anything.  
 13 There was no interaction at all. For your daughter they  
 14 dropped off art supplies by the house once ---

15 A. Yeah.

16 Q. --- which begs a few questions. Was there a plan  
 17 regarding your daughter's educational needs communicated  
 18 to you when schools were closed?

19 A. There was no plan. There was a discussion of how  
 20 dangerous COVID could be and there was a discussion that  
 21 it was similar to the flu . Obviously, with having an  
 22 immune system that is compromised, I understood why the  
 23 school had to close, but I was quite shocked at --- we  
 24 were just left to get on with it really and to find out  
 25 information through the local news. I just felt we were

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1 just forgotten, we were just --- it was really difficult .  
 2 She'd just become lost and --- I'm not quite sure of the  
 3 words I'm looking for, but we were --- there was just  
 4 nothing. We could go and look at YouTube videos and we  
 5 could pretend we were doing school work and I could try  
 6 and write up a plan of what I was going to be doing.  
 7 Again, I'm not a professional, I'm just a mum and I'm  
 8 a tired mum, but I'm trying --- I was trying to still  
 9 give her a sense of normality, which, again, is very  
 10 difficult when you've got somebody who is so used to  
 11 such a rigid day and thrives on that --- you know, and  
 12 then you take that away, it's just --- it has such  
 13 a profound impact. But there was no plan --- no plan  
 14 that I could --- to speak of.

15 Q. So nothing was offered to you or your daughter in terms  
 16 of how her education would be catered for when lockdown  
 17 was in place?

18 A. No. No, we were supposed to be going through transition  
 19 at that time and obviously we were expecting transition  
 20 meetings, what was going to happen with my daughter  
 21 next, where she was going to be going, what was the  
 22 future going to look like for her, but obviously none of  
 23 that happened.

24 Q. Yes, we'll come to that.

25 A. Yeah.

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1 Q. You've used that word "forgotten". The obvious question  
 2 I suppose is: why? Why do you think --- why this perhaps  
 3 differential between children on the one hand and other  
 4 children like your daughter on the other? Why do you  
 5 think they were forgotten about?

6 A. I think a couple of reasons. I mean, obviously I don't  
 7 know for sure and I'm just speculating really . I feel  
 8 it's because it's very difficult for them to communicate  
 9 via computers or --- they're non-verbal, they've very  
 10 limited signing, it's very difficult for --- you know,  
 11 it's not like they can go online and do classes. It was  
 12 a very difficult --- I think they just didn't know how to  
 13 reach out to them maybe.

14 Q. So you mentioned YouTube, for example, having to look  
 15 for videos and things. What was the reality then of  
 16 your daughter's educational experience when the school  
 17 closed, at home? What did her week look like?

18 A. We spent a lot of time looking at people singing and  
 19 people that --- I put on videos of educational songs,  
 20 playing the guitar, playing the drums. Singing Hands  
 21 has been an absolute lifesaver about a lot of things.  
 22 They're a duo that sing while signing Makaton to songs,  
 23 pop songs, regular pop songs. She enjoyed them, which  
 24 again helped with the signing.

25 We watched a lot of how to draw things, and I would

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1 sit with her and we would pretend that we're drawing and  
2 that they're talking directly to her herself, even  
3 though, you know, I knew they weren't. But it was to  
4 try and keep the world open as much as I could.  
5 THE CHAIR: Could I interrupt for a second, Mr Steven?  
6 Sorry.  
7 I want to go back to the answer you gave before the  
8 last answer, Ms Scott—Crawford. You said — and you  
9 were careful to start out by saying that you didn't  
10 really know and you were speculating to some extent and  
11 that's entirely understood and no criticism at all —  
12 but at the end of that answer you said, and I quote you,  
13 "they ... didn't know how to reach out".  
14 A. Yes.  
15 THE CHAIR: I see that. Whilst I accept this must be  
16 speculation as well, but I'm inviting you to speculate,  
17 why didn't they try? Did they make any attempt, for  
18 example, to seek out the thoughts of you or people like  
19 you, carers like you, so that they might begin to form  
20 a plan that might be any use?  
21 A. I can't answer for them —  
22 THE CHAIR: True.  
23 A. — but I don't know why they didn't try. I don't know  
24 whether it was because of my daughter's age and she was  
25 meant to be transitioning into adult services — maybe

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1 it was an awkward age or — because I don't know what  
2 happened with the other children. But my experience was  
3 there was nothing. There was just — the school was  
4 closed and that was the end of it. Just get on with it.  
5 THE CHAIR: That's very candid. Thank you very much. Sorry  
6 to interrupt, Mr Stephen.  
7 MR STEPHEN: I'm obliged.  
8 At paragraph 62 of your statement you mention PAMIS,  
9 Promoting a More Inclusive Society. Did you find that  
10 organisation — was that during lockdown, when looking  
11 for support for your daughter?  
12 A. Yeah. You know, I would go online and try and find  
13 resources, and I was getting quite stressed because  
14 I felt that her health and mental health and her  
15 physical health and everything was in decline. So  
16 I would start trying to find different resources to —  
17 one, for support for me but also support for my  
18 daughter, and that's where I found them.  
19 Q. Was that because you didn't feel that you were getting  
20 the support you needed from the school?  
21 A. Well, it was because I hadn't heard from anybody.  
22 I wasn't quite sure where to turn, to be honest. I knew  
23 that — what her needs were, but who do you go to when  
24 nobody is in the office? Who do you phone? Who do you  
25 contact?

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1 Q. And what help, if any, were PAMIS able to offer you?  
2 A. They managed to get a laptop to us so that we could —  
3 for my daughter and she was able to interact with a —  
4 they put on a virtual disco, they put on a virtual sort  
5 of singing group, interactive stories that she would log  
6 into — similar to this really, but they were able to  
7 say her name and actually communicate back to her, so we  
8 had a couple of them a week.  
9 Q. I suppose in terms of lessons learned then, I'd like to  
10 ask you, do you think that the Scottish Government, in  
11 implementing a decision such as lockdown and therefore  
12 to close schools has happened — do you think they gave  
13 sufficient consideration to the learning needs of  
14 children like your daughter?  
15 A. No. I think a lot of resources — you know, I can  
16 understand how difficult it was and it was unprecedented  
17 times and things, but I just felt that, as a carer to  
18 somebody with such profound needs, we were just left.  
19 There was — you know, the other kids got to do online  
20 homework, they got to do online activities and things  
21 like that. There was nothing put in place for children  
22 like my daughter.  
23 Q. And what more do you think could and should have been  
24 done? What would you have expected to have happened?  
25 A. You know, even interactive videos, even downloading

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1 things locally from the school on to YouTube, if that's  
2 how you're going to access it, so that the children  
3 could see their — people that have been such a huge  
4 part of their life had just disappeared out of their  
5 life.  
6 Maybe video messages, video calls, group calls —  
7 just keep them in the loop, just keep them that they're  
8 still part of this — they're still part of something,  
9 they're not just shut in their houses and shut in their  
10 bedrooms and shut away from everything, everything  
11 they've ever known. It's a big ask for somebody,  
12 especially somebody that is autistic, to take all that  
13 away and have nothing — to have to go and hunt and look  
14 for strangers to teach her or a parent that's not  
15 a teacher, that's trying to be a teacher and trying to  
16 be a carer and up day and night and just stumbling.  
17 It's like you're stumbling in the dark.  
18 Q. Did you encounter any other families, through PAMIS or  
19 otherwise, who were experiencing the same as you, ie  
20 perhaps that gap in education for the children with  
21 similar needs?  
22 A. It's very difficult to actually make contact with other  
23 parents, if you like, because you don't get the time to  
24 go and to talk. You're so busy in your caring role  
25 that — I don't get downtime. I can't go and have

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1 a coffee with somebody and have a chat and find out  
2 what's going on in their life. It just doesn't work  
3 like that.  
4 Q. Thank you. You mentioned that word "transition" a few  
5 times. I want to move on to that now, the stage that  
6 your daughter was at at that time. What age was your  
7 daughter when the pandemic arrived?  
8 A. She would be 17/18 -- 17.  
9 Q. Therefore at the final stages of school?  
10 A. Yes.  
11 Q. At paragraph 28 of your statement you say that there was  
12 an option I think for your daughter to stay at that  
13 school, where you said she was very happy, until her  
14 26th birthday; is that right?  
15 A. That was my understanding at the time. They were like,  
16 "You know, we can have children here till they're 26",  
17 and I presumed it was part of the school because it's in  
18 the school building, it comes under the same name as the  
19 school, and I was quite happy for that. I just thought  
20 things would stay the same right up until she was 26 and  
21 it would give us more time to decide my daughter's  
22 long-term future.  
23 Q. So that's the option that you would have chosen?  
24 A. Yes.  
25 Q. At paragraph 29 you say that allied health were meant to

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1 have completed reports and sent these to the new adult  
2 service run by the NHS. Just so I'm clear, what was the  
3 purpose of these reports being prepared? What were they  
4 there to do?  
5 A. Well, I didn't know this at the time -- when obviously  
6 I chose for my daughter to go back to Stanmore,  
7 I thought all her allied health would still be under the  
8 same roof because she's still within that building.  
9 This is learnt after, that the reports go -- because the  
10 allied health within the school only do children's  
11 allied healthcare and, although my daughter is now  
12 classed as an adult, it had to go to adult services and  
13 adult allied healthcare, which is done by the NHS.  
14 Q. And what was the function of these reports?  
15 A. The reports, sorry, were to -- so that there would be  
16 a streamline in her care and everything that the school  
17 had wrote in the reports would go to the adult services  
18 and then they would just take over and they would do  
19 their input and they would do their reports and then  
20 they would report to the day service and myself and --  
21 it was like to be a continuation of her care.  
22 Q. So those reports would enable that transition to happen?  
23 A. Yes.  
24 Q. And when were those reports supposed to have been  
25 submitted, filed?

