

All-Party Group on Coronavirus - Oral Evidence Session 14

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Layla Moran MP

Well, welcome everyone. Welcome everyone who's watching at home, welcome to our panellists and our Parliamentarians on today's session. This is the 14th evidence session of the All-Party Group on Coronavirus and today we'll be focusing on children who are suffering from Long Covid, so people will be aware that we had a debate on the floor of the House on Long Covid more generally a couple of weeks ago now and from that it has been clear that there is mounting evidence of the differing impact of Covid and Long Covid on children and that is what we want to explore in today's session which will last up to an hour. And we're very lucky to have with us three and we might well be joined by a fourth panellist, but I'll introduce the three that are with us now, so we've got Sammie McFarland, thank you for joining us Sammie. Sammie and her daughter have been ill with Covid-19 for over ten months now and Sammie is the Founder of Long Covid Kids which has been an incredibly important support group now evermore, an advocacy group for children who are suffering with Long Covid, so welcome Sammie, thank you for joining us. We also have Fran Simpson, Fran is a mother of two and who has been experiencing symptoms for almost seven months and she herself is also a sufferer of Long Covid and has been a founding member of the campaign group Long Covid SOS, so thank you Fran and thank you for helping to found that group and all the work that you do in that, it's a delight to have you with us. And we've also got Charlie Mountford-Hill, Charlie is the parent of five children with Long Covid and thank you all for being with us and sharing your stories and I'll start by just asking the question how did this happen. So, can you tell us your story as a family but if you could also focus in a little bit on the children, how did they get it if you can know how they got it, how did they present and how are they now. That would be really helpful to set the scene for further questions. And I'll start with Sammie.

Sammie McFarland

Thank you Layla. So, my daughter and I both got ill in March and I became ill first and then within seven to ten days unfortunately our 14 year old daughter Kitty became ill and at that time she started with a very minor cough and we asked her to isolate in her room, even though she wasn't feeling unwell. Within four days of being isolated she started to present with symptoms and started to feel unwell. They were symptoms of just general unwell, nothing significant, she had a mild temperature, she was a bit achy, she felt very tired and nothing too concerning, you know in terms of significant symptoms that we were panicking about. And then during the course of the period of time she was in isolation in her room she started to become quite I suppose a vacant expression and it was hard to communicate with her, she became very weak and floppy and she started to look very pale, had dark circles under her eyes. She was not really wanting to eat and it was a little while that she was like that before she then started to become quite unresponsive and we started to get a lot more concerned. We did at that point call 111 and their only response was, well if she's breathing OK she needs to be at home, and so we continued to manage her symptoms at home.

Fortunately, in our case she did come through that initial period of illness and made a recovery within two to three weeks I'd say, where she seemed a bit tired and a bit out of sorts but not, you know drastically unwell or anything alarming, just as you would expect after any virus really. And then we

started to do some very small amounts of exercise, so just walking, we've got a sausage dog so it's not long walks, a little walk in a flat woodland and we noticed that she would be then back in bed and making noises about being very tired and not wanting to come down and we didn't really think too much of it at first and then we did some gentle exercise in the garden as a family and we thought that maybe, you know she needed a bit of geeing up and after having been unwell and in her room for a long time and it was during that gentle session where she started clutching her chest and complaining of heart pain and she went very pale and very floppy and almost didn't make it back into the house to be able to get to her bed. And then she stayed there for pretty much the next seven months.

Unfortunately, all of her meals needed to be taken in bed, she didn't have the energy to sit up, she couldn't hold her head up, she was too weak. She had to use the walls and us to support her to get to the toilet, she would fall off the toilet because she didn't have the energy to sit on the toilet. She was unable to do any simple tasks, so showering sort of went out of the window and really her days were just spent in bed for the majority of time between March and August. Where we did have windows of hope and we could see a little bit of the old Kitty coming back and maybe we tried to plan a picnic, my husband would drive us somewhere and we would get out and sit down straight away and we might be successful in enjoying that for an hour and a half to two hours and you know it kind of felt like progress, but we soon came to learn that unfortunately with Long Covid everything has a kickback and if you do something then you can then end up having a long period of relapse, which we didn't realise was relapse at the time but we now recognise that as a pattern. And we learnt that actually those periods of activity didn't warrant the length of recovery and the more sinister and concerning symptoms that would be triggered by doing anything at all.

Just recently she has started to turn a bit of a corner and we put that down to being fortunate enough to invest in some private testing which identified that she is missing certain minerals and vitamins and that she's not absorbing well from the food that she eats, because we're quite food conscious, we're into our nutrition and unfortunately she hasn't obviously been able to absorb what she was getting. And since working with a Naturopath she is now able to be out of bed and she can manage, she's been going to school for two or three hours just before the lockdown, she was going to school for two or three hours but that wasn't every day and sometimes the school would call us to pick her up and often she would need to take days off between those two to three hours to recover. At this point in time she's managing Zoom school on most days for some hours, but often she does that in her bed and her activity levels then for the rest of the day are just in bed, so we are definitely not recovered but we have seen some improvements and we don't have any answers.

Layla Moran MP

Thank you so much Sammie, that sounds really, really difficult for everyone involved. Thank you for sharing that story and we'll come back to some of those themes that you've raised. If I could ask Fran please the same question.

