

COVID-19 Recovery Committee

Long COVID inquiry

19 February 2023

1. The NASUWT welcomes the COVID-19 Recovery Committee inquiry focusing on diagnosis, treatment and current support available to those with Long COVID.
2. The NASUWT is the largest UK-wide teachers' union representing teachers and school leaders in all sectors of education.

GENERAL COMMENTS

3. The effects on society of the COVID-19 pandemic have been deep and wide-reaching, causing long-lasting issues that will undoubtedly be felt for many years.
4. The NASUWT has been consistently campaigning for education and health and safety policy to support teachers who are suffering from Long COVID in order to:

- raise awareness of the experience of teachers who are suffering from Long COVID;
 - call for statutory recognition of the illness within legislation and inclusion in the definition of disability under the Equality Act 2010;
 - challenge education employers to support teachers experiencing Long COVID and ensure they are treated fairly by:
 - guaranteeing access to decent sickness absence provision;
 - recognising Long COVID as an illness; and
 - making reasonable adjustments available at work, including the right to time off and access to flexible working.
5. The Union is also seeking to address the current inadequacy of the Scottish Teachers' Pension Scheme (STPS) in responding to cases of teachers who are unable to continue working because of Long COVID and demanding financial compensation for teachers who have contracted COVID as a direct result of their work.

SPECIFIC COMMENTS

Do you think there is enough awareness and recognition of Long COVID by the general public, medical professionals, employers and/or policy makers in Scotland?

6. As a Union, we recognise the life-changing impact Long COVID has had on members' lives and we believe it is time legislation, the Government and employers did, too.
7. Estimates around the prevalence of Long COVID vary, but the ONS estimate, of nearly two million people suffering from Long COVID in the UK, suggests 175,000 are in Scotland.
8. It appears that around 25-50% of people infected with COVID-19 will experience Long COVID.

9. The NASUWT has been urging schools and local authorities in Scotland to recognise Long COVID amongst teachers and provide the necessary support. The Union's appeal followed data from the ONS which shows that teachers and school staff are one of the most likely professions to be affected by Long COVID, only just behind health and social care workers, and many of these individuals will have contracted COVID-19 through their employment. Between teachers, schools and local authorities the experience of those with Long COVID remains variable.
10. The NASUWT Wellbeing at Work survey 2021 ran from mid-December 2021 to early January 2022.¹ The survey uncovered that 17% of those respondents in Scotland with Long COVID had not disclosed this to their employer, suggesting a lack of trust and support.
11. The NASUWT understands that many members remain reluctant to inform their employer if they are suffering from Long COVID for fear of punitive action being taken against them.

What more could/should be done to raise awareness and recognition of Long COVID?

12. The NASUWT has been calling on the Scottish Government to press for an entitlement to reasonable adjustments, flexible working, and access to ill-health retirement and financial compensation for teachers left unable to teach as a result of contracting COVID at work. Such compensation already exists for NHS workers whose careers have been prematurely ended by Long Covid.
13. Teachers have stepped up to the frontline of this pandemic and have put their health at risk to educate our children and young people. The result has been that, for some, they are now experiencing the life-changing impact of Long COVID.

¹ <https://www.nasuwt.org.uk/news/campaigns/teacher-wellbeing-survey.html>

14. With continuing high case rates, more teachers could still be vulnerable to developing this condition and find themselves unable to work, at threat of financial hardship and without sufficient legal protections.
15. No teacher experiencing Long COVID should be forced to live in this fear. Legislation needs to catch up and ministers need to put legal provisions and protections in place to recognise and support those impacted by Long COVID.
16. An important first step should be to support the recognition of Long COVID as a disability under the Equality Act.
17. The Equality Act 2010 defines disability as a 'physical or mental impairment [that] has a substantial and long-term adverse effect on [the] ability to carry out normal day-to-day activities'. Government guidance makes clear that 'long-term' means 12 months or more. Many of those who have Long COVID already meet this criterion and should therefore be protected under the law rather than be forced to go through the stress of employment tribunals.
18. Extending the protections under the Equality Act 2010 so they cover workers with Long COVID would ensure employers could not legally discriminate against them. It would also place a duty on employers to make reasonable adjustments that remove, reduce or prevent any disadvantages that teachers with Long COVID face, as with any other enduring condition or disability.
19. In addition, ministers should also recognise COVID-19 as an occupational disease, entitling employees and their dependents to protection and compensation if they contracted the virus while working.