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1 A. Just as COVID hit.  
2 Q. And I understand from your statement those reports were  
3 not filed. When did you find out that they had not been  
4 filed?  
5 A. This makes me sound terrible. Two years later.  
6 Q. And were you given an explanation as to why that was?  
7 A. No, not really. Basically I had phoned up because my  
8 daughter needed some extra physio. I was very concerned  
9 about her right side and when I -- it took a little  
10 while to find a phone number for -- a contact for them.  
11 I knew it was adult services. I'd phoned through to  
12 physiotherapy and they kept saying, "We can't find her,  
13 we can't find her". And I was like, "What do you mean  
14 you can't find her? She should have gone seamlessly  
15 from Stanmore straight through to adult services". And  
16 she said, "Well, actually she's not open to us. We  
17 don't have her here. We've no record of her".  
18 Q. Do you attribute that lack of record-keeping to COVID?  
19 A. I do. I went back to the school and I asked them,  
20 "Did you submit these reports? The services are saying  
21 that she's not there". They were adamant they'd sent  
22 the reports. And when I spoke to another member of  
23 staff, they said, "The only thing we can say is that  
24 she's probably been at the bottom of the pile and  
25 there's been referrals since and she's just been lost".

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1 Q. At paragraph 40 of your statement you then say -- in  
2 I think 2021 you requested that your daughter redo  
3 a year at school, I think having effectively lost  
4 a year.  
5 A. Yeah.  
6 Q. What was the response you received to the request that  
7 you made for that?  
8 A. "No, no, she's -- no, she can't have it".  
9 Q. Were you given an explanation for that?  
10 A. They wouldn't fund it. The education wouldn't fund her  
11 to repeat a year. She's 18 and it was time to move on.  
12 Q. I see. What then was the impact -- sorry, I'll start  
13 again. At paragraph 33 of your statement you say it  
14 should have been a seamless process -- you've said that  
15 in evidence again -- whereby your daughter finished  
16 school at 18 and went on to adult support but those  
17 records then went missing. What has been the impact  
18 upon your daughter of those records going missing in  
19 terms of the support that she was then able to receive?  
20 A. Well, she's had no speech and language therapists -- she  
21 was basically told to go back on the waiting list for  
22 everything, so it's took another year for actually the  
23 professionals to get involved in her care, so that's  
24 like four years now before we've got anybody on board.  
25 She's had no voice for four years. She's just recently

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1 been loaned a communication aid to see how she copes  
 2 with it. She's doing great with it but she should have  
 3 had that four years ago. She's had no physiotherapy.  
 4 I've had to go to a private physio because she had an  
 5 accident and she couldn't walk all last summer.  
 6 I couldn't get them — she was on the waiting list so  
 7 I had to find help elsewhere.  
 8 She has had no OT. She's had — we've had to go on  
 9 the waiting list for orthotics, splints. We're still  
 10 waiting on the new one. She's had her leg scanned.  
 11 Everything just — she's had nothing but me, and I can't  
 12 provide a lot of things without the help of a disability  
 13 social worker or a team. I need a team. The team needs  
 14 to be around the child or the young person that she is  
 15 now and without that team you can't get the supports and  
 16 the equipment and the services that she needs. So it's  
 17 had a profound effect on her.  
 18 Q. You mentioned waiting lists. How long are the waiting  
 19 lists that you're talking about to receive the equipment  
 20 or whatever it is that she needs?  
 21 A. Well, it took another 12 months, so it's took four  
 22 years. We've just — she got it a couple of weeks ago,  
 23 and that's been since — she should have got it when she  
 24 was 18.  
 25 Q. You spoke earlier about phoning physiotherapy. I think

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1 you say in your statement that your daughter had  
 2 a right-sided weakness that you wanted to address and  
 3 there was no record of her at all.  
 4 A. Yeah.  
 5 Q. How old would she have been at that time?  
 6 A. She would have been 20.  
 7 Q. And when you were told there was no record, what was  
 8 it — what was it suggested would happen? You mentioned  
 9 waiting lists, but in terms of that transition to adult  
 10 care, what happened —  
 11 A. She was to go back on the waiting list.  
 12 Q. To be transitioned to adult care?  
 13 A. Yes.  
 14 Q. Were you informed as to how long that would be or ...?  
 15 A. I wasn't. They just said she would have to go back on  
 16 the waiting lists.  
 17 Q. How did that make you feel?  
 18 A. Upset. I was upset. I was upset for my daughter.  
 19 I felt that she'd been let down. I was quite angry.  
 20 I was trying to explain, "Look, she needs input now".  
 21 I had thought, because she had gone back to a day  
 22 service, that, like I say, she was getting that support,  
 23 but obviously she wasn't and it was their duty of care  
 24 to provide that support. It was like just hitting your  
 25 head up a wall, so that's essentially why I went to

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1 a private physiotherapist.  
 2 Q. Yes. At paragraph 30 you talk about these reports being  
 3 lost in the system and you being left with no help for  
 4 I think two years, is what you say there, and you were  
 5 very concerned about her physical appearance.  
 6 A. Yeah.  
 7 Q. Has there been a longer-term physical impact upon your  
 8 daughter as a result of this lack of support?  
 9 A. I would say so. She has — she's very weak down the  
 10 right side, there's a drop in her shoulder you can see,  
 11 her leg's rotated out, she's had a lot more accidents,  
 12 she's had a lot more falls. She's just not as steady on  
 13 her feet as she was. She's actually gained a bit of  
 14 weight because she can't walk, so she's back in her  
 15 chair. It's like catch 22. You can't get her up doing  
 16 her exercises because she can't stand; you know, she's  
 17 in pain. She ripped a couple of ligaments in her leg  
 18 and her foot last summer with falls. So, yeah, it's had  
 19 a profound effect on her.  
 20 Q. Was your expectation that, if the transition had gone  
 21 smoothly, your daughter would have been in full-time  
 22 education or care again?  
 23 A. The hope would have been that she would have stayed  
 24 within Stanmore, but five days a week, the same sort of  
 25 hours, but — you know, they change it from half past 9

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1 to half past 3 because there's slightly different times  
 2 of taking them in. But the hope had been that she would  
 3 still have been doing the very rigid programme that she  
 4 was doing while she was in school, with the same level  
 5 of support and care for her.  
 6 Q. By contrast I think you say at paragraph 35, for  
 7 example, that — I think 18 hours a week is the figure  
 8 that you give as the day service that was on offer.  
 9 That seems, at least at first blush, to be quite  
 10 a difference. What was the impact of that upon you,  
 11 where you're expecting something that was five days  
 12 a week and it's 18 hours that's being offered?  
 13 A. Yes. My understanding was that when these young people  
 14 become adults, that you're not — as a parent you're not  
 15 expected to put in the same level of care and that you  
 16 could actually go and get a job or you can — you know,  
 17 the young person is an adult now and they shouldn't be  
 18 spending so much time with a parent. Had a normal —  
 19 I hate to use the word "normal" — but had somebody who  
 20 didn't need that level of care — at 18 to 21, you know,  
 21 you don't spend all your time with your parent and I was  
 22 always — like I said, I was always told that, "You  
 23 wouldn't be expected to do the same level of care,  
 24 you'll have carers coming in or they'll go to the day  
 25 service or you'll get this", and it's simply not true.

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1 You do twice as much care.  
 2 You know, she's home four days a week. I've got to  
 3 find things for her to do. I've got to be up through  
 4 the night, I've got to get her out the door, I've got to  
 5 get her washed and dressed and I've got to get her to  
 6 any activities that she's going to. So, you know — and  
 7 then you're doing the evenings and you're doing the  
 8 mornings and you're doing the four days, full days, so  
 9 there is — what other option have you got?  
 10 Q. And you remain waiting for a place on this waiting list ;  
 11 is that right?  
 12 A. No, that's not correct. She has — the waiting list was  
 13 for the allied healthcare. They have now started coming  
 14 in. That's been another year. They've started to come  
 15 in, hence she's got a loan of the voice box. She is  
 16 doing the 18 hours, which they class as three days at  
 17 this day service, and we have had a meeting as recently  
 18 as last week just with a social worker that basically  
 19 was — "What's the dream?" was the question that I was  
 20 asked, and I was like, "Well, the dream is that she has  
 21 her five days. I would like a weekend a month off", and  
 22 basically was told, "Well, that's not how it works". So  
 23 I have to wait on another assessment now of my need to  
 24 find out if my daughter can get these extra days in the  
 25 day service or a carer.