Fran Simpson

Yes, of course. So, I became ill on March 11th, the week before lockdown, the first lockdown. And about three days later my five year old son started to present and his first symptoms actually testicular pain, although I didn't make the connection until later on because obviously I didn't realise that that was a symptom, but he said he had pain in his testicles. And then he went on to have fairly mild, his was fairly mild initially so he had a bit of a cough, he had a bit of a temperature, he had really strange insomnia, he'd be awake you know throughout the night, wide awake. And obviously at the time we weren't aware of what it was, it was only as we kind of pieced it together going forward. He went on to have varying symptoms, so he sort of got a bit better and then he got worse again and his has

fluctuated up until now. So, he has things like blurring vision, he gets headaches, he's nauseous most days, he has fatigue frequently so if he does anything you know he has fatigue like Sammie was mentioning. He went through quite a long spell of having something called Alice in Wonderland Syndrome where he would see people's heads shrinking, so he'd be watching a film and say you know Mum why has that man's head shrunk, you know it's got smaller and it turned out to be something called Alice in Wonderland Syndrome, which has emerged in various kind of people since.

My daughter who was nine at the time, she became ill about a week after I was ill and hers was much worse, she started with a sore throat, earache and then she was ill for six weeks with various, she was really fatigued, she was really pale, she stopped eating, she couldn't eat anything she felt so sick, she was dizzy, she nearly fell on the stairs one day as I was helping her down, she collapsed. She was either on the sofa or the bed for about six weeks. And she has since had rashes, she's nauseous most days, she has terrible anxiety and moods, OCD. She's had some cognitive changes, I would say she finds any kind of work hard and she's really quite a bright girl. She's had spells where she's felt like her throat is closing up, she has problems breathing, quite often she will say I can't get a full breath in. She's now on inhalers, I give her antihistamines and again hers gets worse and better, so you know she'll have spells where she's a bit better and then she's worse again. So, it's on-going.

And I think, you know just to echo what Sammie said you know we have no answers for this.

Layla Moran MP

Thank you, Fran, thank you. And Charlie, with your five, crikey!

Charlie Mountford-Hill

I apologise if there's any background noise because they are all in the house.

Layla Moran MP

That's fine! They're very welcome to join us if they want to.

Charlie Mountford-Hill

So, for us end of February I got a really weird cold that I couldn't shift, I had a hoarse throat, I felt tired and cold and I just, there was a couple of days that I spent in bed, so I think that was the beginning for us and then the day that the children started getting sick, Mimi was four at the time, it was my husband's birthday, it was the 6th of March and she woke up with just screaming in pain with a sore neck and we thought she had slept funny, she would potter around and then begin to cry again, she was very lethargic, tired and this kind of went on for about a week and she started to have belly aches, headaches and she just, we sort of ... she went to school a couple of days and she just couldn't cope basically. Within the next week my ten year old, well he's ten now, began with horrific gastric symptoms, feeling sick, severe lethargy but really gastric for him and again Mimi was getting a lot of upset tummies, really bad tummy pains. And then I began to feel worse and worse, I had a lot of chest pain around my heart, we're a very fit, active family. I remember trying to go for a run and having to stop because I just felt like I was gonna pass out. I got a lot of gastric pains and then it sort of hit its peak on Mother's Day, the 22nd of March, it just hit me like a wall and all of a sudden I couldn't breathe, I couldn't stand, I was shaking, my husband is a pharmacist and he started with a dry cough and a

temperature, so he got the typical symptoms, whereas for us, he was very gastric as well but the children had had these symptoms which weren't necessarily deemed Covid at the time.

We then spent 14 days obviously isolating, the two children who were obviously sick continued with this lethargy, Mimi ended up with ear infections, we barely got out of bed. I remember lying in bed one day and thinking I really need a glass of water and not being able to reach out to get it. We were that poorly. I had three other children at home who seemingly weren't sick or it was very mild. So, we got through that 14 days and it was horrific, it was horrendous, we were all very sick. But you know we were then told, you know it only lasts 14 days, we thought we would then begin to get better. Somehow my husband managed to go back to work, I still couldn't get out of bed, Mimi couldn't get out of bed, Indie began to have breathing difficulties at this point and actually the initial illness was awful but the next, it's coming up to almost 11 months now for us, has been much, much worse. So obviously I've got a lot of them so I'll try and keep it to bullet points.

But, for Mimi aged four obviously we were told it didn't affect children, she couldn't get out of bed, if she did get out of bed we were lying her on the sofa downstairs or maybe trying to bring her out in the garden to get a bit of fresh air. If she tried to walk she was clutching her chest and telling us her heart felt funny. She couldn't walk on her feet, they hurt too much. She was hospitalised in April because she was losing so much weight, she had gastric pains, rashes, headaches, the list was endless. She then continued to get worse and was hospitalised again, this time via ambulance because I watched bruising spread from her temples all across her face. Her heart rate was really high. She had three different skin rashes, she had strawberry tongue, she had mouth ulcers. She would have these episodes where you'd call her name and she wouldn't respond. She didn't get off the sofa. Constantly passing pale stools. Constantly, she would wake up every morning crying in pain with her stomach. Her hands were peeling, her feet were peeling. She was covered in bruises and she got admitted and they ran some blood tests and they said there's nothing wrong with her and I asked them, by this point I had lists of symptoms and what I'd written down multi-inflammatory syndrome, I'd written down vasculitis, I'd written down you know all these storms that are happening in the body but no, they ran some blood tests and because those blood tests came back normal she was sent home with no support and no help.

