The Health and Social Care Alliance Scotland (the ALLIANCE)

Living with Long Covid: an anthology

September 2022

Contents

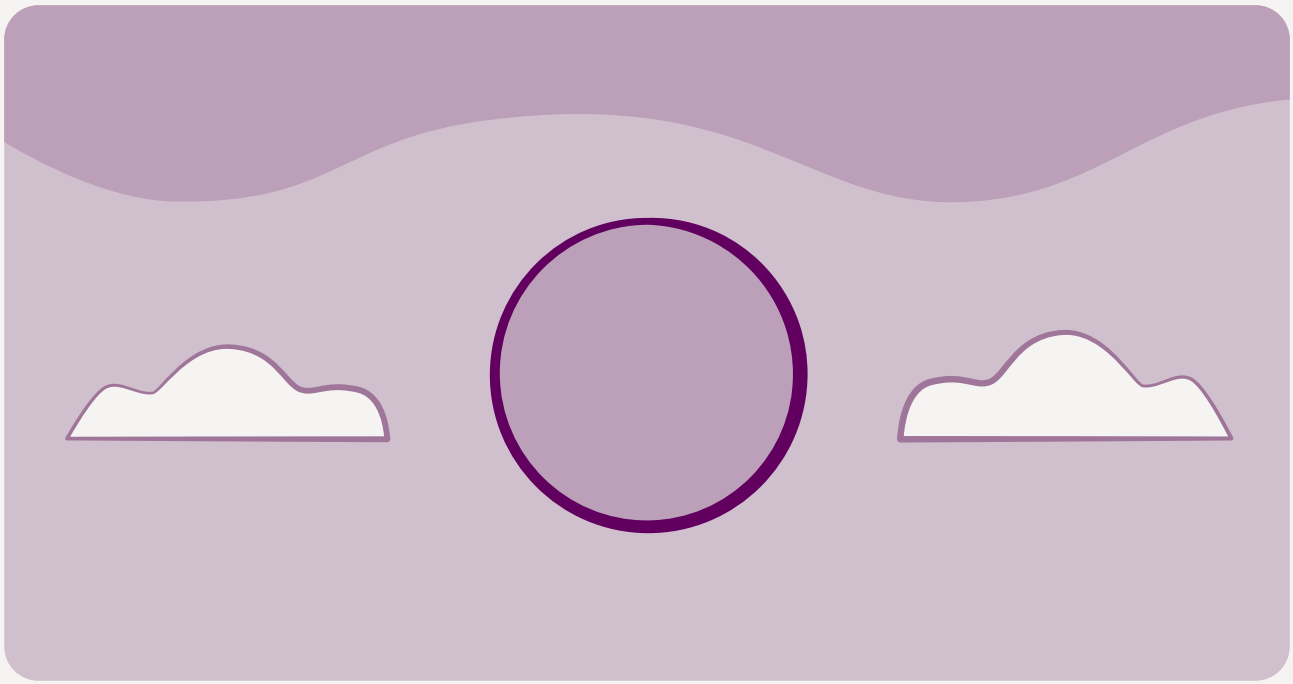
Foreword

Hannah Tweed, Senior Policy Officer, the Health and Social Care Alliance Scotland (the ALLIANCE)

In Spring 2022, the ALLIANCE invited a range of people to contribute to an Opinion series, focused on their insights into Scotland's support for people living with Long Covid.[1] The series spanned people with lived experience of Long Covid, to those researching supports and treatment options, and people working within the third sector to support people with Long Covid.

Rereading these Opinions, two things stand out. Firstly, the breadth and depth of people's commitment to improving support and treatment options for people living with Long Covid. The writers in this anthology represent only a fraction of the wider work in this area, but are still remarkable for the range of insight they offer. Secondly, two and a half years on from the first recognised cases of Long Covid, the relative lack of progress in ensuring structured support for people living with Long Covid, and their families, is striking. This slow progress is a clear challenge on how far Scotland has to go in terms of meaningful support for people with Long Covid.

That said, there remain key opportunities for Scotland to embed support for people living with Long Covid within policy and practice. The National Care Service, which is currently progressing through the Scottish Parliament as the National Care Service (Scotland) Bill, stands in a position to potentially improve people's access to social care. Streamlined access to social care could make a significant different to many people living with Long Covid's day to day life.