What are your thoughts on the use of Long COVID assessment clinics?

20. Greater recognition needs to be given to supporting those with Long COVID. The Government must recognise the extraordinary and unsustainable pressures that sufferers face, in gathering information and navigating the appropriate systems to access healthcare, all while experiencing debilitating symptoms. (Please see the more detailed comments from two case studies enclosed with this submission, which highlight the lack of access to Long COVID assessment clinics in Scotland).

Do you consider that the correct mix of services are in place to help people who have Long COVID?

21. The wellbeing of teachers with Long COVID cannot be written off as collateral damage, but must instead form part of a package of support. The pandemic has strained us all, but teachers have been tested with unimaginable pressures over the last two years. Whilst the country stayed home, teachers braved the frontline of the COVID pandemic to deliver education for our children and young people. But soldiering on against the odds is not a sustainable model that encourages healthy workplace practices, nor does it support teachers to perform at their best. As a result, we are witnessing a high prevalence of burnout amongst the school workforce. Add on top of that the stress and worry associated with having Long COVID - including financial worries, concerns around recovery and the challenges navigating healthcare systems – and you have a perfect storm.

22. Embedding the promotion of good wellbeing and mental health into the workplace and healthcare systems supporting Long COVID sufferers is essential: wellbeing and mental health must no longer be an afterthought.

23. In the NASUWT Wellbeing at Work survey 2021, which ran from mid-December 2021 to early January 2022, very few teachers viewed national support for the wellbeing of the profession as positive, whilst school-level issues were also highlighted as being of concern:

- eighty-one per cent disagreed/strongly disagreed that government policies support schools to respond to mental health and wellbeing issues that affect teachers, with only 4% agreeing/strongly agreeing;
- fifty-seven per cent disagreed/strongly disagreed that their school/college gives the same consideration and support to mental health as physical health, including in the management of staff absence;
- fifty-three per cent disagreed/strongly disagreed that government policies are focused on tackling the stigma around mental health, with only 12% agreeing/strongly agreeing; and
- almost half of teachers (47%) responding strongly disagreed with the statement 'My country's inspectorate regime takes teacher mental health and wellbeing into account when assessing schools', with a further 29% disagreeing, and only 2% agreeing or strongly agreeing.

What support could or should be available for people who are supporting or caring for people with Long COVID?

24. It is clear that being absent from work with Long COVID is having a substantial and detrimental impact on teachers' finances. Additional financial support for those caring for people with Long COVID would be beneficial. Equally, those undertaking a caring role will also require signposting to appropriate health, wellbeing and mental health supports.

What should be the main priorities for study and research into Long COVID?

25. The teaching and education sector had the second highest rate of prevalence of Long COVID (though the sector has now dropped a little to the third-highest rate). Women aged between 35 and 69 are most likely to experience Long COVID. Some racial or ethnic minority groups and people with disabilities can also be at greater risk for developing post-

COVID conditions. Counter-intuitively, the ONS figures show a much lower prevalence rate in non-white populations, which is illogical, given the higher impact the virus has had on Black people. This suggests significant underreporting in Black people. It is essential that study and research into Long COVID takes an intersectional approach and considers impact by protected characteristic.

26. It is impossible to distinguish the prevalence and impact of Long COVID from the mitigations and measures which should be in place. If fewer people are catching COVID, this should correspond to a reduction in the numbers of new Long COVID sufferers. The NASUWT has been urging the Scottish Government to take the following preventative measures:

- Provide additional funding and direction to schools to improve ventilation

National oversight of a programme of maintenance should be provided to assess and improve natural ventilation: all windows should be able to be opened and air vents be cleared. Other forms of ventilation should also be considered, where necessary. A study in Italy overseen by the Hume foundation in March last year found that efficient mechanical ventilation systems can reduce the transmission of COVID-19 in schools by more than 80%. Research also indicates that keeping CO₂ levels below 1,000 parts per million helps cognitive functioning, which is obviously vital in any learning environment.