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1 Q. I've touched on the physical impact on your daughter and  
 2 also on her education. I wanted to ask you now just on  
 3 the mental health side of things. I appreciate, as you  
 4 told us earlier, your daughter is non-verbal, but have  
 5 you observed any changes to your daughter's behaviour as  
 6 a result of lockdown and the pandemic?  
 7 A. Yes, this has been a huge change in her personality.  
 8 She is very frustrated, she is very angry, she's  
 9 physically violent at times. She's violent to herself,  
 10 she's self-harming, she's pulling clumps of hair out.  
 11 It's very distressful to actually watch how she's  
 12 become.  
 13 Q. And what do you attribute those changes to, if anything?  
 14 A. Firstly, the change in routine. Her world has got even  
 15 smaller than it was before. She's not got the same sort  
 16 of activities or — to do. She's shut in quite a lot  
 17 still. It's difficult to find activities to get her to  
 18 and then obviously — again, it's picking and choosing  
 19 your battles. Are you going to fight to get her out?  
 20 She doesn't like going out the house, she doesn't like  
 21 walking through the door, she doesn't like getting in  
 22 and out of the car. All things that she enjoyed doing  
 23 before she just doesn't want to do anymore and you have  
 24 to — I don't want to use the word — when I say "force  
 25 her", I mean you have to sort of — "encourage" is

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1 a better word — you have to try and encourage her to  
 2 get out the door. It's like she's developed this fear  
 3 of the outside world. Once she's there, she enjoys it,  
 4 she's quite happy to be there, but it's getting her  
 5 there to certain events. She doesn't — yeah, she pulls  
 6 her hair out, she hits her head. These are all new  
 7 things that she's done since COVID that she didn't do  
 8 before. She was happy before and now she's like an  
 9 angry young lady.  
 10 Q. Because at paragraph 45 of your statement you also  
 11 mention I think your daughter being offered an  
 12 anti-psychotic medicine; is that correct?  
 13 A. Yes, yes.  
 14 Q. Was that because of the behaviour that you're  
 15 describing?  
 16 A. Yes. She'd injured a couple of staff members and — so  
 17 she was sent to see a psychiatrist, who advised that  
 18 they could put her on an anti-psychotic, which  
 19 apparently calms them down and basically sorts the  
 20 aggressive behaviour.  
 21 Q. Is that a route that you chose to go down or not?  
 22 A. No. No. I think, because she's got so many other  
 23 medical conditions — you know, she's epileptic and all  
 24 the rest of it — she takes enough medication and I was  
 25 not happy to pump her full of drugs for a problem that

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1 she didn't have pre-pandemic. I feel there's got to be  
 2 a better way.  
 3 Q. So if you were to sum up your daughter's personality  
 4 now — and I think you did to an extent a moment ago —  
 5 post-pandemic, how would you describe her now?  
 6 A. I would describe her as an angry young lady, an upset  
 7 young lady and frustrated young lady.  
 8 Q. In terms of lessons learned, then, in paragraph 72 of  
 9 your statement, you talk about your daughter and those  
 10 like your daughter transitioning, moving from child to  
 11 adult, during the pandemic as — a "forgotten  
 12 generation" I think is the way you put it.  
 13 At paragraph 73, you say that people like your  
 14 daughter turning 18 at the start of the pandemic seemed  
 15 to fall into a black hole.  
 16 A. Yes.  
 17 Q. Why do you think that happened?  
 18 A. I think it happened because services all closed so there  
 19 was no streamline from child services into adult  
 20 services, and what happened was then you had — the  
 21 following year the next lot of young people were  
 22 transitioned, paperwork on top of theirs, the next year  
 23 you had another lot of paperwork on top of that, so the  
 24 ones that were three years back were just left,  
 25 forgotten at the pile. You know, these professionals

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1 are getting this workload in and obviously they're going  
2 to stop — start from the top of the pile and the ones  
3 at the bottom of the pile are just left .  
4 Q. Do you consider there to be any key lesson or lessons  
5 that should be learned from what happened in respect of  
6 your daughter?  
7 A. Maybe keep services open, even if it's online. Don't  
8 close things. Or allow them to repeat a year in  
9 education so that they can have a smoother transition  
10 when all the services are back open. I think those are  
11 the two big key issues .  
12 Q. All right. I don't have anything else to ask you so if  
13 there's anything I've missed or you would like to  
14 elaborate on now — or the Chair might have  
15 a question — now is the time.  
16 A. Well, I think we've pretty much covered everything.  
17 Just thank you for allowing me to speak.  
18 THE CHAIR: No, thank you, Ms Scott—Crawford, for that very  
19 powerful and helpful evidence. I'm very grateful to  
20 you. Thank you.  
21 A. Thank you very much.  
22 THE CHAIR: Good. We are ahead of schedule, Mr Stephen.  
23 I don't know what the situation with the incoming —  
24 I know that you're doing the incoming witness so we'll  
25 put the responsibility on you. If we were able to start

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1 at 1 o'clock I'm happy to do so, but obviously I can't  
2 promise that. It depends on availability of the witness  
3 and so forth .  
4 MR STEPHEN: I'll check now.  
5 THE CHAIR: Thank you very much. Good.  
6 (12.02 pm)  
7 (The short adjournment)  
8 (1.15 pm)  
9 MRS PATRICIA GRAHAM (called)  
10 THE CHAIR: Good afternoon, Mr Stephen, and good afternoon,  
11 Mrs Graham. Right, when you're ready.  
12 Questions by MR STEPHEN  
13 MR STEPHEN: Could you confirm your full name, please?  
14 A. It's Patricia Mary Graham.  
15 Q. Thank you. Your age and contact details are already  
16 known to the Inquiry. I won't ask you for those.  
17 You've helpfully provided a second witness statement to  
18 the Inquiry and, for the record, the Inquiry reference  
19 number for that statement is SCI—WT0417—000006. Are you  
20 happy for that written statement and the oral evidence  
21 you give today to form your evidence to the Inquiry?  
22 A. I am.  
23 Q. And you're happy for that to be recorded and published?  
24 A. Yes, I am.  
25 Q. And everything you've said in that statement will be

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1 taken into account by the Inquiry, even if we don't  
2 touch on every single aspect of it today.  
3 A. Okay.  
4 Q. Finally, just a reminder about the restriction order.  
5 The Chair has granted a partial variation of that order  
6 so we're able to talk about your daughter today but  
7 please don't name any other individuals when you're  
8 giving your evidence.  
9 A. Okay, I'll do my best.  
10 Q. Thank you very much.  
11 You previously gave evidence to this Inquiry on  
12 13 March of this year as part of a panel with your  
13 colleague, Jenny Miller, representing the organisation  
14 PAMIS or Promoting a More Inclusive Society, in your  
15 role as chair of that organisation. Today you're here  
16 to give evidence in your individual capacity, I suppose,  
17 regarding one of your daughters and the impact of the  
18 pandemic upon her and upon your family; is that right?  
19 A. That's right.  
20 Q. Could I start then by asking your daughter's name?  
21 A. My daughter's name is Lauren, Lauren Graham.  
22 Q. And what age is Lauren?  
23 A. So Lauren is 35.  
24 Q. And I noticed at paragraph 74 of your statement you talk  
25 about the importance of individuals like Lauren being

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1 seen as a person. So I wanted to start in a logical  
2 place, I suppose, with asking about Lauren's  
3 personality. How you would describe Lauren?  
4 A. Hmm. Well, she has complex epilepsy, she has a profound  
5 learning disability, she is non-verbal, she is doubly  
6 incontinent, she has some mobility issues, but she is  
7 still mobile. She has severe communication difficulties  
8 because of her learning disability and probably, if  
9 I had to give her developmental age, it would be around  
10 the age of two. So that sort of describes her medical  
11 condition, but actually she still has, you know,  
12 a really vibrant warm, spirited personality, despite all  
13 her disabilities and she still has the capacity to  
14 learn. It just takes a bit longer. And she — I would  
15 characterise her as being an extremely brave person,  
16 like anybody with PMLD, in that the amount of obstacles  
17 that they have to overcome in their everyday lives, all  
18 the time, is — most of us would think would be  
19 insurmountable and yet she does it with a smile and some  
20 charm, it has to be said.  
21 And she enjoys her life. You know, there are lots  
22 of things that she likes to do. She likes picture books  
23 and music and TV and swimming, she likes spending time  
24 on her swing in the garden and she likes companionship,  
25 she likes to be with other people. When she — she went

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1 into supported accommodation or residential setting,  
 2 housing support service, however you want to describe  
 3 it, when she was 22, and the reason for that was because  
 4 she didn't sleep. She could be up two times a night for  
 5 a couple of hours at a time or 24 times a night.  
 6 I think that was probably what pushed us over the edge  
 7 and so that's when we sought a housing support service  
 8 for her. It wasn't because we didn't want her at home  
 9 and we've continued to see her umpteen times a week  
 10 since --- in all of those years --- so she was 22, that's  
 11 13 years ago --- at least four times, sometimes five  
 12 times a week, and I've always supported her for all  
 13 her --- any medical issues, for everything else.  
 14 Everything to do with Lauren is something that I'm  
 15 actively involved in and always have been and, you know,  
 16 I've always considered myself to be part of Lauren's  
 17 care team.  
 18 Q. Thank you. You touched on Lauren's condition there, the  
 19 range of needs that she has. I think epilepsy was one  
 20 of the ---  
 21 A. Yes, she has very complex epilepsy.  
 22 Q. So does that result in Lauren having seizures; is that  
 23 correct?  
 24 A. Yes, it does. She has --- as a child, she was diagnosed  
 25 as having cryptogenic infantile spasms, which is quite