The third sector, and a rapidly growing body of Long Covid charities and campaign groups (especially those, like Long Covid Kids and Long Covid Scotland, which are run by and for people living with Long Covid and their families), offer significant expertise to influence how State supports should engage with and support people with Long Covid – from health and social care professionals to social security – and offer a range of peer support and self management strategies.

Many of the groups and individuals included in this anthology are participating in the newly-founded Long Covid Network (hosted by the ALLIANCE in partnership with Asthma + Lung UK and Chest Heart & Stroke Scotland), which aims to establish a network for people affected by Long Covid to gain views from a wide range of people to inform service delivery.[2] Finally, research into effective treatments for Long Covid as well as self management is key to progress and improving the quality of life of people affected by Long Covid, and – as outlined by Nick Sculthorpe – has the potential to benefit people with a range of other energy limiting conditions.

There is a risk, in some quarters, that as the rhetoric of "moving forward" and "living with COVID-19" increases, less attention is paid to Long Covid. It is essential that stakeholders and decision-makers in Scotland maintain a clear focus on treating Long Covid. This work should include supporting research into effective treatments, designing efficient access routes and information about State entitlements (including social care) for people living with the long-term effects of Long Covid and their families, and supporting the vital work of the third sector.

Navigating without a map: the impact of Long Covid on children, young people and their families

Helen Goss, Representative for Scotland, Long Covid Kids

> **Childhood is the best of all the seasons of life, and the longer it lasts with happy memories, the stronger the emotional stability in adulthood.**
>
> (Venugopal Acharya)

In Scotland, we have set ourselves the ambition of getting it right for every child, and we are working hard to embed the UN Convention on the Rights of the Child into day-to-day life. We want the best for Scotland's children. We want them to be happy and healthy, to thrive and succeed in whatever path they choose. We want to support them to overcome the challenges and adversities they face. When they cry, we comfort them. When they get sick, we do our best to provide treatments and services to help them recover.

But imagine taking a child to the doctors because they are in pain, experiencing fatigue so severe that their body and brain feel like wading through treacle, suffering nausea, and they are unable to learn due to cognitive impairment, only to be told, "we don't know anything yet" or "I can't understand why they're still like this". This is the reality for some families who are finding out that, as with adults, for children and young people the impact of a COVID-19 infection doesn't always end when their isolation period does.

We are only starting to see what lies ahead for children and young people infected by SARS-CoV-2 and to understand the damage that it can cause to young bodies. How many children will be affected by Long Covid is not yet known. Current prevalence estimates vary between 1% and 51%. We do not yet know what the impact of reinfections will be. We do not yet know if, like Polio, further problems may occur in years to come. There is still much we need to learn, and the World Health Organisation has identified it as an area for priority research.

My own daughter first had COVID-19 in March 2020. Since then, we have been desperately trying to navigate a strained health and social care system not equipped to deal with the complex presentation of symptoms that can arise in children after a COVID-19 infection. In July 2021, we contracted COVID-19 for a second time, which knocked her recovery back to square one. Currently, she is so unwell that she has not had any formal education since September 2021 and my now 9-year-old, who was previously fit and healthy, requires the support of a wheelchair on the rare occasion we are able to leave the house.

It's now been 23 months since she first became ill and yet, it was only two weeks ago that the diagnoses of Long Covid and Paediatric Acute-Onset Neuropsychiatric Syndrome (PANS) triggered by COVID-19 infection were officially confirmed. We had to fight hard to get a diagnosis and we have struggled to access the support we need. Waiting lists are long, staff are overstretched and the nature of her illness can make it difficult to attend scheduled appointments outside the house. Although her school has been exceptionally supportive and the digital technology now exists to support online learning, the Local Authority are unable to offer home tutoring provision. In order to ensure her right to education is met, we have resorted to paying for independent provision. Many families would not be able to take on this additional financial strain.

With no clear map, we have had no choice but to keep trudging forward, seeking answers ourselves whilst the media, and even some medical professionals, downplay and minimise the risk of COVID-19 to children and young people, often bypassing the topic of paediatric Long Covid entirely. It's been a frustrating, exhausting, and arduous journey which, at times, has tested our resilience as individuals and as a family.