Indie, his breathing got worse, he started to have allergic reactions to food, we had to rush him to A&E in May as well, by this point he had all the whites of his eyes had turned red, he had bruising all over him, his eyes had sunken and he had these nose bleeds which we couldn't get under control. And I mean I've got four boys, they're always having nose bleeds and split lips and stuff but this was nothing that I've ever seen before, just, you know copious amounts of blood. Again, I took him in and I was told there was absolutely nothing wrong with him, they didn't even run blood tests. I broke down and was completely hysterical because I kept saying since March, no, no, no we don't want to know about March, I want to know what happened now. All children have nose bleeds. And I was hysterical and they actually opened a multi-agency referral form against me saying I was an unfit mother because of how I presented because I literally broke down and sobbed and begged them to listen to me.

On top of this obviously I had a lot of heart issues, I presented at A&E five times with chest pains, repeatedly told there was nothing wrong with me, it was only when the GP ran a specific blood test it showed my heart was at an increased rate of failing and I saw a Cardiologist via the phone and I was diagnosed with pericarditis. As well as all this going on three children who didn't seem to be ill began to have rashes, one came out in shingles all down the back of his leg, really flushed cheeks, the whites of their eyes were turning red, persistent headaches. My 12 year old, his feet got so sore he couldn't physically wear shoes. My 15 year old had a lot of testicular pain and he was actually hospitalised in November with it again, and again no one would listen to me that it was related to having Covid in March. They said it was torsion yet they couldn't find any evidence of torsion. And it's still on-going.

So, a bit like Sammie we have seen improvements, very, very slow improvements. I mean if I look back now I can see where we've come but it is very up and down and Emmett who is eight who never seemed ill at the time is now presenting with you know really red cheeks, gastric symptoms still, we are waiting for an ENT referral for him because he seems to have sleep apnoea, the way he describes it as an eight year old, as I fall asleep Mummy my heart stops and I can't breathe and now I have Mimi sleeping in my bed because she still feels unwell, I have an eight year old sleeping at the end of my bed propped up on pillows because he repeatedly wakes up in the night gasping for air. Indie has recurrent rashes all over his thighs, mouth ulcers, headaches and Mimi she's made improvements for sure but I look at all my children and none of them are the same children who they were before we got sick, before March I had children who were outside playing, doing sports everyday and now I have children who all look shattered, all need more sleep, Indie in the snow on Sunday kept having to stop to catch his breath. This is a child who plays in two different football teams and does all the after school sports that he can get his hands on and yet he can't breathe properly still. And both me and my husband are still sick as well.

Layla Moran MP

Thank you, Charlie, my goodness me. That was really moving that account, thank you for sharing it. And thank you all. What we're hoping to do now is to drill into different aspects of that, so I'll pass to other Parliamentarians to do that and I'll start with Lord Strasburger please.

Lord Strasburger

Well, good morning ladies, thank you very much for coming to share your stories with us. They're really horrific. I'm hearing from you that the symptoms that your children are suffering from are fluctuating a lot, could you give me, you already have given some indication but could you give me a bit clearer indication of what the direction of travel is for the symptoms, are they overall getting better, getting worse or staying around the same? Charlie would you like to go first?

Charlie Mountford-Hill

I would definitely say it's been a very slow upward improvement but with big dips as well and I think for me personally my concern is the long-term effects this is having on my children. My 15 year old with his testicular pain, will he have fertility issues. They've all had heart pains, could they then go onto have cardiac issues. We have seen improvements but if they do too much you then seem to take two steps back sometimes as well.

Lord Strasburger

So, it's all very slow.

Charlie Mountford-Hill

Very slow, I mean it's 11 months on the 6th of February that Mimi got sick and she's still not right at all.

Lord Strasburger

Thank you, and Fran?

Fran Simpson

Yeah, I would have said about three weeks ago I would have said that we were making improvements and then I took my children out in the snow a few weeks ago, we went to the forest and we had a very short walk in the snow and the day after my daughter was really ill again, she was back in bed. Then my son the following day he woke up and he had a fever, his vision went blurry again, he couldn't see properly. He had a strawberry tongue again, so you know that was another week where they were both as ill as they'd been really at various points. So, for me it feels like we kind of make progress and then I start to feel optimistic and then something happens or they just for whatever reasons we're back to square one again, so I don't see huge amounts of improvement. You know my children everyday struggle to eat because they feel sick at various points in the day. You know my daughter's breathing is probably worse now than it has been before and you know again I think like Charlie was just saying about her children, she wakes up, she'll say I'll wake up in the night and I can't breathe properly, it feels like there's no air or I've stopped breathing. So, the symptoms are bizarre and they change and sometimes they get a bit better but then they'll get worse again, so I don't really see improvement I just see change and to echo what Charlie just said, I don't know what the long-term implications are.

Lord Strasburger

You seem to be saying that any sort of exertion brings on a relapse is that fair to say?

Fran Simpson

I think so yes, I mean they complain about being very tired. I said to my daughter the other day it would be really nice to go for a walk with you tomorrow and she said I'd really like that Mummy but I can't. I can't, I'm too tired.

Lord Strasburger

Thank you very much, and Sammie what's your experience?

Sammie McFarland

So, very similar to Charlie and Fran. I would say we had absolutely no improvement for the first seven months actually and then we have had a very slow glimmer of improvement. Recovery isn't linear, it's like being on a constant roller coaster of unwell, there is no point where we have felt well, we just sometimes feel less unwell if that makes sense. It's really very difficult because with children especially you know you're having to try and explain to them they need to pace so if they do have a period where they feel a bit brighter they obviously want to use that energy immediately and we are as parents having to say please slow down, please reserve a little bit, you know trying to explain the spoon theory of not using all your spoons in one go, save some because you're gonna need to have a shower later and you're gonna need some energy for that. Or you're going to need to sit at the table to have your meal and you need some energy for that. And it's very difficult because at the beginning

their friends are very supportive and then as the months go on their friends find it very difficult to understand because you know some of the children don't look different, they look you know a little bit sort of paler perhaps or a little bit more tired looking but they don't look as a younger child might consider as being sick. So, our children find it difficult to explain to their friends why they can't participate and join in and it's really hard, really hard.