- Provide HEPA air filtration devices to all schools

This is an immediate and necessary measure required while schools improve their ventilation. Feedback from our members continues to indicate that the availability of CO₂ monitors is patchy and there remains considerable variability in terms of their training and use. HEPA filters are a long-used and proven technology removing all types of airborne particles and have been proven to remove aerosols containing COVID-19 particles from the air. For example, a study undertaken at a hospital in Cambridgeshire early last year

demonstrated that virus levels in the air of a ward treating COVID-19 patients were reduced to undetectable levels when HEPA filters were employed.²

- Commit additional funding for schools to cover supply costs for teaching and support staff absences

All measures must be taken to minimise the impact on teaching and learning. Supply cover has been a major additional expense over the last two to three years and local authorities/schools need to be reassured that they will receive additional funding for this, if needed.

- Make lateral flow tests available for free to all staff and pupils in education settings

Rapid identification of someone having the virus remains a key measure in helping to reduce transmission and wider disruption to learning, so we would like to see the return of free lateral flow tests for staff and pupils.

- Issue clear public health guidance for education settings

While we welcome the continued broad messaging from the Scottish Government around COVID, some specific public health advice targeted at schools/colleges on what they should be doing to minimise the chance of infection would be useful.

- Run a broader public health messaging campaign on vaccination

While there is an understandable focus on booster vaccinations for the clinically vulnerable and older age groups, we feel that this messaging should be widened to include others, particularly given the very low rates of childhood vaccination.

- Re-emphasise the need for COVID risk assessments

In our experience, employers need reminding about the importance of risk assessments, so a renewed focus on these, especially for clinically vulnerable workers and pregnant staff, would be welcomed.

² <https://www.cuh.nhs.uk/news/air-filters-on-wards-remove-almost-all-airborne-covid-virus/>

- Reinstate SNCT Arrangements for COVID-19 Absences

SNCT Circular 22/89, which outlined that COVID-19 absence would be treated as paid special leave (up to a maximum of ten days), was dropped by the employers' side of the SNCT on 1 July 2022 without the promised review of it. We have been seeking Scottish Government support for its immediate reinstatement.

- Provide Meaningful Wellbeing Support to Staff

Teacher and school leader wellbeing and mental health have suffered immeasurably as a result of the pandemic. As well as being important concerns in their own right, these have always been central to securing an effective, motivated and resilient workforce, capable of meeting the challenges associated with providing worthwhile and engaging learning opportunities for children and young people. A wide-ranging programme of wellbeing support needs to be developed which has the capacity to reach all staff who require it.

27. Given what has been learnt about the level of educational disruption and illness this virus can still cause, and with education staff having among the highest rates of Long COVID (according to the ONS), in our view, there is no reason why the Government should not enact these helpful measures.

Is sufficient data publicly available on the prevalence of Long COVID in Scotland?

28. While the ONS figures give excellent data, there needs to be more research into why the ONS figures do not tally with the experience of employers – why are employees not reporting Long COVID in the same numbers as the ONS is finding? NASUWT research (see par. 10) suggests this is because of a lack of trust in employers by employees.

29. It is important to secure accurate data to inform policy, but the absence of further information should not act as a barrier to taking immediate action. We already have a number of stark statistics which show, for example,

that six in ten of people who lost their lives to the coronavirus pandemic were disabled. We also know that more than one million people in the UK are now living with Long COVID, with teachers and education support staff being the second most likely profession to be affected.

30. As flagged above (par. 10), many teachers are worried about disclosing to their employer that they have Long COVID – self disclosure is one significant barrier to ensuring accurate statistical data. Nevertheless, through our engagement with members, we as a trade union can confirm that some employers continue to fail to support school staff with the necessary reasonable adjustments they require. We have evidence showing that some school employers are now deploying draconian absence management procedures when school staff with severe debilitating symptoms are seeking time off. Furthermore, there was evidence during recent teacher strikes by sister trade unions, when our members were required to report for work, of extremely unsympathetic treatment by some employers of members of ours who had Long COVID.

