

UK teacher Kathleen Munro speaks of “devastating” effects of Long COVID

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Kathleen Munro, 51, began teaching Design and Technology in secondary schools in north-west England in 2010. She caught COVID-19 in March 2020, most likely from pupils who attended a school skiing trip to Italy at the start of the pandemic. She has suffered from Long COVID for 22 months.

Kathleen is an active member of Facebook groups “Teachers with Covid UK” and “Long Covid Teachers and Support Staff UK”, as well as Twitter campaigning group “Long Covid Kids”.

Long COVID is a worsening public health crisis. 1.3 million people in the UK have Long COVID, defined as those with symptoms lasting longer than four weeks after infection. At least 506,000 of these suffer symptoms for over a year, according to the Office for National Statistics (ONS).

Researchers from the University of Michigan estimate that 100 million people globally either have had or still have symptoms associated with Long COVID. They extrapolated this figure from a World Health Organisation estimate of 237 million with COVID-19 in the middle of October 2021.

Scientists are still learning about COVID-19 and its impact on the human body. But with so many people developing persistent symptoms and complications—everything from skin lesions to organ damage—medical experts and scientists have described Long COVID as a public health time-bomb.

Of huge concern to parents, Long COVID is impacting growing numbers of children. 149 children have died with Covid in the UK, according to government data compiled by Long Covid Kids. At least 117,000 children in Britain live with Long COVID, including 20,000 whose symptoms have persisted for more than 12 months. The group’s published data is based on information from the ONS and other government agencies up until January 23, 2022.

In her testimony to the Global Workers Inquest into the COVID-19 Pandemic, Kathleen bears witness to the devastating effects of Long COVID on her own health and livelihood, and that of her 13-year-old niece, Ellie, who caught COVID-19 on her first day at school last September. As a result of Kathleen’s illness, her employment has been terminated.

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I am staggered that I am still unwell. I thought that by now I would be truly recovered. It is dawning on me, because it has gone on for so long, this could be the new me and I just have to make the best of what I can do.

In March 2020, a pupil had subtly coughed towards me after being told off for misbehaving. There were many absences on the registers for fever and coughs. I had sent a student home who had a fever and cough.

On the last two days before schools closed [for Easter], I was very fatigued, had a gravelly throat, anosmia [lack of sense of smell] and suspected COVID, but as I had no high fever or continuous cough I started to think not. Over the next few weeks, I gradually worsened. Then on the 12th of April after getting out for daily exercise with my family, my body felt like I’d been in a car crash. This was the start of my

torturous debilitating symptoms.

My school would not accept that I caught it there. Testing was not available then. Two doctors stated I have Long COVID and many Long COVID sufferers’ journeys start off as an initial mild illness.

My school seemed to not want to accept responsibility for my illness. Schools are not adhering to the Burgundy Book [conditions of service for teachers] which stipulates full pay for infectious disease. I was on 50 days full pay, then 50 days half pay, then after my third phased return, 75 days full pay and 75 days half pay.

My GP has stated I am unfit to go back to school. My school’s idea of a phased return is not aligned with or supportive of Long COVID sufferers. On my first phased return, my GP requested two hours every day, to be gradually increased. My school disregarded this and implemented its own policy. They were not understanding that this is a novel illness, with no treatment or known recovery timescale so it doesn’t fit the textbook school ill health policy.

The last time I left school, after my third failed phased return, I started the Nuffield Long COVID rehabilitation programme. It has been a supportive network helping me pace my activity levels. There are many NHS [National Health Service] workers on the programme who are being supported with alternative roles and significantly reduced hours in line with their recovery. I know from the chats on the teacher forums that schools aren’t willing to be supportive in that way.

The 12-week Nuffield programme was started for the rehabilitation of Long COVID patients. I was on their first wave [of patients] at Chester hospital. It is not a graded exercise; it is more about gentle exercise movement. The programme helped me understand where my baseline was so that I wasn’t doing too much. It allowed me to know what I can do and know my limit to avoid relapse. I’m still continuing there at 10 months, with many from my initial group and other groups.

Debilitating symptoms

My base line has improved over the 22 months. But even now, often I am not able to cook tea. I’m not managing to do all the things in the house that I used to do so efficiently. For example, I struggle keeping on top of cleaning out my daughter’s pets as much as I used to, and particularly with paperwork because of my concentration, memory and brain fog. I am not on top of everything at all.

If I don’t pace myself, I run out of energy and that is me done for the day. Often, I have to lie down and build in rest throughout the day in order to be able to do tasks. Schools won’t accommodate that inconsistency. They’ve already said they wouldn’t offer me another phased return because they have given me reasonable adjustments, giving me a key to the lift as I can’t get upstairs without getting out of breath. I haven’t got

the power to project my voice—I had asked for a microphone which never arrived. I had a few lessons reduced on my timetable. I needed more support and communication from my line manager, but this was not given.