And we're not well, you know we're approaching ten months and for example Kitty can now make her breakfast, she can stand and make her breakfast but that's an activity, that's nothing more than an activity that then requires her to rest.

Lord Strasburger

Thank you and I realise that none of you are medical experts but in the course of your work in the group can you tell me anything about what is the prevalence of Long Covid amongst children, what's your understanding of that? Would you like to go first Sammie?

Sammie McFarland

We've actually surveyed our group and had 222 responses as a rapid survey and we have ... sorry now my brain fog has kicked in, please may you repeat the question?

Lord Strasburger

I'm asking what you know about the prevalence of Long Covid in children.

Sammie McFarland

Thank you. So, we have a large proportion of the group are affected and have been affected for many months and the symptoms, there are over 100 symptoms. Fran would you like to contribute here?

Fran Simpson

Yes, sure OK so I wrote something for the BMJ Opinion back in October about counting Long Covid in children because there hasn't at that point been any quantitative data, nobody had been counting this, and you know I did a brief survey at the time which gave me an indication that this isn't just an anomaly, I'm not an anomaly there are lots of children out there. The ONS have just released data that says 15% of children are symptomatic after five weeks, now I'm not sure how accurate that is, I expect that's an under-estimation because we are seeing quite a lot of children who are better after the initial acute illness and then the Long Covid comes in two to four weeks afterwards, which actually lines up quite well with the PIMS and MIS-C Kawasaki-like syndrome. We're also in our group, we surveyed and we found that 8% of children with Long Covid were asymptomatic in the acute stage and 37% were very mild. So, you're looking at largely 50% of our group who had very mild or asymptomatic acute infection and went on to have Long Covid. So, there's questions around how many children out there may have Long Covid but the parents aren't even aware that they had Covid in the first place and therefore how do you count something that you're not able to measure.

Lord Strasburger

I can see that being difficult. Charlie have you got anything to add?

Charlie Mountford-Hill

I don't have any data as such but my husband as a pharmacist is seeing a massive, massive increase of children and adults coming in with new allergies, random skin rashes, peeling feet, eye issues, these red eyes, viral conjunctivitis and he said it's insane, it's just literally gone through the roof and all he can think is, and obviously with our situation, it has to be related and a lot of these people don't know or don't think they've necessarily had Covid and yet they're presenting with a multitude of Long Covid symptoms.

Lord Strasburger

Well thank you ladies, back to you Layla.

Layla Moran MP

Thank you very much. That's really helpful and it's clear that there's a lot more research that needs to be done, it's certainly one of the things that we'll press on your behalf. If I could just quickly ask a question about schools, so for those who are in school how has this affected their school work, obviously that will vary over time but I'm also interested to know how has the support been from the school and what accommodations have had to be made for the kids, and perhaps I'll start with Fran this time.

Fran Simpson

OK, thank you. So, my children had no learning at all in the first wave, you know they were too ill to engage with any online learning and I contacted the school on a number of occasions and said you know I really am struggling, I don't know what to do and at the time of course Long Covid wasn't really known about anyway and certainly Long Covid in children. But, you know to be fair on my children's school they have been quite supportive compared to an awful lot of the schools that we hear about in our group. And they went back to school in September but had to have frequent days off for not feeling well enough to go in and then I kept them off because they were finding it really hard, and also you know to put it into context I do feel that we have ... the fear of reinfection for us is very, very real. You know for people in our position, the idea that we may get ill again, that we may have to go through this or worse again makes us, well certainly for my family but I'm echoing what lots of people say, very, very reluctant to put our children into schools where they may get reinfected. But that has had an impact.

For working now, they can do, depending on how each day is different and on some days they can do a bit more, other days they can't do anything at all. And the school like I say have been quite supportive, but it is very, very difficult, you know. I feel they've missed an awful lot of education through ill health.

Layla Moran MP

Thank you. And Charlie and who's with you, hello!

Charlie Mountford-Hill

This is Mimi. So, for Mimi she's not done one full school day since she's been sick. I've had to fight for that. I mean the school were supportive at first, I don't think they realised how sick she was obviously because when she was at her worst we were in the lockdown and the school holidays, but she just couldn't handle anything more than a couple of hours in school and you could just see it in her, so she's done half days ever since. I've had a lot of pressure to have proof for why I'm not sending her all the time, I've repeatedly asked my GP and even in writing but I haven't received anything proof wise yet. Indie and Emmett have had reduced hours, they were having very big relapses and actually we kept retesting them thinking that maybe they'd got Covid again because the relapses were so severe but they came back negative. So, they've missed days. Nico and Beck who are both at secondary school, Nico is meant to be doing his GCSEs this year, again they've had reduced hours, their attendance isn't great. I must admit their school was amazing in the sense that they acknowledged what was going on. They said that they had other children supposedly that seemed to have these symptoms but it's definitely affected all of them and you can just see as well, even if they were going to school they had nothing left in the tank afterwards and like I said normally I wouldn't pick them up till like four or five because they'd be doing hockey and tennis and so yeah, it has really affected their attendance. For me personally I couldn't work for five months and even now I'm on reduced hours.