15. Do you have any other comments?

31. Our members with Long COVID typically consider themselves to have been ignored, forgotten, overlooked and silenced. There are significant barriers for many to engage directly with this parliamentary inquiry due to the complexity and severity of many of their ongoing symptoms. In order to amplify their voices, the Union captured two case studies directly from members. The real life experience of those with Long COVID must provide a foundation for policy-making moving forward – see anonymised narratives below.

32. The NASUWT would be happy to meet with the Committee to discuss all of these issues in more detail.

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Dr Patrick Roach

General Secretary

Case Study 1: Female ASN teacher

I am 59 years old and I am a learning support teacher. I was a primary teacher, but my school became a 3-18 setting, so I was covering secondary as well. I was working three days a week Monday to Wednesday. I worked in that job for about 12 years. My first degree was computer science, but I have been a teacher for around 18 years.

During COVID, I did extra work for my school. I have an IT background and because of that, I did a lot of extra work by telephone supporting people who were not getting connected and supporting those who did not have internet. I provided this support to both parents and staff. When we went back to school, I gave extra hours to cover for teachers who were shielding and worked extra hours.

I started feeling ill in October 2021 when I had a bad cough. I kept going through that and then over the Christmas period, I caught COVID. It was not a particularly bad dose and almost went unnoticed. I felt the symptoms I had were quite common: I had fatigue, everything was just exhausting – I wanted to sleep and but then couldn't sleep. I had muscle and joint ache and also brain fog. Concentrating on something was difficult. Even talking was really difficult – like wading through treacle. I also had heart problems. Even when walking upstairs slowly, my heart rate increased to up to 150 beats per minute and I was out of breath. They now know it is a vascular disease, so this all makes sense. My heart and brain were compromised and the symptoms continued for a few months.

I started feeling a little bit better in April, at which point I thought I would get back to work – I felt guilty still being off. I went to see the doctor, who advised against a return. I thought I could do a couple of hours Monday and

Wednesday as the school were so short of staff. I tried that, then after the second two-hour stint, my line manager wanted to build in a return to work which would mean moving to full hours after four weeks. I felt that it would be really difficult to be back to full hours within four weeks. It was acknowledged I had Long COVID on medical documents. In my view, returning to work with Long COVID needs to be a longer process.

I tried to increase my hours, but I was making myself worse – basically, I was coming home and just sleeping to then go back to work for a few hours the next day. I was making myself much, much worse. But the Council were insisting I do more. In the end, I had to stop going back as it was making me so ill.

It takes me over an hour to drive to work so I also felt it was dangerous. A couple of times I lost concentration and did not know where I was. I have a smart car which was constantly telling me to stop for coffee. I do not want to risk my life. So, four weeks later, I stopped work and I have not worked since. I have not been any better at all, in fact I am worse than this time last year.

I feel my employer did not understand at all that I would need a long phased return to work. As I did not fit into a box of a four-week phased return, they were not supportive at all. I felt my line manager was quite abrupt and cold and did not understand what the problem was. My employer seemed to think they were doing their best. When I went back on the phased return, I felt isolated from line management: none of the management came to say 'hello'. I felt they were avoiding me which was upsetting as I was doing my best. In hindsight, I should not have gone back as it was the worst thing for my health. My colleagues, other teachers, were lovely but management were horrible. My line manager only contacted me to get a line - that was it.

I have now had my last Occupational Health appointment in December which said I was no better and still not fit for work. I received this just before Christmas in an email attached with the OH report and a note saying we would discuss it in the new term. My heart dropped as I thought 'they are

going to try to get rid of me' – it was a horrible thing to get just before Christmas. I have never been in this situation before – I do not know what the letter or process is – I have contacted my line manager since and have been told because I have made no progress, they want to give a level 4 disciplinary hearing (I did say what happened to 1-3) and one thing that could happen is I would be dismissed. I am very worried about it and about money.

Also, my feeling is that I am sure I caught it at work and the lack of support leaves me feeling betrayed. I am really worried as I am 59: is anyone going to be able to employ me when I'm ready? Some people have Long COVID for 3+ years and others recover quicker. It is a big unknown as to whether I will get better and whether anyone will employ me. I love my job as a learning support teacher and I enjoy doing it. Will I ever get the chance to get another job doing it?

Do you think there is enough awareness and recognition of Long COVID by the general public, medical professionals, employers and/or policy makers in Scotland?