We are a family in crisis, and yet, our situation is by no means unique – we are just one family out of tens of thousands of families in the UK struggling to navigate the reality of caring for a child or young person with new chronic illness and varying degrees of disability. The most recent Office for National Statistics (ONS) estimates suggest that 117,000 children and young people in the UK are suffering from Long Covid.[3] This is likely a conservative figure as the recent preliminary data from the world's largest study into Paediatric Long Covid, the CLoCK Study led by UCL and Public Health England suggests that up to 1 in 7 (14%) of children who are infected by SARS-CoV-2 will go on to develop Long Covid.[4] COVID-19 is not a low-risk disease for many and Long Covid is not a benign condition.

For the parent of a child or young person with Long Covid, the future can be a painful contemplation whilst we wait for the research to catch up with our lived experience. Will they recover? Will they be able to play with friends again? Will they manage to sit school exams? Is this their life now? Who can help us? What could I be doing to make this better? As we find ourselves in unchartered territory, the obstacles and challenges that families have to face are numerous and unrelenting.

I discovered Long Covid Kids Support Group in January 2021 during one of many desperate Google searches looking for answers as to why my child was still so very unwell. Whilst my family's experience has presented us with monumental challenges, untold stress, and moments of utter defeat with ugly crying on the bathroom floor, I am strengthened and bolstered by the incredible Long Covid Kids team around me.

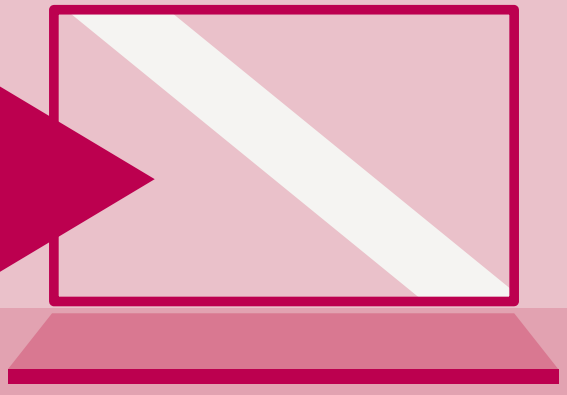
In June 2021 I took on the role of Long Covid Kids Lead Representative for Scotland and am now working with others to improve awareness and understanding of the impact that COVID-19 can have on children, young people and families, to ensure their rights are upheld and that children, young people and their families receive the support and services they so desperately need.

Long Covid Kids work with multi-disciplinary teams to help them gather better research data to increase scientific knowledge and understanding of the effect that COVID-19 infection is having on children and young people. The knowledge and experience of the over 7000 members in our peer support group is helping to shine a light for other families who follow behind, who are now also finding themselves lost in the fog, searching for services and support. Our support groups offer a safe, welcoming space for families to come together to share experiences of what may work to aid recovery, to discuss issues and challenges and to explore ideas for overcoming these. Increasingly, we are also responding to queries from professionals who are working with children, young people and families. They too are struggling to find answers. More and more professionals across health, social care and education are keen to learn about this illness and to better understand the challenges that children, young people and their families are facing in order to improve their own practice and be able to provide better support to those they are working with.

The route ahead for children and young people with Long Covid is unclear but we are determined to find answers and a way through this together. If "living with COVID" is to be inclusive, we must ensure these children and young people are not left behind and that their rights are upheld. We also need to take more preventative action to stop children falling in to the icy Long Covid waters in the first place. This means making use of evidence-based public health measures and addressing the issue of unclean air so that our environments are safer for everyone. Whilst the last two years have felt long, we know we are still only near the start of the Long Covid expedition. As time goes on, we will discover and learn more, and we must not stop until every family and every child has the care and support they need.

> **Childhoods never last. But everyone deserves one.**
>
> (Wendy Dale)

For more information on Long Covid Kids, and the support they offer, visit their website.[5]



Looking ahead with Long Covid

Tracey Binnie, Community Involvement Co-Ordinator (Long Covid), Chest Heart & Stroke Scotland

I caught COVID-19 in March 2020 and was diagnosed with Long Covid four months later when it was clear I wasn't getting better. I was relatively fit and healthy before the infection, enjoying long walks with my dogs and getting back into hillwalking as well as being an active Girlguiding leader. Being a part of the first wave of people affected by Long Covid was scary and frustrating – I didn't know what damage had been done to my body by the virus and didn't know if or when I would get better. I often felt quite lonely too; despite having the full support of my family, it was hard to explain to people what was happening to me because I couldn't understand why I wasn't recovering either.