Layla Moran MP

Thank you, Charlie. And Sammie, and also if you could expand into what else you know from the group that would be helpful. We've heard for example about some parents receiving fines for not being able to get their kids to go in, other stories like that would be really helpful for us to understand the whole picture.

Sammie McFarland

Of course, so for us we were obviously ill in March and so the school had nothing to compare it to that we didn't really know what was wrong and when we talked about going back to school in September and I approached the school and said look, Kitty's not going to be well enough to come back for full days, you know could we come in and have a meeting and we did go in and have a meeting and it was very challenging because we don't have any evidence and schools want evidence just as Charlie said, so there was a lot of pressure around you need to provide some medical advice. The school have been supportive but I feel are completely unable to understand what it's like to have a child with Long Covid. They suggested things like Kitty could come into school and then they could give us a ring if she got too tired, that she could put post-it notes on the front of her desk if she got tired to let her teacher know she needed a time out and not to be asked questions. I asked if there was going to be anywhere she could rest during the day because one of her concerns was that she was going to go back to school and then if she suddenly had a significant deterioration which often happens, it can go from being OK to not OK in a very short space of time and I'm talking like five or six minutes, where could she go to get that respite or to know that there's going to be a place of safety for her. And also fear of embarrassment and all the things that you know go along with being a teenager anyway, all of those types of things were her concerns.

And they said well there isn't really anywhere she can go because she can't go in a room on her own that would be a safeguarding issue, she could come and sit in an office with a teacher and I was trying to explain she can't sit, if she gets bad she needs to lay down, she won't be able to hold her head up. And she may not even be able to stay awake. You know it's not practical to wait for that to happen and then get a phone call and come and pick her up, as it happens I'm not able to be back to work myself due to Long Covid and we do live reasonably close to our school and right now it would be possible, but it wouldn't help her recovery because it would trigger a relapse if we let her get to the point of being that unwell then it's going to take her days, possibly even a week to recover from that incident.

One thing that we've continually struggled with is the question of please can we have some medical evidence and you know the best I could get from a doctor was writing one paragraph to say that Kitty had had symptoms of Covid and that that should be considered. And unfortunately, you know right up until this week I've had a phone call from the school, Kitty didn't log into one of the maths lessons on Zoom and they saw that she hadn't logged in and so they called us and I explained that she was very tired, that she was going to take a break and they said well she needs to log in in the mornings because we're monitoring attendance and I explained that she wouldn't be attending because she wasn't well enough and they felt that she should still be logging in so that they could monitor the attendance, which I voiced my concerns over.

In our group we have stories of fines, harassment, bullying behaviour and these are the words that the adults, the parents, the carers describe from the treatment from schools. They are getting either contacted daily or certainly weekly. We've had parents issued with fines, threatened with Inclusion Officers, asked to attend various care meetings and we had one parent voice her concerns really clearly, she's a clinically vulnerable parent and she was worried that if her child went back to school she might get reinfected and the Head Teacher said well, you know that's not really my problem, she needs to be in school. And you know these are big questions that we as a group are raising, there isn't currently a registration code that schools can put to mark children absent and I feel that that puts a lot of pressure on schools to try and get their attendance marked in, because obviously they want their numbers, they want their attendance rates. But we really have a much bigger picture here, we have to look at how we can safeguard the health and wellbeing of these children for the long-term and if we force them back to school then my fear and many of the parents in our group's fear, and I know Fran echoes this too, is that we are going to trigger long-term health conditions. And we know this to be true from the ME community and we only need to look at the history of the ME community and what they've gone through to understand that we must not let this happen to another generation of children.

Layla Moran MP

Thank you very much. Fran do you have anything to add from your group that's building on that?

Fran Simpson

Well I mean I do, I'm working alongside Sammie a lot now so I'm kind of in both campaign groups because obviously I've been campaigning for children through Long Covid so I've spent quite a long time and now I've linked up with Sammie because together we can actually achieve more for children. But I think the message is clear that children, a lot of parents are really finding the situation difficult with schools because without the diagnosis, while it doesn't exist it's a very difficult situation. We're relying on the understanding really of the teachers and the head teachers, so many people are finding it really difficult.

Layla Moran MP

Thank you, which brings us on I think very neatly to Baroness Brinton.

Baroness Brinton

Yes, thank you and just to say there is statutory guidance for schools on how they should be helping children with long-term medical conditions but most schools I'm afraid don't know about it and you should be covered by that but it relies on medical people identifying that your children have got Long-Covid, so my question is about what support have you had from your GP and has that support changed as they've become aware, either just of your child's problems or more generally about Long Covid in children. And do you feel they understand it? And I'm also interested in whether or not you have had access to other community health support such as physiotherapy and occupational therapy, you know particularly if your children are struggling even to sit up. Could I ask Charlie to go first on that one?

Charlie Mountford-Hill

As of yet, nothing. Even you know I've fought, my GP, I must admit my GP has listened, my GP has seen me, my GP has no answers. He agrees that obviously something happened in March and ever since then, because he never saw my children before that, something has happened. I did have a massive, massive breakthrough possibly almost two weeks ago, a new Consultant took over Indiana's case so he's a ten year old and he has a diagnosis of Long Covid which even now I'm getting quite emotional about it because this is acknowledgement. It doesn't mean I'm gonna get any answers for him or necessarily any treatment but I have it and I can say to schools that my son has Long Covid, this is why he's struggling, they are supposed to be referring him for a lung function test because he can't breathe properly. He will be referred to Oxford I'm told. I then because I'm stubborn, rang back and said Mimi who has definitely been my sickest child is under a different consultant and all they wanted to do was re-run some blood tests, so I asked for a second opinion and I said if you won't give me a second opinion, I want this Paediatrician, this Consultant to take over her case. I haven't got that piece of paper with her diagnosis in my hand yet, but I'm told that it's coming. That leaves my other three children who are in the system for various things, my 15 year old has a heart scan on Thursday, he's under Urology because of the testicular pain, they've all to Ophthalmology appointments because of this eye but whether they will be able to get a diagnosis for all of those things I don't know. But as of yet we have had nothing other than an inhaler for Indie.