No I do not at all. Doctors know very little about it. There are not any Long COVID clinics in my area. I paid to go to a specialist in the UK – I did it online – there are various things that can work but unfortunately for me, they did not make any difference.

The doctors say there is nothing we can do and are reluctant to help. They do not understand it by their own admission and they have not read the research.

In public, there is a lack of understanding, too. I have a blue badge now which is a help as I can go places. Pacing is very important, so I only do a very little amount every day. If I do ten minutes of housework, then I need to stop for a couple of hours.

What more could/should be done to raise awareness and recognition of Long COVID?

Putting stories out in the public domain, like this one, is important. It needs to be discussed more; for example, in social media, so people realise there is such a problem and continues to be. People are so laid back now, they are not even testing to see if they have COVID. By going out in public with COVID, they could be compromising not the first person they see but maybe their sibling, their husband or wife and that person will really suffer. People are still catching and getting Long COVID.

What are your thoughts on the use of Long COVID assessment clinics?

There should be more. I did an FOI and I went to a clinic to speak to my local MP – there is nothing in my area. In the next six months they hope to have someone to signpost people. Even consultants are not interested. I asked for a referral to neurology – a note came back with ‘typical symptoms of Long COVID’. I feel my brain and my reasoning have been substantially impacted: I feel like loads of aspects of my brain are not there.

Do you consider that the correct mix of services are in place to help people who have Long COVID?

Someone like the specialist, who is working out of Falkirk, is needed – we need a specialist in every region who is up to date on research that you can see and that can help you.

There seems to be a lack of understanding in local authorities. If you do not fit into the criteria of a phased return, then they do not want to know.

The health board seem to be having an easier time. A family member works in the NHS and a doctor they work with had a phased return which lasted a year.

What support could or should be available for people who are supporting or caring for people with Long COVID?

There is nothing there. My husband is a chef. He comes home at 3.30am and cooks dinner as I cannot prepare a meal as that is too complex. I can just manage to make porridge in the morning.

What should be the main priorities for study and research into Long COVID?

There still is so much research to do, but there are definite pointers that this is a vascular disease and affects blood vessels which become compromised. There should be some research coming out.

Is sufficient data publicly available on the prevalence of Long COVID in Scotland?

Information is hard to find. There are a lot of Facebook groups which are great for support, but it varies from region to region. For example, some suggest that anti-histamine might help – two types for two receptors: when I asked my GP, they were not interested nor willing to try it. I know there are two or three people with Long COVID who went to their GP with the same research and their GPs were willing to try it. They were happy to try it as an otherwise innocuous drug – support from GPs varies a lot - even within a region.

Do you have any other comments?

There needs to be more support and action. For people who have not been working, there is a fear of losing your job and many people are being sacked. Teachers like myself, nurses and doctors, all of whom have done their bit for society before and during the pandemic, are now really suffering. I feel forgotten, like lost people, as those of us with Long COVID are not going out and not socialising. We are losing our jobs and nobody knows or cares. The thought of losing the job I love is frightening.

Case Study 2: Male primary teacher

I am a primary school teacher and I am 57 years old. I have been teaching from my early 20s. I have taught in primary schools in England and across the world. For the last 20 years, I have been teaching in Scotland. For the last 15 years, I specialised in working in nurture in primary school. So I work with children with social, emotional and behavioural difficulties. All through the pandemic, I supported not only the children in school, but also supported parents via phone calls – it was a difficult period and many parents were struggling a lot.

Looking back, it definitely was a lot – working full time and, because I hold a role within my trade union, also working with my local authority to revise and edit and change processes and agreements when new COVID protocols were being implemented to try to keep staff and children safe that were still in school. I continued doing all of this until October of 2021 - when I became ill with flu-like symptoms.

At that time, doctors were not seeing you in person or doing blood tests. I was classified as having a super cold, given we had all been under restrictions so long. I was off work for around six weeks. I got back on my feet in December 2021 – I definitely felt guilty I had been off and, on reflection, I probably went back too soon. I felt guilty thinking it is just a cold and that I should push through it. I was not on any medication, just paracetamol and ibuprofen.