Two years later, I'm still living with Long Covid. My main symptoms are fatigue, brain fog, breathlessness, costochondritis (chest inflammation), exercise intolerance, GI issues, insomnia and muscle pain as well as being diagnosed with Postural Orthostatic Tachycardia Syndrome (PoTS) and Functional Neurological Disorder (FND). I'm mostly housebound and need a walking stick and wheelchair to get around when I'm out and about.

Throughout the summer of 2020 I was pretty much bedbound and spent most of my time reading everything COVID-19 related in order to try and better understand my situation. I joined online support communities on Reddit and Facebook, filled with people like myself who were trying to figure out what Long Covid was and what it was doing to us. I found myself offering support and advice to people as the pandemic raged on, in an attempt to pass on my limited knowledge of Long Covid and help others.

I joined CHSS in May 2021 to head up the newly created peer support group for people living with Long Covid and to give those with lived experience a chance to share their story. Membership has grown significantly and we meet regularly on Zoom. The Long Covid peer support group is a safe space for people living with Long Covid to share their experiences with others, offering emotional support. We often have guest speakers joining us, talking about subjects chosen by the group. In addition, group members also have the opportunity to help shape our Long Covid services as we continue to develop our care pathway. There are also plans in progress to offer face to face meetings, now that restrictions have been lifted.

The most common piece of feedback I get from group members is that they are grateful for the opportunity to talk with like minded people who "get" Long Covid and understand what it's like to live with a novel condition. Even at the two year mark it's interesting (and worrying) to see that a significant section of the general public are still more focused on the mortality of COVID rather than the morbidities associated with it. Peer support group members have often

mentioned being gaslighted or accused of hypochondria by friends, family and even healthcare professionals and I've heard some very distressing stories. However, group members are very supportive of each other and we quite often have a good laugh about our misadventures, usually involving brain fog. If ye dinnae laugh, ye greet!

It is disappointing, however that despite the information we now have on Long Covid people are still struggling to have their voices heard. I've lost count of the number of people who have told me they were dismissed by their GP and other healthcare professionals, being told that they were suffering from anxiety and they should get out and exercise more. People in employment are also struggling with their employers, with many being forced to go back to work when they're not ready or facing disciplinary action. Dealings with the Department for Work and Pensions have also added to the pressure people are already facing, particularly with PIP applications, with people giving up on claiming benefits they are entitled to because the claims processes are far too exhausting for them.

Having said that, progress is being made. NHS boards in Scotland are putting their own care pathways in place for people living with Long Covid. Social Security Scotland will soon be responsible for disability payments and they promise a more empathetic and person centred approach.

It's been a difficult two years for everyone, not just for people living with Long Covid, though the affect Long Covid has on people's lives should not be underestimated or ignored. Long Covid is the biggest mass disabling event since World War I, with millions of people worldwide mourning their past lives, and the economic impact as well as health and social care considerations is plain to see. Many people are calling for the Scottish Government to follow England and Wales in setting up multi-disciplinary clinics so patients have access to a one stop shop of sorts, enabling them to see multiple specialists on the day and subsequently cutting down on travel to and from hospital appointments. Whether this happens in Scotland or not remains to be seen, but what we do need is clear care pathways, offering empathetic and equitable treatment options as well as social care options and financial support.

Supporting people with Long Covid to get their lives back on track

Joseph Carter, Head of Devolved Nations, Asthma + Lung UK

It's estimated that more than 100,000 people in Scotland are living with long-term symptoms following a COVID-19 infection, and many struggle to access the specialist support they need to manage their symptoms. Asthma + Lung UK has collaborated with a coalition of 15 charities to create an online assessment tool that helps people identify their symptoms and access support services.

Long Covid is a new and unpredictable condition, with wide-ranging symptoms that have the potential to be totally life changing. Many people living with Long Covid have told us that their lives have been turned upside down by symptoms as varied as breathlessness, extreme fatigue, and brain fog, and that they're struggling to get the dedicated support they need to manage these symptoms.