During my last phased return, I tried incredibly hard. Looking back, I can see I was operating well over my energy envelope and so deteriorated dramatically, losing all the improvements I had gained. I simply did not have enough physical energy or cognitive ability to competently complete my role and I suffered a huge relapse.

If I overdo it, I have terrible insomnia, bed bound fatigue, and it knocks you back for days and days. It's like having a battery in a car. You can't run it out—you have to keep it charged and in credit to keep that energy going. So, each day I need to make sure I have energy in my battery to function, and then if you overdo it, you can only rest, rest and rest. One of the first signs that I have, is that I get very dizzy, and I yawn a lot because I can't get the oxygen to my brain fast enough. My legs become heavy like lead. My breathing pattern becomes irregular. It's about making sure that you are breathing correctly, that you can manage to do some of the movement, and that you are not pushing yourself too much.

I was reading some of the comments in the teachers' Facebook group this week, and one lady wrote, "I feel so bitter. Long Covid has ruined my life and has taken away my career prospects. If I could sue the government, I would."

I feel the same way, and lots of people in the groups do. Lots of us are beginning to get very angry about it now. We have suffered so much with the illness, including the loss of our livelihoods.

Schools are covering themselves, holding "wellness" meetings to pretend to be supportive. But the truth is it's about covering themselves. They don't really want you back until you're fully recovered, and this is unknown with Long COVID.

It's becoming more apparent to me that I am not going to get better without some medical intervention. I have recently been reading about micro clots in the blood and there are people going to Germany for HELP apheresis trials which are going on through Dr Beate Jaeger. I've joined the Facebook group page and I am following the participants who are going through the treatment.

The theory they're working on is that we've all got micro clots—makes sense because we've all got post exertional malaise, we've got limited energy. In the future they could test your blood to diagnose Long COVID. At the latest Long COVID conference, they were suggesting that was about a year off.

These trials are experimental, and people are paying tens of thousands of pounds to go from all over Europe and there is a massive waiting list.

I am devastated about having to finish work before reaching retirement and the financial impact that will have on me and my family. I have always been very focused on my overall health, fitness, diet and wellbeing—I used to teach yoga and do marathons before I had my daughter, after more half marathons, paddleboarding, yoga... and I've always stayed healthy. I have always expected to be working until a good old age.

Some days I feel like I have brain damage or dementia. Just talking now during this interview, I am getting abnormal heart rate detected on my watch and my oxygen is now down to 92 percent. I will be wiped out for the rest of the day. The problem for people with Long COVID is that we have no energy to fight back or speak out. We have no one to support us. As teachers our unions cannot support or change the outcomes. And it is not being spoken about in the press, so the public are misinformed.

When I manage to walk my child to school, the other mums sometimes have made unkind remarks showing their misunderstanding of Long COVID. They can't understand why I am not back at work. They see me walking along the pavement, albeit it very slowly, but they can't see the damage that has been done to me—you can't see the pain I am in from my joints, muscles, head pain and pressure, concentration, memory issues.

They are invisible.

I feel like I am 80 years old with that aged body and brain. For me to try to get back to work, I feel like I am a pensioner trying to get back into teaching.

At the moment I feel my best bet is ill health retirement. It worries me that I won't be where I need to be financially. I had my family late, because I was a fit 40 year-old, having my first child, and I felt super fit and well. I didn't feel that I was suddenly going to have to retire in 10 years' time. I certainly hadn't planned financially to do that.

We need a global approach

The whole strategy of the UK government has been that they don't care how many people die. It's about survival of the fittest—and it's obvious they've had this strategy right from the beginning and they're just carrying on with it.

There's lot of things that could have been done in schools to protect teachers and pupils. Some schools have got some things implemented but the fundamentals are not in place. The mask wearing significantly reduces the transmission. It's almost as if they are deliberately now wanting to spread the infection, which we know doesn't create herd immunity, so it's pointless.

The higher the transmission, the more variants we are going to get, so the longer this is going to go on. The new variants will get worse, more deadly. There is nothing at the moment—20 months on—as a treatment to cure me.

Globally, if only we all had the same tactic as China! The Chinese government have done everything they could to stop it. I don't believe the lies about the Wuhan labs having released the virus.

The World Health Organization [WHO] were saying "do what China is doing". WHO haven't been strong enough, allowing all these countries to go off and do their own strategy. It is just an absolute mess.

We need a global, centralised decision-making model that we all follow like WHO should be. It should be the central body that stipulates to countries what they should do in a global pandemic.

It is all down to capitalism. There is money to be made, and a lot of people did make a lot of money. The government in power and the other party too [Labour Party] all colluded in this. This is what is going to ruin the world—greed and money.

It's as if the government think that if these people die or they become ill long-term, there has got to be something wrong with them. They don't care—it's a "you got what you deserve" sort of mentality. It's almost as if they want to reduce what they think is the burden on society. It's always been their strategy to reduce the burden on the National Health Service.

And I don't understand the stance of the unions. What makes them think that they don't need to protect their workers anymore—what is the point of them?