1 a severe form of epilepsy that's identified in young  
 2 children and that can change over the years. But in  
 3 Lauren's case it disappeared for a while during her sort  
 4 of early teen years but came back with a vengeance after  
 5 puberty. And it's quite difficult to control. It's  
 6 refractory epilepsy, which is not responsive or not  
 7 completely responsive to drugs, although there are some  
 8 drugs which are significantly helpful.  
 9 So I guess, you know --- I keep --- Lauren's staff  
 10 team keep detailed records of her seizures. Every  
 11 seizure that Lauren has is recorded on a sheet and at  
 12 the end of the month those sheets are collated and given  
 13 to me and I put them all together on to spreadsheets and  
 14 graphs and all sorts of things so that they can then be  
 15 presented to her epilepsy nurse specialist and her  
 16 neurologist, and that way we can keep a track on how ---  
 17 you know, whether they're getting better or worse and so  
 18 forth, and that impacts on what her medication might be.  
 19 I guess at this point it would be worth saying that  
 20 in January 2020, which was just before the pandemic,  
 21 Lauren had 148 seizures in that month and a lot of those  
 22 seizures --- so she has focal seizures and tonic  
 23 seizures. I don't need to, unless you want me to, go  
 24 into what those actually mean --- so she has different  
 25 types of seizures. She doesn't have tonic chronic

1 seizures, which are the ones that people commonly  
 2 associate with epilepsy, where somebody loses  
 3 consciousness and they fall to the ground.  
 4 But having said that, some of the tonic seizures  
 5 that she has can throw her --- that's what it actually  
 6 looks like --- they throw her to the ground, throw her  
 7 against a wall, and in January in particular that year,  
 8 she was in A&E I don't know how many times with bruises  
 9 and fractures and so forth, and that was as a direct  
 10 result of some of those seizures. We're in a different  
 11 place now, but hopefully --- well, I can talk about that  
 12 a bit more later on in the proceedings.  
 13 Q. Thank you. You talked about that record of Lauren's  
 14 seizures and the number in that particular month  
 15 in January 2020. Does that frequency ebb and flow? You  
 16 talked about obviously the medication being calibrated  
 17 accordingly ---  
 18 A. Yeah.  
 19 Q. --- but does the frequency of those adjust ---  
 20 A. Yes, it does, and that was a --- I guess that was a peak.  
 21 We'd started keeping very detailed records not that long  
 22 before that so it may well have been that it had been at  
 23 that peak for quite a while, but certainly that was the  
 24 highest that we've recorded at any time, and I suppose,  
 25 by way of comparison, last month she had 24, so they

1 reduced significantly. But what happened at that time  
 2 was that she ended up on additional medication to try  
 3 and sort that out, but what happened was they introduced  
 4 new medication but couldn't take away the old medication  
 5 because otherwise they wouldn't have known what was  
 6 making any difference, if indeed a difference was made.  
 7 So she was then, for the first six/twelve months of  
 8 COVID, on a kind of reducing cocktail of different  
 9 anti-convulsant medication and so for the --- the most  
 10 challenging time for that was probably the first three  
 11 months --- three/four months of COVID because she was on  
 12 a very high level of drugs and I wasn't able to see her  
 13 or visit or have any input or make observations or, you  
 14 know, have her at our house at all because we didn't get  
 15 to see her for the first three months of the pandemic.  
 16 And that was --- made it particularly challenging because  
 17 of her --- because of the impact that those drugs had on  
 18 her and also she was still having a high level of  
 19 seizures. It has gradually, as I said, gone down over  
 20 the last three or four years, but at that particular  
 21 time, the first few months of COVID, it was really,  
 22 really high and it was a real matter of concern, not  
 23 just to me and the rest of her family but also to her  
 24 carers as well because it was really frightening for  
 25 them because they were having to manage all of those

1 seizures as well as everything else that was going on  
2 for them.  
3 Q. Thank you. We'll come back definitely to the pandemic  
4 and the impact.  
5 A. Yeah.  
6 Q. You mentioned in your answer there about the possibility  
7 of risk of injury I think as a result of what was  
8 happening ---  
9 A. Yes.  
10 Q. --- with these seizures and I think you said that might  
11 necessitate on occasion a visit to hospital or to A&E,  
12 for example; is that correct?  
13 A. Yes, that's correct.  
14 Q. I think at that point I'd like to ask you then about  
15 acute hospital pathways, if I can.  
16 A. Yes.  
17 Q. In your previous evidence to this Inquiry on 13 March  
18 you'd highlighted this as an issue and seeking to ensure  
19 that those with PMLD were appropriately looked after and  
20 supported whilst they were in hospital.  
21 A. Yes.  
22 Q. You said in your evidence earlier about January 2020,  
23 I think ---  
24 A. Yes.  
25 Q. --- when your daughter Lauren had to visit that hospital.

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1 I think you highlight in paragraphs 25 and 26 of your  
2 statement ---  
3 A. Yes.  
4 Q. You talk about this in the context of that incident, and  
5 a lack of funding I think is the reason that's given ---  
6 A. Yes.  
7 Q. --- to enable social care staff to remain with your  
8 daughter at that time. What was the consequence of that  
9 lack of funding?  
10 A. Well, it's a funny thing. It seemed like a really small  
11 thing --- it seemed --- we found out in October 2018, at  
12 a review meeting with Lauren's care providers, that  
13 should she have to go into hospital for whatever reason  
14 during the night, that she wouldn't be able to be  
15 accompanied by staff and that --- because --- Lauren has  
16 always been recognised by social workers as requiring  
17 one-to-one support at all times and that includes during  
18 the night. But the staff ratio is only two staff to  
19 four service users in Lauren's house and so it was  
20 considered that one of those staff members would not be  
21 allowed to go with Lauren and so, therefore --- bearing  
22 in mind the level of her disability and her  
23 developmental age, that she would have to leave the  
24 house on her own, go into an ambulance with people who  
25 don't know her, go to A&E, potentially sit for a number

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1 of hours with people who don't know her or with no one,  
2 and then, if she had to be admitted and treated then in  
3 A&E and then if she had to be admitted to hospital, she  
4 would be on her own. So the assumption would be of  
5 course that I would do that, but if I wasn't there,  
6 then, you know, who would or who could do that?

7 What we found out --- it took many, many years ---  
8 five and a half years and counting we've been working  
9 away at this, trying to persuade social work of the need  
10 for people for Lauren and for people in Lauren's  
11 situation to be supported by their known carers because,  
12 if they're not supported by their known carers, then the  
13 outlook for them is poor because Lauren can't --- she  
14 can't speak and she can't explain what it is that's  
15 wrong with her.

16 One of the things I was going to mention was ---  
17 3 o'clock this morning I was awake thinking about all of  
18 this and I'm thinking, "Oh my God, I haven't thought  
19 about ..." --- I thought about mentioning interoception,  
20 and interoception is "an internal sensory system" --- I'm  
21 reading now --- "in which the physical and emotional  
22 states of the person are consciously or unconsciously  
23 noticed, recognised and responded to".

24 So an example of that would be today I'm sitting  
25 here and my stomach is going like this (Indicates)

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1 because I'm here and I know why that is. I know why I'm  
2 nervous and I know that in roughly an hour's time I'll  
3 be going away and I'll be having a coffee and I'll be  
4 fine. But for somebody with a profound learning  
5 disability --- and Lauren in particular because we're  
6 talking about her --- she has that awareness within her  
7 body of all of these things that are going on for her,  
8 you know, whether she's got a sore tummy, whether she's  
9 got a sore head, whether she's feeling sad, whether  
10 she's having seizures, whether she's scared. All these  
11 things that we all take for granted, we know we're aware  
12 of, we're not really conscious of it most of the time,  
13 but if you've got a sore head, you know about it. But  
14 for Lauren she can't tell you what it is that's wrong  
15 with her. She can't describe that to you and nobody  
16 with PMLD would be able to.

17 So therefore that emphasises the need for known  
18 carers because they always need somebody to interpret on  
19 their behalf, to interpret from their body language, the  
20 noises they make, facial expressions, all of these  
21 things. And if Lauren was in hospital on her own, then  
22 nobody could do that for her and so the outlook for her  
23 would be significantly reduced as a result of that.