We've worked with a number of other organisations to try and offer people the support they need. This has culminated in the creation of our new tool, *My Long Covid Needs*.[6]

We want to help people with Long Covid get the best advice and support they can

It's unsurprising that people are turning to charities like Asthma + Lung UK for support. We've had thousands of calls to our helpline from people concerned about COVID-19, including many from those who are worried about long-term symptoms and frustrated by the lack of support out there for people in their situation.

Long Covid is a multi-system condition with a range of symptoms. To ensure the *My Long Covid* Needs tool provides the most comprehensive advice and represents the diverse needs of people with the condition, we developed it collaboratively with a number of other organisations with different areas of expertise, including Long Covid support groups and charities Diabetes UK and Stroke Association. More than 70 people living with Long Covid gave feedback and helped test the tool.

More about our Long Covid tool

The new online assessment tool is designed to help people feel better supported to manage the impacts of Long Covid and improve access to support services, including from the NHS and charities. People using the tool input information about their physical symptoms, practical and emotional concerns, and the impact on their day-to-day life, which then brings up useful advice and links to other relevant support services, and automates a report that users can give to their GP or healthcare professional.

The tool's automated report function means people living with Long Covid don't have to tell their story multiple times to different healthcare professionals. This is a frustration that many people with the condition have shared with us. Patients have reported feeling "exhausted" by having to repeatedly relay their symptoms.

One woman told us:

> **"I am fighting to be heard by relevant authorities. My situation has sky-rocketed my anxiety, affecting my breathing.**

Another said:

> **"I feel like I haven't been taken seriously or believed by medical professionals or friends. It has made me angry as I feel weak and trapped in my own body.**

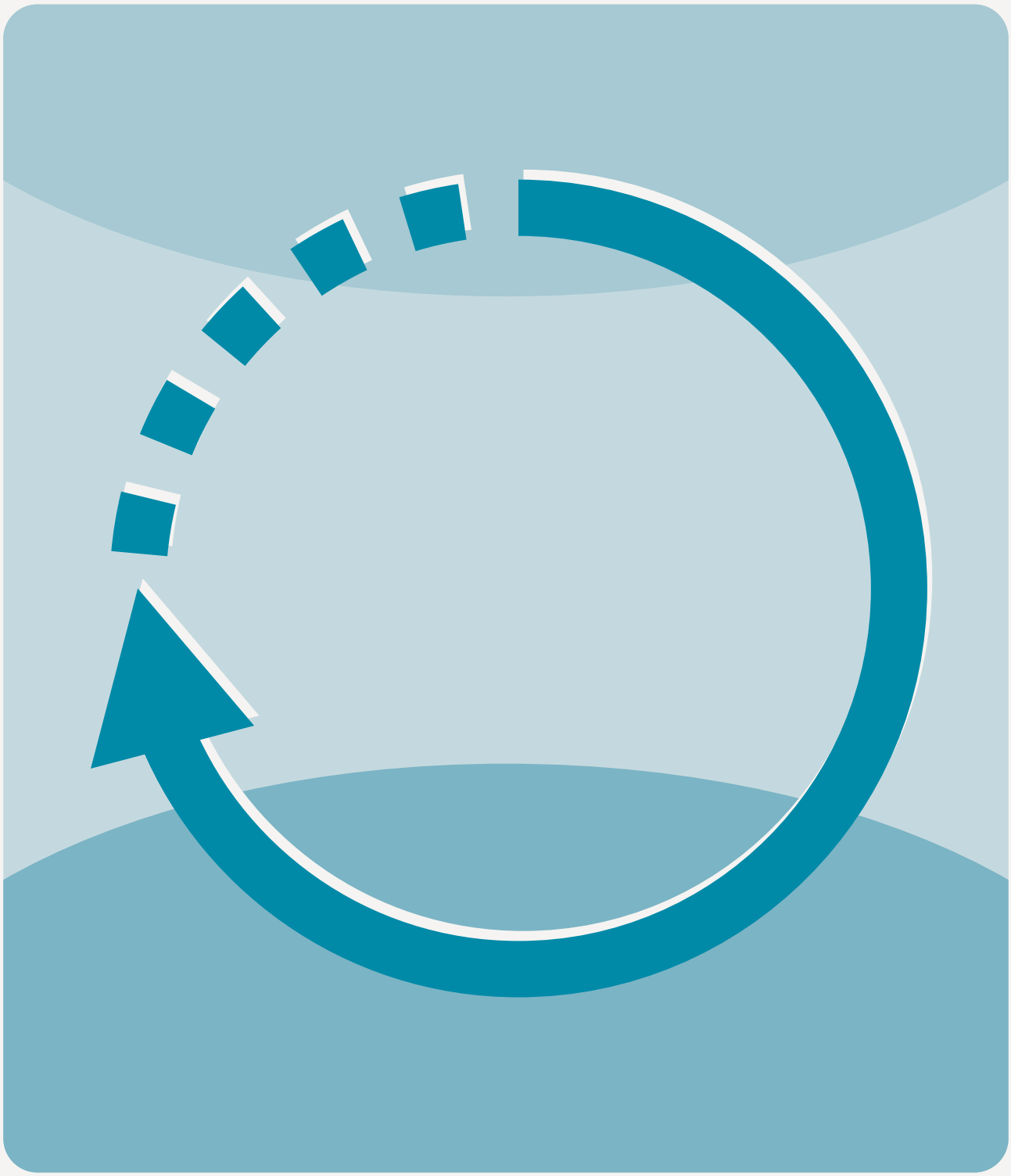
Although services are being developed to address the needs of people with Long Covid, our research suggests many people experience barriers, including feeling that their condition is not being taken seriously. People have told us that their doctors have been "very dismissive" and that there is "very little support" out there for them. We hope the tool will help people manage their symptoms and provide vital support and advice for people living with the condition.