Baroness Brinton

Thank you. Fran.

Fran Simpson

OK, so I think my experience is mixed. You know obviously going right back to the very beginning what I did find was that I had to be careful about how often I contacted the GP, I was very aware that I could become, you come across as a neurotic mother and I think that's a really common experience, you know the fear of Munchausen's or you know being attached to my name and obviously because I was unwell I had Long Covid I didn't know what was wrong with me, so I'm ringing about myself and my son and my daughter and I kind of felt like I had to decide who needed the call the most so that I

wasn't ringing in saying I need to see somebody and both my children. And I've come up against some very good GPs and some very poor GPs. Certainly my experience a couple of weeks ago when my son had a relapse and I rang again to say you know he's not well today, he's got a temperature, he's saying he's got blurry vision again, his tongue is red and looks like a strawberry, he's feeling nauseous and that GP said you know well he's probably, his vision is probably not good because he's just got out of bed and he's got sleep in his eyes, he's about the age where they'll say they feel sick to get out of eating food they don't want to eat, you know he literally minimised everything I said and I was so upset actually the following day I think I spent most of the day crying because it felt like this has been going on for ten months now and then I made an appointment and I actually took him in to see a different doctor the following day and she's referred him onto a Paediatrician and she said, you know his tongue looked like Scarlett Fever but I don't know and I said well could it be connected to the fact that we've had this on-going thing and she just sort of said well, you know I don't know anything about that, you know. So, I have experienced a very good GP for myself but in terms of my children it's been more hit than miss really.

Baroness Brinton

Thank you and Sammie.

Sammie McFarland

Thank you. I've had a very frustrating pathway with the doctors, we were ill at the point where they hadn't seen anybody else so they were initially empathetic when the GP came out to the house about two months, three months after we got infected and they thought I had a secondary lung infection and actually the bloods were negative but it showed some reduced kidney function. So, they sent me into the surgery two weeks later for an appointment with the Nurse to have follow-up bloods and that was the first time I'd seen another human being since I'd been unwell. It was the first time I'd left the house and she asked me how I was feeling and I burst into tears because you know it was an overwhelming harrowing experience because you don't know, we didn't know at any point were we gonna be in the ambulance going to hospital because all we heard on the news were people being put on ventilators. And so it was, you know I cried and she proceeded to tell me that I had depression, I'd never met her before, she's never met my child, I had depression and I reasoned with her that I didn't feel like I had depression but I was really fed up of being unwell and that I was trying really hard to get better and I wanted to get better and I was speaking to my family on the phone and that sort of thing, engaging with life where I could but actually I didn't have the energy to do much. And I said but you know I also have this child who's ill too and she has symptoms, they're not the same as mine but she has symptoms since she had Covid and the Nurse told me that my daughter was mimicking my symptoms and that her own symptoms were related to being locked down and missing her friends.

And it was that experience that led me to create Long Covid Kids and to create the awareness film because I was so angry, so frustrated, so upset and I came home and my husband tells me that I hardly spoke for three days, I stayed in bed, I didn't really eat, I was crying, I slept a lot and then I woke up after that third day and I remember it really clearly, I just thought there must be other people like me, this is not in my head and I then found the Long Covid support group which at the time had 5,000 members and now it's got 34,000 members and I read lots of stories from other people like me and I reached out to other people in the group and said look, are there any other parents who would like to help me make an awareness film about what we're experiencing and then you know the rest is history as they say.

But we have had one blood test, maybe two blood tests for my daughter, we've had one ECG which I had to really, really push for and we've had one Consultant appointment with a general paediatric

consultant who had not looked at our notes before we arrived, he had said he'd never seen Long Covid before, he didn't know it existed in children and my concern is that our daughter put so much hope on that appointment and we went to the appointment and she said to me in the car park it's OK Mum, oh sorry ... it's OK Mum, when we know what we're dealing with it will be OK and we'll know what to do and then we went to the appointment ... sorry, and the doctor said this is really new, we don't know what we're doing, you have to know that we don't know anything about it yet. I can do some research, I'll come back to you and I urged him to ... I'd also obviously done a lot of research before that appointment and sort of tried to deliver the information sensitively in the hope that it would engage a healthy conversation and he sort of was very dismissive of my questions and said that well you've clearly done your own research and I eventually convinced him to actually do a physical examination and he looked at her and he said well she does have some signs of PoTS but you know it's nothing significant and I can hear a bit of a heart murmur but it's an innocent heart murmur and I said but she didn't have a heart murmur before, and unfortunately he said he would go away and do some research and just before Christmas we received a letter to say that no appropriate clinician was available and we'd been taken off the list.