24 So I'm just thinking where am I in my argument. So  
25 that was our concern really, that if Lauren had to go

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1 into hospital, she wouldn't be able to communicate on  
 2 her own behalf and we wouldn't be able to do anything  
 3 for her. So therefore what we thought was that this  
 4 should be relatively straightforward, that we should be  
 5 able to go to Social Work and to the care provider and  
 6 say, "This must be a mistake. You couldn't possibly  
 7 contemplate sending Lauren out the door, you know, you  
 8 hand over the duty of care to paramedics who know  
 9 nothing about her and staff in the NHS who know nothing  
 10 about her", and what we found -- and it took a long time  
 11 to find this out -- was that Social Work had a protocol  
 12 or a set of guidelines, whatever you want to call them,  
 13 that said, as a baseline statement, "We will not fund  
 14 people like Lauren in an acute hospital setting".  
 15 So what that meant was that her care provider was  
 16 not allowed then to support her, even though they wanted  
 17 to, and they did, but they weren't allowed to.  
 18 So over the last five and a half years, Social Work,  
 19 the NHS and the ombudsman have strenuously defended that  
 20 position. What we thought was, "Well, we should be --  
 21 should we not be protected by the Equality Act? The  
 22 Equality Act makes provisions for making reasonable  
 23 adjustment. Surely it's a reasonable adjustment for  
 24 somebody like Lauren that she should be looked after or  
 25 cared for -- not provided with medical treatment but

1 cared for in a hospital setting by somebody who knows  
 2 her". And actually little regard was paid to the  
 3 legislation and we tried really hard to persuade them of  
 4 the value of that, but what we found was that we  
 5 couldn't persuade them of the -- I don't know if the  
 6 right word is the "relevance", but certainly not the  
 7 import of the legislation and they just weren't prepared  
 8 to do it.  
 9 In preparation for this session, my partner and  
 10 I waded through the five and a half years of  
 11 correspondence. What we came up with was something --  
 12 almost 80 key documents. This is key documents. In  
 13 addition to those key documents there would be literally  
 14 hundreds of other documents, including emails, minutes  
 15 of meetings, all sorts of other things, in addition to  
 16 those key documents, which is our correspondence with  
 17 the NHS, Social Work and with the ombudsman.  
 18 We ended up having to go -- after going through all  
 19 the formal complaints processes, we had to go through  
 20 the ombudsman and we went all the way with the  
 21 ombudsman, as far as we could go, and their conclusion  
 22 was that Lauren's needs hadn't been met but that  
 23 Social Work had acted properly, reasonably and the case  
 24 was closed and they weren't interested in the  
 25 legislation. And what we were told was that, if we

1 wanted to take it any further, then we would have to  
 2 seek judicial review.  
 3 As far as we're concerned, it shouldn't ever have  
 4 been about the law and financial constraints and  
 5 procedures; it should have been about humanity and  
 6 decency and empathy and kindness and walking in the  
 7 shoes of people like Lauren, who need to be protected  
 8 far more than their protocols but they weren't  
 9 interested in Lauren. But I guess, to be fair, two and  
 10 a half years in, because Jenny Miller, the CEO at PAMIS,  
 11 knew somebody, she was able to --  
 12 MR STEPHEN: That's a breach, I think.  
 13 THE CHAIR: I think it probably is.  
 14 A. Oh, sorry. I thought because you'd mentioned Jenny  
 15 Miller earlier on that it was probably okay to mention  
 16 it.  
 17 THE CHAIR: I wasn't aware of that. That must have gone  
 18 over me.  
 19 MR STEPHEN: We'll pause there, I think.  
 20 (1.33 pm)  
 21 (A short break)  
 22 (1.34 pm)  
 23 MR STEPHEN: All right. We shall continue.  
 24 You were talking about the campaign I think --  
 25 A. Yes.

1 Q. -- which preceded the pandemic.  
 2 A. Yes. I think I was about to say where we are now. What  
 3 happened about two and a half years in was, because we  
 4 knew somebody who knew somebody who was new to  
 5 social work and they were in a position -- they were in  
 6 a senior position and they listened to our case and they  
 7 listened to our arguments and they accepted that we did  
 8 have a case and they -- I guess that was the  
 9 break-through. They accepted the argument because up  
 10 until that point we had been struggling to get anyone to  
 11 agree that we did have a case and we did have a point  
 12 and that Lauren should be funded with her care in  
 13 hospital. But even then it's still taken a further  
 14 three years to get to this point and the point that  
 15 we're at now -- this is within the last few weeks -- is  
 16 that we have received an apology, care support for  
 17 Lauren is in place should she have to go to hospital  
 18 during the night, they've accepted that there should  
 19 have been reasonable adjustment and that that should now  
 20 be made, they've accepted an equality impact assessment  
 21 should be carried out and that will happen in  
 22 conjunction with -- Social Work in conjunction with the  
 23 NHS and that we will be consulted.  
 24 However, we're still subject to delay and we're  
 25 still, you know, five and a half years down the road,



1 but we do have something that's reasonably acceptable  
 2 for Lauren. It's not all the way there, but what's in  
 3 train is similar arrangements for other people in the  
 4 same sort of circumstances that Lauren is in; not just  
 5 people with profound learning disabilities but people  
 6 with communication difficulties. So we have made some  
 7 serious headway, but it's taken us five and a half years  
 8 to do so and it's a real worry because I guess the fact  
 9 that we were --- we persevered because we were never  
 10 going to give up --- I'm talking about myself and my  
 11 partner --- but we were able to do that only under very  
 12 particular circumstances. Firstly, that we were both  
 13 retired; secondly, that Lauren didn't live at home  
 14 anymore; thirdly, that we had the time and the  
 15 inclination to do it but also our professional  
 16 background meant that we were able to do it and willing  
 17 to do it and the fact that there was two of us, which  
 18 made it easier, so we were able to discuss things. In  
 19 our careers we had had training in legal matters --- not  
 20 these kind of legal matters but enough that we weren't  
 21 intimidated or we weren't prepared to be bullied and we  
 22 did feel that we were bullied and so we persisted.  
 23 But what is worrying is that, if it hadn't been for  
 24 all those circumstances coming together, we probably  
 25 wouldn't have done that and if we'd given up at any

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1 time, it probably would have been kicked into the long  
 2 grass and it would never have happened. Most PMLD  
 3 families are not in those lucky circumstances and so who  
 4 knows what other things are happening that nobody is  
 5 really aware of because families are too --- their lives  
 6 are too difficult, too challenging and, you know --- and  
 7 especially during COVID.  
 8 And actually, I guess, talking about COVID, that  
 9 brings me to the relevance of that acute hospital  
 10 pathway argument as regards COVID because what we  
 11 thought was, when COVID arrived, well that would  
 12 hasten --- everybody would realise, "Oh my goodness,  
 13 we've got to get this sorted because what happens,  
 14 there's a much, much higher risk now of people with PMLD  
 15 now ending up in hospital and they're ..." --- I guess  
 16 what happened was we found out that their family carers  
 17 wouldn't be allowed to support but neither would  
 18 professional carers and --- you know, at a time when  
 19 there was a much higher risk of people with PMLD  
 20 becoming ill and needing that support. And actually  
 21 what we were told was that they weren't prepared to  
 22 treat it with any degree of urgency because they were  
 23 too busy with COVID, so it was a sort of catch 22  
 24 situation, and that hiatus delayed things significantly.  
 25 I mentioned earlier about the numbers in terms of

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1 correspondence that we have and there are lots of gaps  
 2 in that key correspondence, and those gaps are filled by  
 3 me sending endless emails and reminders saying, "What's  
 4 happening? What are you doing?", and I was just  
 5 ignored. There was one particularly significant piece  
 6 of correspondence to --- I can't remember whether it was  
 7 NHS or Social --- I think it was NHS. It was 30 months  
 8 before I received a reply and every month I would  
 9 religiously send another email --- I wasn't a civil  
 10 servant for 40 years for nothing --- but nothing.  
 11 I guess one of the things that puzzled my partner  
 12 and I was that in our departments of the Civil Service,  
 13 that wouldn't have happened. We wouldn't have been  
 14 allowed to. We would have been made accountable for  
 15 that. And actually that is the worrying thing, that  
 16 nobody has been made accountable for that, because what  
 17 would have happened if something awful had happened to  
 18 Lauren --- and actually there were a few awful things  
 19 that did happen to her.  
 20 So if I can go back to the example that I mentioned  
 21 earlier about Lauren's seizures in January 2020, and we  
 22 were in hospital because of a massive seizure that she  
 23 had, that did throw her, and half of her face was black  
 24 because her head was hit off against the bathroom wall,  
 25 and so then we got an emergency EEG for her and the

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1 neurology consultant's view was that, "We'll change  
 2 Lauren's meds but she needs to stay in hospital in  
 3 Edinburgh for a week for observation", and we phoned  
 4 Social Work and they said, "No, we won't fund".  
 5 So --- because I couldn't have done it 24/7 on my own  
 6 and there was nobody else that could have done it --- she  
 7 was sent home because it was considered that she would  
 8 be safer in her supported accommodation with her care  
 9 team rather than being observed, you know, by  
 10 neurologists in hospital because the nursing staff said  
 11 that they didn't have the resources to do it. They  
 12 wouldn't have been able to look after her. And that's  
 13 happened on two other occasions when she's been in A&E  
 14 and they thought that it would probably be better if she  
 15 stayed in for observation, once for concussion and  
 16 once --- I don't know if she had concussion, but, you  
 17 know, as a result of seizures, and both times they  
 18 concluded --- the consultants concluded that she would be  
 19 safer at home with her care team.  
 20 So that sort of clinical decision was passed over to  
 21 a team of carers, and while I have the utmost respect  
 22 for Lauren's carers, they're fantastic, they're not  
 23 medical people, they're not trained, you know, to make  
 24 those observations. They know Lauren but actually what  
 25 a responsibility to pass on to them should anything else

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1 have gone wrong.  
 2 THE CHAIR: Now, Mrs Graham, I'm not ticking you off or  
 3 anything like that but you must have asked as many  
 4 questions as poor Mr Stephen intended to ask you this  
 5 afternoon and I think it would probably help us all if  
 6 you just answer the question as Mr Stephen asks it --  
 7 A. Okay.  
 8 THE CHAIR: -- without going into -- I know you have an  
 9 awful lot you'd like to tell us and I'm sure Mr Stephen  
 10 will get that out of you, but let's do it in a more  
 11 efficient way.  
 12 MR STEPHEN: I'm obliged, my Lord.  
 13 We'll move on from acute hospital pathways.  
 14 You mentioned earlier that your daughter, Lauren,  
 15 lived with you I think until the age of 22; is that  
 16 correct?  
 17 A. Yes.  
 18 Q. She now resides in a house supported by a housing  
 19 support service?  
 20 A. Yes.  
 21 Q. Is that living alone or with other --  
 22 A. No, she lives with three others.  
 23 Q. Given Lauren's needs that you've helpfully described  
 24 earlier today, what level of care package does Lauren  
 25 receive in that supported service?