The return was fine as I had the two-week holiday over Christmas. I then returned in January 2022, at which point in time most restrictions had been removed. The pupils were no longer eating lunch segregated in classrooms. Now we suddenly had 500 children in the dining centre as if nothing had happened. On my first day back that term, three of our senior management team were off with COVID – this was the omicron phase. There was no one to supervise lunches, so I did that for two days. Even although I wore a mask and kept the windows open, a week later I tested positive for COVID.

My first two weeks of having COVID were horrendous. After a two-week period when technically I could return, I still remained positive: I was doing COVID tests every day. There was no way I could return, so I got in touch with a doctor. When I went in to pick up a sick note, a week later the GP took some blood tests. The tests came back that I had had glandular fever in the October. My immune system was very compromised. I came back not knowing and then, with the restrictions removed, my failing immune system was left wide open. I was diagnosed with Long COVID.

I started to improve by March. The only advice or suggestion from my GP was that if I felt like going back I should give it a try. I felt very guilty because schools were struggling with reductions in staff and my role is to work with children with complex needs who need stability. I felt bad that I was not supporting my colleagues. I said to my GP that I seemed to be getting better. I was tired, but I thought I should be able to manage if I was careful and hoped it would pass. At that point, no one knew how long it could or would go on for.

So I went back for the last week before Easter in 2022 on a phased return, only working mornings. I was being very careful and told myself I was fine. I was going home in the afternoons and I was sleeping for three hours then starting to come around by evening. I suppose I thought this was part of the journey.

We had the Easter holiday - then I came back after Easter still doing half days. It was then I started noticing other symptoms. My right eye started closing and I had difficulty swallowing. My head felt ten times the size it was and really heavy. I ended up holding my head in my hands as it felt so strange and so heavy. So, for three weeks after Easter, I did half-days – still doing the same thing, in the same pattern, getting home and sleeping through the afternoon. On one occasion, during the third week of the four-week gradual return, I tried to do a full day and worked till 5.00pm. The next day I could not get out of bed in the morning.

I started to worry and rang my doctor again. During the following week on half-days, I realised this was not working. I could not stick at half-days – the local authority would not allow any more time to gradually return. So I was faced with the choice of either be off sick or return full time. I was too unwell to work full time and my doctor agreed. My symptoms were also getting worse: my eye was almost totally closed and swallowing was extremely difficult. I also started to slur my speech a little bit when I was tired.

So I went off sick again. The GP did every test in the book, but this took time – every time I needed to speak to the doctor or be referred or have a test, it took 2/3 weeks. It took weeks and weeks to go through different tests, including blood tests, chest x-rays and numerous CT scans. This all took a long time and there were huge waiting lists. As I was not dying, I was not a priority, so that is why it took the time. By the end of June, I was starting to feel a bit better, because I had been resting. It seemed to me as though I was slowly improving. I was told I was going on to half-pay which terrified me as I did not know what to do. My doctor said “maybe try to return and then you have got the holiday period of the summer which might help and you might be ok by the time you go back in August”.

So, for the last ten days of the summer term, I went back to work on a phased return. Even the first few days back, my symptoms went haywire: my eye was almost closed, I found swallowing difficult and had slurred speech. I got to the end - just - and then we had the summer holidays. My body gave in totally at this point and I started having difficulty eating. I remember being with the doctor in the beginning of July and they were sat staring at me and looking through the computer. They said “I think you have got Myasthenia gravis (MG).” My immune system had gone into overdrive and was attacking the chemical that interacts between nerves and muscles. I was referred to neurology. I was already on the waiting list for ENT, but I had been there for two months. I was marked as an urgent referral to neurology, who gave me an appointment at the end of August.

As soon as I got an appointment, I rang the hospital every day for an earlier cancellation. I rang all the way through July. Eventually, in the first week of August, I got a cancellation, which was a week before the schools went back. I saw the neurologist who said all the symptoms were the symptoms of motor neuron disease. At this point, I had lost 10kilos in weight: I was only able to eat in the morning before my mouth seized up. My eye was totally closed and I could not raise my arms above my head. This all related to the fact my muscles were not getting messages from my brain.