So, to this day our daughter has not had any investigations and still has the same symptoms and still has a heart murmur that we have no diagnosis or screening for. She's also had to see an Optician; her eyesight has deteriorated so she's had to have very strong new glasses which the Optician thought was unusual and has called her back in for another appointment within three months. And community support we've had nothing and actually worse than nothing we don't get any support now at all, you know I don't feel, like Fran was saying, I don't feel I can phone the surgery because I'm concerned what they think of me and whether you know it's going to cause more problems than benefit, so at this moment in time, nothing.

Baroness Brinton

Thank you all so much.

Layla Moran MP

Thank you, thank you all. Just before I pass over to Baroness Masham, can I just ask Sammie, how big is the group now?

Sammie McFarland

So, as of this morning we've got 688 families, about 50% of the families that we've surveyed have one child and other families have between two and, is it eight children Fran I think, with Long Covid and I actually don't know the exact numbers because obviously it's the parents that come into the group but yeah it's a significant amount. And we're growing of a rate of about 30 families a day since Christmas it's been going up quite quickly. So, yeah it's definitely a growing problem and we imagine that there are many, many more children as Fran said earlier in the community that don't know that they have Long Covid and also we fear that there are lots of children who aren't getting tested and will even know that they have Covid because the testing criteria on the Government website asks questions that relate to the symptoms that adults have and actually don't ask questions that relate to the symptoms that children present with. So, we often get emails from parents to our support group asking whether we think they should get their child tested and we of course always say if your child is unwell you must seek medical advice and get a test. Because we've learnt that any symptom of unwell can be Covid in a child.

Layla Moran MP

Thank you, Sammie, that's really very helpful. We've got technically five minutes left, I will push that envelope a little bit but as we look to the future now, the present and the future is what I'd like to focus on in our last five or ten minutes. Baroness Masham.

Baroness Masham

So, when Covid restrictions are lifted, what are your worries for your child's future and I'd just like to congratulate you for what you're saying and what you're doing, and your group and I wanted to ask you also what can we do to help you because that's why we're here. First of all, we'll have Sammie.

Sammie McFarland

Thank you, I'm actually feeling quite emotional that someone's asked us what they can do to help because we don't often hear that, thank you so much. There's a reluctance to accept Covid in children and I believe it's because it could induce a mass panic but that's not a good enough reason to sacrifice the long-term health and wellbeing of children and not my child, not anyone else's child, and we feel very strongly that we desperately need help. We need Long Covid to be accepted in children. We need the very senior medical professionals to accept Long Covid in children so that we're going to see a difference at a local level. When lockdown is lifted my concerns are that the schools are not safe places, unfortunately we know that the virus is transmitted via aerosol transmission and until that is accepted schools are not going to be safe and children understand so much more than we think, they hear it everywhere, they are fearful of going back to school. You know of course they want to see their friends, we want children to be educated but more than that we want our children to be safe. Our families are fearful of reinfection and one of the concerns that we have is that there's never been a Government campaign that highlights what happens to children, what the symptoms are, the long-term lasting effects, when to get a test and so therefore parents don't have the information that they need to make informed decisions. And in the absence of any strong leadership on this we really feel that parents have the right to at least have the information so that they can make informed decisions, because without that how are we going to keep these children safe, how are we going to allow education to continue?

Baroness Masham

Thank you very much. And Charlie?

Charlie Mountford-Hill

Hello, yeah my biggest fear coming out of lockdown is schools reopening if I'm honest, I don't think they're safe. For me I definitely have post-traumatic stress disorder from all this so every time they cough or they sneeze I panic, we've actually, my daughter actually tested positive again in November so for us we have had it twice in our house now and I think my concern is we are constantly told that children don't get sick, we are constantly told that children ... you know we've been told for months that children don't spread it, that they're safe and they're not. You know I've got five children who clearly have suffered from this virus. Children aren't safe and schools aren't safe. And it's not safe for people who are working in schools as well so actually I feel like at the minute because they're talking

about reopening schools, don't get me wrong, home schooling is really hard when you've got five children but I know my children are safe at home and I want them to remain at home until it's safe for schools to reopen because at the moment I don't think it is and I think the Government really need to accept that. And the Government really need to accept that children are affected by this and that Long Covid is a massive thing for children as well.

Baroness Masham

That was such a difficult message that went out that children didn't get it, children ... you know that was a hugely difficult thing and Francis, have you got something to add?

Fran Simpson

Not really, I think both of them [inaudible 1:08:36.6]. I've been banging this drum since August and I've faced a real lack of curiosity by medical experts, by researchers, you know almost everyone I've spoken to when I have said I think children are getting this and they just [inaudible 1:08:59.2] and I've never been quite sure why there's such a desire to not explore this as a situation, as a problem. But I think they've just summed it up, you know the school thing, the PTSD, you know I think on two separate parts, there's the part that doesn't want other people to be where I am, you know the preventative part, I really, really want people to know that this is possible and please don't end up where we are. And then there's the mother part of me that is frightened for my children, frightened for their long-term health, whether they'll ever get better again, you know so yeah lots of things, you know that I worry about post-lockdown.

Baroness Masham

Well thank you very much and we will try and do our best to help.

Fran Simpson

Thank you so much.

Layla Moran MP

We certainly will and off the back of that and a couple of you have now mentioned PTSD which is entirely understandable, could I ask a more general question about both your mental health but also the mental health of the children in going through this process. Fran, it's clearly very worrying, how has that manifested for you and your family?

Fran Simpson

Well I think again, I think there's two things that go on with Covid, I think Covid itself causes neuropsychiatric symptoms, I think the more that we learn about the role of the virus and the brain and I certainly have seen that in myself and I've seen that in my daughter, extreme mood changes, anxiety and then of course the whole experience of living through this, you know these bizarre unsettling symptoms, the constant hypervigilance of watching to see whether this symptom is gonna be the one that you have to take them to hospital or not. You know what does this mean, what can I

do about this, can I turn to anyone? So, you know it's had a huge and appalling effect on our whole family's mental health.