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1 A. So it's 24/7 support.  
 2 Q. And that's one to one?  
 3 A. One to one, yeah -- one to one at all times, except, as  
 4 I mentioned earlier, during the night.  
 5 Q. Thank you. During lockdown that was where Lauren would  
 6 have been residing?  
 7 A. Yes.  
 8 Q. It would have been in that housing support service.  
 9 Prior to the pandemic, at paragraph 20 you say that  
 10 Lauren likes routine --  
 11 A. Yes.  
 12 Q. -- and we've heard that in evidence from other witnesses  
 13 also, so you would try to keep the same pattern of  
 14 activities for her.  
 15 Prior to lockdown in March 2020, what would  
 16 a typical week for Lauren look like in terms of  
 17 activities and things that were going on?  
 18 A. Well, she would have gone five days a week to her day  
 19 service. She'd have been picked up in the bus and taken  
 20 to a day service and they would have gone out and about  
 21 and involved her in all sorts of different activities,  
 22 sometimes on the premises and sometimes out and about,  
 23 you know, swimming and, you know, for walks and that  
 24 sort of thing.  
 25 When she came home, you know, she would have her tea

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1 and she would maybe go out with her staff or they would  
 2 do things in the house. And four times a week she would  
 3 come to our house and her staff would bring her --  
 4 Lauren has a Motability car and they would bring Lauren  
 5 down in the car and she would stay with us for four  
 6 hours or so and we would do lots of activities and  
 7 things with her.  
 8 Q. And what visitation rights would you have had at that  
 9 time to go and see Lauren in her house?  
 10 A. I could have gone any time.  
 11 Q. So there were no limits and times for when and for how  
 12 long?  
 13 A. No, absolutely not. No. They were always very pleased  
 14 to see us. It was always another pair of hands.  
 15 Q. Yes, I think at paragraph 22 you talk about working  
 16 closely with those staff to maximise Lauren's happiness  
 17 and the activities that she was able to partake in.  
 18 I think you said that you had a lot of input into that.  
 19 Can you give an example of what that input would be from  
 20 you?  
 21 A. Well, I guess, apart from that short period, that hiatus  
 22 during -- well, I say "short period"; three months. It  
 23 felt like a lifetime -- apart from that, I support them  
 24 with anything medical. I take her to all her hospital  
 25 appointments, her doctor's appointments, dentist

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1 appointments. I have meetings with care staff --  
 2 anybody that's relevant to Lauren's well-being. I buy  
 3 her clothes, I buy, you know, toiletries and things like  
 4 that. I keep an eye on things like her diet and her  
 5 weight and her general well-being, and if I've -- if  
 6 there are areas for concern or just areas that I want to  
 7 discuss with staff, then I'll do that. Anything that  
 8 they need me to do, I'm happy to do, I'm happy to  
 9 support, and that's always been the case. That's not  
 10 reduced in any way since Lauren first went there.  
 11 Q. Thank you. If we get now into lockdown, do you remember  
 12 when and how you were informed by the housing support  
 13 service that lockdown had been entered into?  
 14 A. It's quite a difficult one because I don't really  
 15 remember exactly. I would imagine that it would have  
 16 been as a result of a phone call but we were aware that  
 17 it was going to happen anyway. We had discussed it  
 18 prior so we knew what was likely to happen. I guess the  
 19 perception at the time was that it was just going to be  
 20 for a few weeks, few days, and it wasn't -- you know, it  
 21 wasn't going to be that significant. Of course we were  
 22 all proved wrong on that count. But, yes, yeah, I think  
 23 that was how I was told. But I was in sort of daily  
 24 contact with them anyway, as a matter of course, either  
 25 by phone or text or email or face to face because we

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1 would see them regularly when they came to drop Lauren  
2 off at the house or pick her up or whatever, so we saw  
3 them on a regular basis.

4 Q. Do you think Lauren understood why that was happening at  
5 that time?

6 A. Oh, absolutely not. She wouldn't have understood any of  
7 that because --- and you said yourself about routine and  
8 so on --- so I guess people with PMLD, one of the ways  
9 that they make sense of their life is that sort of  
10 structure and framework and they know what's going to  
11 happen when, and so when things get a bit out of kilter  
12 that's really confusing for them. It's not necessarily  
13 that they need routine, although some will need routine,  
14 but it's that that routine kind of makes sense of their  
15 environment, it makes sense of what they do and how they  
16 do it. So what happened was all of the things that  
17 Lauren did, apart from within the house --- everything ---  
18 everything stopped. And I mentioned her hobbies and  
19 interests and things before. She likes to be outdoors,  
20 she likes to be doing things, she likes to be active and  
21 she's mobile, so for her it would have been absolutely  
22 devastating.

23 Q. For how long a period were you unable to have physical  
24 contact with Lauren at that time?

25 A. It was three months.

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1 Q. And what was the impact upon you and your family as  
2 a result of that lack of contact?

3 A. Well, it was awful. It was just terrible. Again, it  
4 was a gradual realisation that we weren't going to get  
5 to see her for a while, and so I would fill my time and  
6 try to do things for the house and things that would  
7 help them because they were --- you know, they were  
8 struggling, and it was really, really hard for them and  
9 of course Lauren wasn't in a good place because of the  
10 medication.

11 But she wouldn't have understood and I've seen  
12 photographs at the time of her just looking really sad  
13 and withdrawn, and that was what her staff were saying  
14 to me, that, you know, she's really probably depressed,  
15 not motivated to do anything. Part of that might have  
16 been to do with COVID and part of it might have been to  
17 do with the extra medication or a combination of both.

18 And, yeah, it was just a terrible time for her.

19 The reason that at the three-month point the care  
20 provider decided that she should get to come back to the  
21 family home again was because of her mental well-being  
22 and they felt that it would help to lift her out of that  
23 a bit. And actually I think things had moved on a bit  
24 in terms of the guidelines and there was scope where  
25 somebody had, you know, mental well-being issues, for it

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1 to be slightly reduced, and, you know, we drew up risk  
2 assessments and all the rest of it to make sure that she  
3 was safe.

4 Q. In terms of the impact upon your family, I noticed at  
5 paragraph 53 you talked about the close relationship  
6 that Lauren had with her sister. Of course I won't name  
7 her sister.

8 A. No.

9 Q. But I think you highlight the COVID regulations perhaps  
10 as one of the reasons why they weren't able to see each  
11 other as sisters; is that right?

12 A. Yeah, that's right, and they are very, very close.  
13 I think partly that's to do with the fact that for many  
14 of the years that they were growing up, we were a single  
15 parent family and Lauren's sister essentially helped me  
16 to bring Lauren up and to look after her and care for  
17 her and keep her safe. So it's always been, you know,  
18 probably much more than the normal sister bond, and  
19 because her sister lived on the other side of the  
20 Forth Bridge from us, she was two miles away, she  
21 couldn't come to see her. So even when we got to see  
22 her, Lauren's sister couldn't get to see her. And even  
23 though she worked a few miles away, because she lived in  
24 a different local authority area, she couldn't get to  
25 see her. And actually she was devastated really and

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1 actually still is. I was talking to her this morning  
2 about it and it really upsets her. She said, "I can't  
3 think about it without crying still. I can't bear to  
4 think about it". So it was a really awful impact for  
5 her.

6 Q. Thank you. The Inquiry has heard evidence from a lot of  
7 witnesses about things like video calling, garden  
8 visits, window visits, to stay in touch with family  
9 members.

10 A. Yeah.

11 Q. Was that something that you were able to utilise with  
12 Lauren?

13 A. No. She just --- she wasn't interested. She just --- she  
14 couldn't --- I don't think she could --- she loves  
15 watching television and, you know, she's happy with  
16 a phone and iPod and tablets and that sort of thing, but  
17 I don't think she --- she didn't understand. She  
18 couldn't make the connection between the person being on  
19 a phone, for example, on a Skype --- she couldn't  
20 actually make that connection that that was a real  
21 person talking to her live. And actually it was just  
22 more distressing. She would just shove it away.