It was eventually confirmed that I had not got MND or MS and my diagnosis of MG was confirmed. The good news is it is treatable, although I will have it forever. It is a recognised disability. I had to inform the DVLA for driving, but was told that, over time, once we get the medication right, while I may not return to full health, I might get back to 80 or 90 per cent of full health. With young people, I believe the statistics are improved and they would have a better chance of a close to full recovery. It is very individualistic: 11,000-12,000 people in the UK have MG and they are all very different. So I was told to start on the medication (they would tweak it) and that this will take time.

I call them my 'wonder tablets' and these are the ones the neurologist gave me to replace the chemical my body is attacking. It meant I could function once I took them for an hour to 90 minutes - then I would start to deflate again. Initially, I was taking them in small doses and increasing them gradually – once every eight hours.

As planned, I started back at school in the second week in August continuing my phased return, but I only managed three days. Those were the three days of in-service and it was obvious that I would not cope, so I was off sick again.

Since then, there have been a combination of doctors and neurologists involved, tweaking my medication to the point where we are now - February 2023. I am currently on the maximum dose of steroids and other medications. I am on about 6/7 different medications – all of it timed. When an alarm goes off on my phone, it reminds me to take certain tablets. As I have been on

steroids, this has totally dissolved my muscles and I have now got a moon face – because my body retains water I have reduced my salt and increased potassium. They want to start to reduce the steroids and I am now on a different medication to suppress my immune system. I am having a bit of a horrific time of it, as the side effects are horrendous and embarrassing, including incontinence and problems with my stomach and digestive system.

Looking forward, I have got a referral from the doctor for a Personal Trainer to support me coming off steroids. How do I do some kind of exercise to build muscle when there is such a fine line? If I do too much, it kick starts my immune system which creates more antibodies to attack the chemical I need so it can be counter-productive. If I do nothing then my body cannot function: it sees exercise as something to attack. I need to slowly build up strength and stamina. Hopefully I can get to a point where I am fit and the medication will keep my immune system in check. Then I can think about a phased return.

I am on half pay just now which is a big struggle. I have used all my savings up. I am in arrears with council tax as it was the easiest thing to cut. I am in negotiations with my mortgage lender to go into arrears with that, too. On the horizon, it looks like I will lose half pay near the middle of May. My GP and neurologist think I might not be in a position to return to a phased return then - but we do not know. As I have recently been changing medication, I have had a bad three weeks. Reducing medication had a really negative impact – hopefully I am back on track after my recent neurologist appointment. Recovery is not a linear journey, it is unpredictable.

Before Long COVID existed, it was believed there was a correlation between MG and viruses and that it was thought this was triggered by viruses making the immune system weaker. But there is no evidence to say that Long COVID virus is the reason I have got MG. With MG, they say try to rest as much as possible, which is the same advice as Long COVID. I do not know if I still have Long COVID and those symptoms, as well as coping with MG. Once I get MG under control, will I still have Long COVID? These are questions the doctors cannot answer as they do not know – they do not know if I am

experiencing a combination of Long COVID and MG or just MG. It is very unpredictable, but I know I am not going to die. Up to August 2021, I thought I must have MND and that I was going to die.

Before all this, I was a very active person with lots of energy. I was active in my union, active in amateur dramatics and outdoor sports, and enjoyed seeing friends and socialising. I was always doing something. In my personal life, I have a son with ASN and my ex-wife also has medical conditions, which means I need to take responsibility for looking after our son at short notice. It can be very stressful. Of course my ex-wife had a mental health condition and my son had ASN before COVID. But then I felt I could cope as I had good fitness and health and outside interests. I had a bank of things to cope with everyday life. My job was very stressful because of the mental health, social, emotional and physical challenges facing the pupils I worked with: but I could cope with that. I have been robbed of all of my coping mechanisms and it has made my whole life situation very difficult. I do not have the same things to support me. I used to swim every day and I cannot now - I would sink to the bottom of the pool. Financially, things are difficult too. I live in a rural area so to go anywhere costs money. My son lives 15 miles away and his school 20 miles away. Even picking him up and dropping him off costs money and it is tiring to go backwards and forwards and drive. My life is on hold. I cannot plan. I was building a waterfall in back garden – I had it all dug out and the construction materials have been sitting at the side of the house for 18 months. Since I got glandular fever, everything stopped.