The *My Long Covid Needs* tool offers vital advice and support for people as they navigate their way through this new and unpredictable condition, and provides patients with an easy-to-read report that they can share with their doctor. We'd encourage anyone experiencing Long Covid to visit the tool and for healthcare professionals to share this resource with their patients.

We will keep fighting for people with Long Covid

We hope *My Long Covid Needs* will help people manage their symptoms and provide vital support and advice for people living with the condition. But we know this isn't a replacement for specialist health care – this is something we will keep campaigning for.

The problem of Long Covid is not going to go away, and it's vital the Scottish Government invests in training and employing more specialist NHS staff to ensure that people with Long Covid can access the specialist care they so desperately need.



Long Covid in healthcare staff

Aileen Grant and Nicola Torrance, Senior Research Fellows, School of Nursing, Midwifery and Paramedic Practice, Robert Gordon University

The first UK wide lockdown of the COVID-19 pandemic took place on 23 March 2020, and little was known about the short and longer-term effects. It has since become apparent that for some people, the effects of COVID-19 infection can last significantly longer than the acute viral infection.

Most people who catch COVID-19 do not become severely ill and get better quickly. However, some people experience symptoms and long-term effects that last long after the main infection. Sometimes these symptoms emerge sometime after recovering from the original infection even if the symptoms were mild in the first place.

"Long Covid" is the name given by patients to describe the longer-term effects of COVID-19 infection, and the Office for National Statistics (ONS) estimates about 1.3 million people in the UK (2% of the population) have Long Covid (with symptoms lasting more than four weeks).[7] These persistent symptoms commonly include fatigue, "brain fog", shortness of breath, chest pain and palpitations, joint pain, and many other complex symptoms that make life harder for them. These diverse symptoms can come and go, and can have a devastating impact on the long-term health and wellbeing of those affected.

Long Covid in healthcare workers

Healthcare workers, at the heart of the pandemic, account for between 10% and 19% of the worldwide COVID-19 cases. In Scotland, the risk of healthcare workers testing positive for COVID-19 was seven times higher than for non-essential workers, and their households contributed to a sixth of cases admitted to hospital. Recent estimates found approximately 122,000 NHS workers in the UK were suffering from Long Covid, with a prevalence of almost 14% at 12 weeks post-infection.[8]

There is still a lot of uncertainty around the progression and future prognosis of Long Covid. Clinical investigations and potential treatment options are at an early stage, and the impact of vaccines on the incidence of Long Covid is still uncertain, although emerging reports are encouraging.

With NHS staff shortages a concern before the pandemic (up to 8% of posts vacant in Scotland pre-pandemic), it is highly likely there will be more shortages due to the impact of Long Covid on staff. As this is a new condition, there is very little information about the experience of Long Covid in healthcare workers, how it affects their health and wellbeing, their use of healthcare, and the impact on their work and personal finances.