23 We also thought about, you know, for example, window  
24 visits, garden visits, that sort of thing, and we  
25 concluded that it was probably just something that would

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1 make her even more upset because she wouldn't be able to  
 2 understand why she couldn't get out. She wouldn't  
 3 understand why we were out in the garden. So we  
 4 didn't — I don't know whether that was the right or the  
 5 wrong decision but actually that was the decision that  
 6 we made, with the best of intention, but I don't know  
 7 whether it was the right decision retrospectively .  
 8 Q. You felt it would have been counter-productive perhaps?  
 9 A. Yes, exactly so.  
 10 Q. Thank you. The Inquiry has also heard evidence,  
 11 including from a witness last week, discussing their own  
 12 son in supported accommodation, that they viewed  
 13 themselves as a key part of the care team for that  
 14 person that they were caring for; you know, a role that  
 15 was then taken away from them by lockdown. I think that  
 16 particular witness described that as — "a slap in the  
 17 face" —  
 18 A. Yes.  
 19 Q. — I think was the way that they put it. Is that  
 20 a sentiment you would share?  
 21 A. Very much so. It did feel like a slap in the face. Not  
 22 from the care team because we understood the position  
 23 that they were in, but from whoever it was that was  
 24 making those decisions, it felt to us that they didn't  
 25 understand the life of the person with PMLD or the

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1 nature of their disability or the setting that they were  
 2 in. And I or we, like any other PMLD family, had spent  
 3 a lifetime — our child's lifetime protecting them and  
 4 keeping them well, trying to keep them — in some cases  
 5 keep them alive and making sure that they were as safe  
 6 as they could possibly be. And actually we were at  
 7 home, just the two of us, taking every single precaution  
 8 that there was and so for Lauren to come to our house,  
 9 that would be the safest environment that there could be  
 10 for her, much safer than in her own house, because the  
 11 carers, obviously, they didn't live on the premises and  
 12 they would be going — there's a large care team because  
 13 there's a high level of need for the individuals in the  
 14 house and they would be going home to their own  
 15 families, which obviously would expose them to greater  
 16 risk. That is not in any way a criticism of them.  
 17 That's just the way it was.  
 18 But we were much — we'd have been a much safer  
 19 option for Lauren. She could still have come to ours  
 20 and we could still have looked after her and we would  
 21 have been — we were in touch with no one and it did  
 22 indeed feel like — a bit insulting to then be told,  
 23 "Well, you might have been looking after her and keeping  
 24 her safe for 30-odd years but actually now you can't".  
 25 Q. "Now you can't be trusted"?

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1 A. Yeah, now we can't be trusted.  
 2 Q. At paragraph 77 of your statement I think you say that  
 3 there should be recognition that families and other  
 4 unpaid carers are essential to the well-being of those  
 5 with PMLD.  
 6 A. Yes.  
 7 Q. Is that a lesson you think needs to be learned from what  
 8 happened?  
 9 A. Yes, very much so.  
 10 Q. I think at paragraph 57 of your statement you talk about  
 11 having obviously been hands-on, very hands-on, up until  
 12 that time of the lockdown. I think the word you use is  
 13 you felt "impotent", you felt there was nothing you  
 14 could do.  
 15 A. Yeah, yeah. Yeah. It's a strange thing. In my head,  
 16 all the time, I'm saying, "I'm coming, Lauren" — she  
 17 doesn't know that because she doesn't understand — but  
 18 that's what I'm saying to myself, "I'm coming, Lauren",  
 19 but actually, during that whole three months, I couldn't  
 20 come because I wasn't allowed, and that was awful. That  
 21 feeling of impotence was almost physically painful.  
 22 Q. You've mentioned earlier about Lauren's epilepsy and the  
 23 medication that perhaps can help to control that  
 24 condition. Was that medication kept under review during  
 25 that lockdown period as it should have been?

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1 A. It was — I can't remember the exact dates now but it  
 2 was probably somewhat protracted as a result of that.  
 3 She certainly didn't get to see the epilepsy nurse  
 4 specialist, but I think probably six months in there  
 5 was — that's not correct. She had an EEG some three  
 6 months after the first one, so that would have been  
 7 in April, and it was felt that it was acceptable at the  
 8 time. But actually it's been — it's difficult to say  
 9 because it's been a progressive reduction in the level  
 10 of medication since then, so it's really quite difficult  
 11 to work out exactly when it was, but it was progressive.  
 12 So she was being monitored throughout that time but  
 13 possibly not as much as she would have done if there  
 14 hadn't been a pandemic.  
 15 Q. The Inquiry heard, including from evidence this morning,  
 16 about the importance of postural care for those with  
 17 PMLD.  
 18 A. Yeah.  
 19 Q. What was the physical impact of lockdown upon Lauren?  
 20 A. Well, quite a serious impact really because, as  
 21 I mentioned, she'd had lots of injuries and potential  
 22 injuries as a result of the seizures that would throw  
 23 her around the room, on to the floor, against the walls  
 24 and so forth, and we'd been in A&E quite a few times  
 25 because of that. But what happened during lockdown was

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1 that her posture rapidly deteriorated, so she was  
2 leaning to the side, she was leaning forward, her  
3 posture -- when she was sitting, but when she was  
4 walking, it was the same thing, she was -- her balance  
5 was affected.

6 We tried to get her seen by physios. It took --  
7 I don't know -- a long, long, long time, at least  
8 a year, to get a physio to see her, and even then they  
9 weren't particularly constructive in, you know,  
10 suggesting what it might be. It was only, whatever, two  
11 years down the line and she was still leaning over to  
12 the side and her head was still forward and clearly she  
13 was uncomfortable -- whereas before she'd always had  
14 pretty good posture and it was only when I thought --  
15 thinking, "I have to do something, I have to do  
16 something, but I don't know what to do. Nobody is  
17 listening, I've nobody to speak to, nobody really  
18 understands" -- eventually I went to see a private  
19 chiropractor and the chiropractor has made an enormous  
20 difference.

21 She still -- she went to the chiropractor twice  
22 a week for quite a long time and then it's gradually  
23 reduced. It's now once every three weeks. So the  
24 chiropractor can tell when there's something wrong, he  
25 can tell when she's had quite a large seizure, so he can

1 tell by the tension in her body and so forth. But  
2 I couldn't actually get anybody to touch her, anybody to  
3 sort of lay hands on her. Everybody would observe her  
4 from a distance and it was enormously frustrating. But  
5 anyway, the chiropractor, very hands-on.

6 But his view was that probably what had happened was  
7 that Lauren had acquired an injury that had been  
8 undiagnosed, probably either just before COVID or after  
9 COVID, probably as a result of those seizures, and that  
10 what she had done was she had locked herself round it,  
11 so she was completely locked in her upper body, her  
12 shoulders, her arms. You couldn't get her to move her  
13 arms away from her body. They were locked there. So  
14 she was sort of, like, in that kind of position, you  
15 know, locked in, with leaning over to the side and the  
16 head forward, and she still does a little bit but it's  
17 significantly better than it was before. But she has to  
18 have exercises all the time to try and keep her loose --  
19 you know, keep her muscles loose and keep her mobile.

20 Q. So is that a longer-term effect then or impact, would  
21 you say?

22 A. Yes, very much so. It appears so. I think that that  
23 three months of inactivity would have had quite  
24 a serious impact and actually, if that had continued  
25 long term, there's no telling how that might have ended

1 up in a sort of scoliosis and just becoming worse and  
2 worse and worse. It deteriorated such a lot over  
3 a three-week period -- a three-month period rather, and  
4 I do remember her key worker at the time speaking to me  
5 on the phone and saying, "We're really worried about why  
6 it is that Lauren is leaning over to the side. We don't  
7 know why it is", and it was a long time before we found  
8 out that it was probably a historic injury.

9 Q. Do you think that should have been foreseen when these  
10 restrictions were put in place, that people like Lauren  
11 who have PMLD might suffer deterioration like that in  
12 terms of their posture?

13 A. Oh, absolutely, because there's always a -- there's  
14 a greater risk and also there's -- some of the  
15 medication that they have to take for epilepsy is  
16 bone-thinning potentially and so, you know, that should  
17 be monitored also, you know, before it leads to  
18 osteoporosis or other issues like scoliosis that are  
19 then uncorrectable, and of course scoliosis can have an  
20 impact on internal organs and we know that some people  
21 have died -- people with PMLD have died as a result of  
22 that.

23 We spoke to the chiropractor about that. He did say  
24 there was certainly the potential for that to happen  
25 with Lauren if it had carried on. And hopefully we've

1 caught it in time and it's not -- it's not completely  
2 better, but it is a bit better and it's not getting  
3 worse, so that's really important.

4 Q. Thank you. Now at paragraph 69 you talk about Lauren  
5 having contracted COVID I think in 2021.

6 A. Yeah.

7 Q. Now, I was going to ask you what the effect of that was  
8 on Lauren. I think you might want to put the record  
9 straight or straighter than it is in your statement at  
10 this point.

11 A. Yes. So at 69, and what I said was:

12 "Lauren did get Covid in 2021 but was not badly  
13 affected by it. She is no more likely than you or me  
14 with regards vulnerability to Covid as she is physically  
15 quite strong."