Do you think there is enough awareness and recognition of Long COVID by the general public, medical professionals, employers and/or policy makers in Scotland?

For all these people, 'no', there is not enough awareness and recognition. It is viewed as just another one of those things. People think COVID has passed and we 'just' have after-effects for some people. Decision-makers tend to be people who are still working – so they are unlikely to have Long COVID. So decision-makers have no idea what they are talking about – you

can see that across all sectors, the people in charge just do not seem to understand.

What more could/should be done to raise awareness and recognition of Long COVID?

The quickest way would be to give all decision makers Long COVID for a month – every one of them - then see if they can understand what difficulties or problems are caused by having Long COVID.

What are your thoughts on the use of Long COVID assessment clinics?

I asked and was told there are none in Scotland. I knew that was happening in England, but I was told there were none. I believe the Scottish Government have given money for additional services, but these services are not working together. Nothing is joined up. You can see that when trying to get ENT or CT scans. I even had to go and get my own eye assessment with my own optician. This meant the time involved was crazy. To get an appointment, the only way was to be constantly on the phone to get a cancellation.

Do you consider that the correct mix of services are in place to help people who have Long COVID?

No, it affects different people in different ways. We need a triage system in place to work out what elements we have and what service someone can go to. It cannot be left to GPs or one specialist. Even the neurologist kept shrugging their shoulders; when it comes to Long COVID, the system does not have a clue.

What support could or should be available for people who are supporting or caring for people with Long COVID?

I did not come across anything in terms of support.

What should be the main priorities for study and research into Long COVID?

There is so much contradictory stuff out there. When I first had Long COVID, the doctor told me to do a little bit of exercise every day and try to push myself a little bit. Then new research came out to say do not do that, as you are aggravating things and you should rest and it takes time: you must not push it. What is the right thing to do? This is what needs focus: patients need to know how they can best help themselves with recovery.

It is the stress as well of not knowing what the best thing to do is. I read research journal after journal and articles on MG; there is not enough research generally. There is a big problem because viruses affect people in different ways. There is no one set of symptoms so no one fix for all people.

Is sufficient data publicly available on the prevalence of Long COVID in Scotland?

No – although the Union may have information on teachers who have Long COVID through casework data to supplement the workforce data. I hope that this will be clearer after the Long COVID inquiry.

Do you have any other comments?

The biggest thing is the stress. Viruses are affected by stress. The stress of getting appointments, to get to the top of queue for referral and then to work out what you have got. Then on top of that, there is the financial stress of local authorities following fixed and set procedures. I am worrying about money.

It was a crazy situation where the Government put in place measures that if you have Long COVID you got three month's full pay no matter the state of employment, but the doctors on the sick notes could not put Long COVID electronically, they had to put Long COVID in the summary as it was not in the

drop-down list. So all my original sick notes had symptoms; the Council was logging just the symptoms, not Long COVID. So I was not logged by the Council as having Long COVID. I had to fight for sick notes to be redone and resubmitted and the coding on the computers to be changed. Also, because I was stupid and conscientious and trying to get back to work and worrying about my colleagues, I broke the three-month allocation at the point I tried to go back to work. So I suffered financial detriment because I tried to get back to work. There is no support there.

With my contractual sick pay, I get six month's full, then six month's half pay. But, because of the pandemic and NHS services being under stress, everything is taking longer. If I had these medical issues before the pandemic, I may have been diagnosed quicker, got tests quicker, got treatment protocols in place quicker to help recover. Maybe I could have returned within the year? But because of COVID and the stress the NHS is under, everything has been so elongated and things are taking twice as long. As a result, the sickness period on pay is not fit for purpose.

The doctors think I am going to be ok. My treatment though is not finished, and my pay is going to stop. I feel under pressure to take early retirement or retire on disability which is wrong as I am an experienced teacher. I would have thought the Government and my community would need experienced teachers to help the system get over this pandemic. The last thing they should want to do is pension-off teachers. With time and support (financial and other), teachers like me would be able to return and contribute to the rebuilding and support of children's education. It is such a missed opportunity.

I miss the children, my colleagues, and my career. I wish I could be supported by the Government to get back to the teaching I love.