There are teachers coming into the Long COVID groups who have been double jabbed. There was a flood coming through from the beginning of September, even with the vaccination. I assume it is down to the high viral load in class and the lack of ventilation. I'm concerned how many will be affected by Omicron.

I think there will be a lot of teachers who will want to join the Global Workers Inquest. There have been a lot of times recently where teachers have posted on Facebook groups saying, 'What can we do? Do we write to our MPs?' and really, they need direction to your organisation. At the moment there is nowhere for teachers to go, and they don't know how to go about looking for help—they're so angry and frustrated.

Niece has Long COVID

My niece Ellie, 13, has Long COVID. She caught COVID on the first day back to school on September 2, 2021, at the beginning of Year 8, and has only attended for four days this school year.

She returned to school after 10 days, feeling much better but still a bit tired. On the second day she had PE (physical education) and ran 3,000 meters. The next day she felt dreadful and couldn't go to school. The following day she tried to go but collapsed at school. Since then, she has only been to school once to visit the school nurse and again try to attend for two hours as a test, but didn't manage to make it into class. She is seeing the school nurse again next week to help keep in touch.

Her worst Long COVID symptoms are extreme fatigue, hypersensitivity, concentration and migraine/headaches. Other symptoms include problems regulating temperature, insomnia and dizziness.

Ellie enjoys all her subjects. She is one of the brightest in her class. Her favourite subjects are science and art. She previously used to sail before lockdown, enjoyed running, ballet, reading, watching TV, Girl Guides and is learning to play the flute.

Long COVID prevents her from being able to complete any schoolwork or do most of her hobbies. Most of the time all she can do is just sit on the sofa. However recently she has been able to begin to do some fiction reading.

She had her best friend over last week for a couple of hours and they sat just watching TV together and catching up. After that she spent three days in bed—overdoing it from the concentration of having a friend there and trying to follow a film. Ellie feels that despite the impact of visits it's important to keep in touch as she has little contact with friends.

Ellie's school, fortunately, have been very supportive and seem to understand the condition. They have had regular calls. A plan is in place for when she is able to return to give her access to a quiet room. Her school nurse has been in contact with the community nurse to push Ellie's hospital referral at Alder Hey Children's Hospital. Her school has arranged an English lesson via zoom with a tutor.

Ellie has improved a little and is now able to read children's fiction which is one of her favourite hobbies, and she is finding it therapeutic. She reads much more slowly than before. Her hypersensitivity to noise has improved a little and she is more tolerant when speaking with more than one person.

It has been proven that one in seven children that have been infected with COVID will have Long COVID. Long COVID is the worst mental health situation for children because the isolation is horrific. They see their friends' lives are carrying on, on social media and think, 'oh I am missing out'. Initially my niece was the same, 'I am missing out on this party or Halloween', but now she has accepted where she is at and is focusing on her recovery.

Luckily Ellie's mum works part-time so she can look after her a lot of the time and prepare food recommended by her private natural health doctor. Ellie's mum is fortunately very knowledgeable about Long COVID and was able to identify and highlight it to her GP after three or four weeks. Despite this, it has taken four months to see a paediatrician.

Other children may be pressurised into going to school, making them worse through trying to concentrate but probably not achieving much. Otherwise, they'll just be stuck at home on their own.

The *Guardian* reported on COVID deaths in children by saying only seven 'healthy' children had died, ignoring all the children they deemed to be 'unhealthy'! My daughter is asthmatic. Despite her asthma she came first in a recent school cross country championship. Her condition is not going to stop her from achieving in life—or living a long life.

It worries me, each time she goes to school, that she may catch COVID and end up with Long COVID. She wears a mask but is the only one.

Long COVID in children is not being talked about in the media and other parents are unaware of the risks.

Each day on the Kids With Long COVID group, there are new members arriving, confused with why their child has not recovered from COVID and finding that their GP (general practitioner) can't help. There is no information given to parents.

It appears to the Long COVID community to be a cover-up. Why aren't the government advising parents on symptoms and the importance that children thoroughly rest and don't send them back if they're still struggling as it'll make them worse? My niece did exactly that and went downhill after her isolation as she was rushed back to school, concerned she had missed so much, and ended up with Long COVID.

I expect there are lots of parents out there who do not understand changes to their child and may think it is anxiety.

With the transmission rates, especially amongst children, I think schools should be shut at the moment as they have not been made safe to prevent transmission and no mitigations are in place. Nobody knows if their child's class has a carbon monoxide reader or HEPA filter in place.

My niece's mother believes vaccines were offered too late and schools should be safer to prevent more children developing Long COVID. She thinks children have been treated as second class citizens. The government should not have misinformed the public that children weren't affected. Accurate information should be given to parents. She believes affected families need much greater access to support as the Long COVID clinics were only available initially for adults. More publicity and research are needed.

These children have got their whole lives ahead of them. We do not know how long recovery will be. Will they fully recover? Are they going to be damaged for the rest of their lives? That's scary and devastating for me, thinking about my niece.



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