16 And I think that's probably true as far as it goes,  
17 and what I should have added there was it was more the  
18 social aspect of it because Lauren couldn't be  
19 contained -- for a start, she couldn't wear a face mask  
20 and she couldn't be contained in her room, which meant  
21 that, in her house, everybody else had to be contained  
22 in their room and so that had an effect. But also that  
23 again restricted her ability to be able to leave the  
24 house or to even go for a walk, and I guess, you know,  
25 as regards that and the postural issue is that that lack

1 of mobility is really significant for somebody in  
 2 Lauren's situation.  
 3 Q. Thank you. I think you mentioned at the beginning of  
 4 your evidence about the mental health impact on Lauren.  
 5 I wanted to come back to that now, if I can, because  
 6 I think at paragraph 44 of your statement you talk about  
 7 receiving a call from Lauren's key worker, expressing  
 8 concern about her low mood and I think the possibility  
 9 of depression is what you say there.  
 10 A. Yeah.  
 11 Q. What action, if any, were you or those supporting Lauren  
 12 able to take as a result of that phone call?  
 13 A. So that was around late May. COVID started in March.  
 14 We --- so I guess it was another month or so before we  
 15 actually got her home, so I was able to talk to staff,  
 16 but there was nothing really that I could do. I mean,  
 17 I saw photographs of her and I could see that she was in  
 18 distress and I could talk it through with staff and  
 19 I could make some suggestions about what they might do,  
 20 but actually, without seeing Lauren in person, it was  
 21 really, really difficult and enormously frustrating.  
 22 Q. How did Lauren appear to you when you were able to visit  
 23 her and see her again in terms of her mood? How did she  
 24 appear to you?  
 25 A. So we didn't go and visit her in the house because of

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1 the potential risks to other people living in the house,  
 2 so she was brought down to our house by a member of  
 3 staff and she was very low, very subdued, not animated  
 4 at all and clearly confused and puzzled, because  
 5 I suppose for people with PMLD, loss is often akin to  
 6 a bereavement because they can't distinguish the  
 7 difference between the two. So if somebody or something  
 8 disappears, they don't know that --- they don't know why  
 9 and they don't know if it's ever coming back.  
 10 So for Lauren, potentially what she was thinking  
 11 was, "I'm not going to see them again. I'm not going to  
 12 go there again. What happened to them? Where  
 13 are they?", and --- yeah, so there were no --- there was  
 14 no outpouring of joy or happiness when she came. It was  
 15 just quite sad.  
 16 Q. And has that continued or ...?  
 17 A. She hasn't really recovered. We would always have said  
 18 in the past that Lauren had a sort of joie de vivre.  
 19 She was quite a joyful, happy, animated person, which  
 20 made it hard work, but actually it was all worthwhile  
 21 because she did have a really good quality of life and  
 22 she was a happy person.  
 23 I wouldn't say that that was the same now. She has  
 24 spells now when she's --- you know, she's laughing and so  
 25 on, but far less than previously. I suppose you can't

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1 automatically put that down to COVID, maybe that's just  
 2 because she's getting a bit older, but certainly she was  
 3 much happier before than she was since, and she's a bit  
 4 better now but she's never really gone back to the way  
 5 that she was before.  
 6 Q. At paragraph 62 of your statement I think you make the  
 7 important point that those with PMLD like Lauren, they  
 8 don't have the same outlet for expressing the  
 9 difficulties that they might be facing. We've heard  
 10 evidence --- the Inquiry has heard evidence about, for  
 11 example, those with PMLD perhaps showing challenging  
 12 behaviour.  
 13 A. Hmm---hmm.  
 14 Q. Is that something that you saw in Lauren or not?  
 15 A. Yes, she has always had challenging behaviour --- I guess  
 16 that's the term that's used for it --- but actually the  
 17 way we would characterise it is that it's an attempt on  
 18 her behalf to communicate something that's wrong with  
 19 her. So it might be something that's physically or  
 20 emotionally wrong with her, but she's trying to tell you  
 21 something. The difficulty then is trying to work that  
 22 out. But, you know, it's a worry that for people with  
 23 PMLD challenging behaviour can often be --- it's the  
 24 behaviour that's looked at and addressed rather than  
 25 trying to understand the underlying reason for that

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1 challenging behaviour.  
 2 I don't think --- you know, challenging behaviour  
 3 doesn't appear out of nowhere and so Lauren does have  
 4 certain things that she does. You know, she ---  
 5 grabbing, nipping and squeezing and that sort of thing.  
 6 You know, we can understand why that is. We know that  
 7 that's her trying to tell us something and then we try  
 8 to address that, try and work out what it is that she's  
 9 trying to tell us.  
 10 Q. Thank you. Is there anything else in particular in  
 11 terms of lessons learned that you would like to share  
 12 with the Inquiry, giving your evidence today?  
 13 A. Well, I suppose --- I mean, I've spoken at length about  
 14 acute hospital pathways, I don't think I should say any  
 15 more about that. But I guess that the main lesson that  
 16 I would like to be learned is that the people who make  
 17 decisions about the lives of those with PMLD, they don't  
 18 know what they don't know and they need to find out.  
 19 And if we're trying to tell them, then they need to  
 20 listen because, you know, we often speak about feeling  
 21 invisible and I guess at the start of COVID we were  
 22 invisible, but actually we shouted long and hard to the  
 23 extent that we were no longer invisible, but we were in  
 24 essence ignored and sidelined. I think what needs to  
 25 happen is that there is an understanding that people

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1 with PMLD have valuable lives that are valued by others  
 2 and that they need to be given that respect. It's their  
 3 human right to have that and to not be ignored or lumped  
 4 in with others.  
 5 Q. I don't have anything else to ask you. I gather you may  
 6 have something that you would like to read?  
 7 A. Yes, if that's okay. So one of the things that I have  
 8 done before, during COVID and since, because of my other  
 9 responsibilities, is that I give lots and lots of  
 10 presentations about Lauren and about PAMIS and about  
 11 people with PMLD and I was invited to — and I do write  
 12 poetry. It tends to be, you know, mostly related to  
 13 learning disability and Lauren in particular, and I was  
 14 invited to write a poem for a trauma resource for people  
 15 with PMLD.  
 16 It's my imagined impression of what Lauren  
 17 experienced and how she must have felt or how she might  
 18 have felt during the pandemic. The idea behind the poem  
 19 is that Lauren might not be able to express herself  
 20 verbally but she still has the same thoughts and fears  
 21 and dreams and worries that everybody else does. So  
 22 what I wanted to highlight was that if you don't  
 23 understand the value of a person's life, then you can't  
 24 possibly appreciate what COVID took away from them.  
 25 So the poem is called "Going Home":

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1 "I can't say the word 'Lauren' but that's who I am.  
 2 I maybe can't speak but I'll do the best I can.  
 3 To know how I feel, then you just have to listen.  
 4 Pay close attention and you'll hear what I'm  
 5 thinking.  
 6  
 7 "I can't say the word 'Mum', but I know who she is.  
 8 The only problem is, I don't know where she is,  
 9 Where my sister, my brother or our sausage dog.  
 10 Why is it there is no one who can give me a hug?  
 11  
 12 "I can't say the word 'sad' but I know what it's  
 13 like.  
 14 No day service bus trips and no rides on the bikes,  
 15 No music therapy with my dad and my mum,  
 16 No guitar or piano or banging the drum.  
 17  
 18 "I can't say the word 'love' but I know how it  
 19 feels.  
 20 It's when I cuddle people and they cuddle me.  
 21 When someone understands me and makes me feel safe.  
 22 It's knowing I'm cared for that helps me to be  
 23 brave.  
 24  
 25

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1 "I can't say the word 'armchair' but that's where  
 2 I sit  
 3 And dream about my home when I could still visit.  
 4 My dad reading my stories seems so long ago.  
 5 I hope they're all still there but I really don't  
 6 know.  
 7  
 8 "I can't say 'lonely' but I know how to miss.  
 9 I wonder how long it can go on like this.  
 10 My family, my friends, my routines have all gone.  
 11 Might this be the day when I get to go home?  
 12  
 13 "I can't say I'm in pain but I know how it hurts.  
 14 My heart's breaking inside but I don't have the  
 15 words.  
 16 My shoulder's so sore so I'll just hold myself  
 17 tight.  
 18 Maybe someone will come soon to make it all right.  
 19  
 20 "I can't say the words 'thank you' to my lovely  
 21 staff.  
 22 Although I might be sad, they can still make me  
 23 laugh.  
 24 All the claps and the rainbows were just not enough.  
 25 They smile and they sing but for them it's been

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1 tough.  
 2  
 3 "I can't say 'swimming' but love kicking up my heels  
 4 And splashing and diving like a slippery eel.  
 5 I can't swim because of what's called COVID—19.  
 6 They tried to explain but I don't know what that  
 7 means.  
 8  
 9 "I can't say the word 'park' but remember the fun,  
 10 The swings and the ducks and the picnic and the sun,  
 11 The wee boats on the pond in all their bright  
 12 colours,  
 13 The wind in the trees and the scent of the flowers.  
 14  
 15 "I can't say the word 'happy' but see how I smile.  
 16 It seemed that the sun hadn't been out for a while.  
 17 So I'm sorry that I've reached the end of my poem  
 18 Because this is the day when I get to go home."  
 19 MR STEPHEN: Thank you for that.  
 20 A. Thank you.  
 21 THE CHAIR: Yes, thank you very much indeed.  
 22 And that's all for today, Mr Stephen.  
 23 MR STEPHEN: It is indeed.  
 24 THE CHAIR: Good. Tomorrow morning then. Thank you all.  
 25 (2.13 pm)

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1 (The hearing adjourned until  
 2 Wednesday, 15 May 2024 at 9.45 am)  
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