Layla Moran MP

Thank you very much. Charlie.

Charlie Mountford-Hill

Yeah, I would say my mental health has been stretched more than it ever has in this last ten months. I've been on the floor on my knees in A&E begging doctors to listen to me. I've wailed on a paediatric ward when I was told my daughter was just lying around watching more TV because all kids were watching more TV in lockdown. I have five children, my husband works very long hours and I'm used to packing them in the car and taking them out and spending all day with them, I now am so anxious that I can't take them out for a walk on my own, what if they touch something, what if they go near someone, what if they get it again, what if people don't want to come near us. And when my daughter tested positive again I didn't eat or sleep for three days because I was like, you know we're back here, we're back at the beginning again.

The children thankfully, like I have noticed, I can see their frustrations because they're not as well as they used to be but they kind of potter around and it's more my 12 year old that has had concerns, his tutor has mentioned he's very quiet, that he's very much a closed book anyway and he's kind of internalised it all, I mean they've watched their sister go off in an ambulance, they've watched their parents be sick. For me and my husband it's been a massive strain on our relationship and just in general and I just, I'm not sure I'll ever get over it and I just feel like every day is survival at the moment and it's just really tough.

Layla Moran MP

Thank you, Charlie. Sammie.

Sammie McFarland

Thank you. So as a group we recognise that all children have been affected by the pandemic but we would say that children that have experienced Covid at first hand are affected the most. Their inability to participate in life, their loss of health, their inability to maintain education or friendship groups, the fear of reinfection, the fear of losing a parent or a teacher is huge and we desperately want the Government to recognise that wellbeing needs to be placed into the heart of education, we want our children back in education, we desperately want them back there but if it's not safe and they're continually fearful and the parents are continually fearful it's going to make getting back to education very difficult. So, let's just really be honest and make schools safe, please join the dots and recognise mental health is being affected, education is being affected and until we get those places safe for our children we're not gonna move this forward.

Layla Moran MP

Thank you very much. And to round us off Lord Strasburger.

Lord Strasburger

I just want to speak on behalf of all of us Parliamentarians to say how much we admire what you're doing and what you've done. I can't believe you're still at it, still vertical. You're very brave, this is a national scandal, you've been ignored, you've been marginalised, you've been disbelieved, you've not been offered any treatment for you or your children, you've not been offered any support, you've not even been offered any interest. So, it's a really dreadful situation and it's an outrage. So, I've got one last question for you, if you could give one message to the Government what would it be? Do you want to go first Sammie?

Sammie McFarland

I would ask the Government to recognise that this virus is transmitted via aerosol transmission because until they do how are we going to stop people getting infected, we do not want other families to share our story, we do not want a generation of long-term health condition in these children, just please, please recognise it.

Lord Strasburger

Absolutely. Charlie.

Charlie Mountford-Hill

Very similar I would like the Government to acknowledge that children can get very sick, acknowledge that children do spread this virus and put in place support for those who need it and make sure this filters down to those who are going to be seeing the children because I think that's a massive thing, like you know now Long Covid is beginning to be talked about and yet a consultant I talked to last week does not accept it, so yeah acknowledging Long Covid and acknowledging children and keeping them safe.

Lord Strasburger

And Fran.

Fran Simpson

I was very moved by your words, I think the realisation that yes this is a national scandal and that we haven't been validated in any way and it has been incredibly hard and I think for me, I think it's about honesty, I think I'd like to say can we be honest now with the public about what we know because people still believe that this is a respiratory virus and its flu or a cold, that people will be over it in two weeks and we know it's a multi-systemic virus, it affects all parts of the body and it doesn't just affect old people and clinically vulnerable people. You know we need to count morbidity as well as mortality, you know that people being ill and sick and children as well as young people, children and I think part of that honesty for me is saying about the aerosol transmission, you know that in schools simply saying that washing your hands is going to be sufficient, we know that that isn't true and so I think for me

policy changes around lockdowns, around schools must be based on the truth and not just what is economically appealing.

Lord Strasburger

Well thank you very much and I've been in tears listening to you.

Layla Moran MP

No, thank you very much and I think Paul's final words there are as strong as I could end on and it just leaves me to say an enormous thank you to all three of you for your incredibly moving contributions today. As an All-Party Group we have always sought to be the voice of those who have been unheard and I hope we shift the dial just a little bit today and we know that we have hundreds who are watching now but even more who will watch this later, so your words are being heard and what we will also be focusing on is action. So from this we will be obviously writing to the Prime Minister with recommendations that fall out of what you've been calling for and the evidence you've been giving and we're gathering, we are also going to have a further session on transmissibility in children picking up on some of the scientific aspects of what you've been raising, so just a marker in the sand and we will advertise when we have that, hopefully in a couple of weeks' time. The Government is making decisions now about whether its going to reopen schools before or after Easter and we want to make sure that we're feeding in the latest evidence, the latest truths that we know into that conversation.

So thank you all, thank you Fran and Charlie and Sammie for your time, thank you to all in your groups who I'm sure will be watching avidly you give your accounts today and just to encourage all of them to keep writing to us, to write to their MPs and to raise the profile of this and we'll continue to work with you, I hope, in raising the profile of coronavirus and its impact on children. So, thank you all very much, take care, stay safe. Goodbye everyone.