Why is research needed?

For some people the impact of Long Covid on their physical and mental wellbeing has been catastrophic, and this may mean they are not able to work at all. For others, it might mean they work for fewer hours or are doing a different job. Over half of healthcare workers who have returned are likely to experience ongoing lack of energy or fatigue, and it is likely that their colleagues are supporting them, which means the impact of Long Covid will extend beyond the person with the actual symptoms.

It is highly likely that Long Covid is affecting their home life too. They may not be able to keep up with domestic and family life as well as they were able to before they took ill with COVID-19 and Long Covid. This could also have an impact on personal and household finances.

What we're doing: The Long Covid in NHS Workers study

Long Covid in NHS workers (LoCH) is a questionnaire and interview study and includes any NHS workers in Scotland who believe they have Long Covid. We have collected data from NHS workers using an online questionnaire survey and then interviewed NHS staff to explore their experience of living with Long Covid. NHS workers involved in the study include nurses, midwives, doctors, allied health professionals, and administrative and ancillary staff (such as secretaries, porters, cleaners and other support staff).

Recruitment to the study is now closed and we are analysing the data collected. We will be getting back in touch with the people taking part in the next few months to find out how they are getting on and if there are any changes to their Long Covid symptoms, health and wellbeing and their work situation. We intend to publish findings in high impact journals, and hope that this research will help in understanding the lived experience of NHS staff with Long Covid, and improve workplace support, now and in the future.

This study is funded by the Chief Scientist Office (COV/LTE/20/32).

Leveraging the experiences of people with Long Covid to generate better research

Nick Sculthorpe, School of Health and Life Sciences, University of the West of Scotland

For many people, infection with COVID-19, while unpleasant, is thankfully relatively short-lived, but for others symptoms persist for far longer. Cases of individuals experiencing symptoms, months after infection, are frequently reported. Initially referred to as "long haulers", reflecting the duration over which the symptoms persisted, the name "Long Covid" was later coined by those with the condition. The fact that the name came from the Long Covid community and that they have largely resisted attempts to rename it (e.g. post-covid syndrome) speaks to their engagement with researchers and medics. I want to make the case that researchers should capitalise on this engagement using public patient involvement to improve the quality, relevance, and impact of their work.

Our work focuses on fatigue as the most common and debilitating symptom. In Long Covid, fatigue is better described as a cluster of symptoms, including complete mental and physical exhaustion, far out of proportion to any effort that preceded it. The phenomenon is commonly referred to as "Post Exertional Malaise".[9] The only real help for PEM is extended rest, and the best approach is to try to avoid PEM in the first place using a technique called pacing. When pacing, individuals aim to manage their energy demands by matching what they do with their available energy. While pacing sounds simple, it can be extremely challenging and when we talked with people with Long Covid many reported finding it difficult. It requires keeping track of some poorly defined concepts, such as how much energy you feel you have, how much you think you have expended, and how much the tasks you want to do might take. PEM might also occur several days after an activity, meaning the individual must track all of this information over many days, and all while trying to simultaneously manage "brain fog".

Our pacing study aims to use activity trackers to reduce the overhead required to pace well. Trackers themselves are of limited use in pacing (since they promote extra activity). However, by reprocessing the data, we can provide better information about activity levels throughout the day and send alerts messages when participants risk doing too much. Also, because the data is stored, we can review activity levels for several days before a bout of PEM to help identify a likely trigger. Of course, activity tracking is not the whole answer. Cognitively challenging activities such as focused reading and writing, or emotionally draining activities such as family visits (or emergencies), are likely to contribute to PEM while being broadly invisible to activity tracking. Nevertheless, by helping to manage the areas where activity tracking works, we hope to create a little more headroom so those other factors are perhaps less debilitating.

As we developed our study, we were exceptionally fortunate that people with lived experience of Long Covid were prepared to give their time and energy to help. Early in its development, we spoke with Long Covid Scotland to make sure our research addressed questions that are important to people with Long Covid, and they continue to help us have regular public patient involvement meetings. Their experience, advice, and suggestions have informed everything from the big themes such as initially identifying the difficulties with pacing, all the way through to of how our app displays activity information. As a result, we have a better study that addresses a question that matters to people with Long Covid and does so in a way that they are likely to find acceptable.

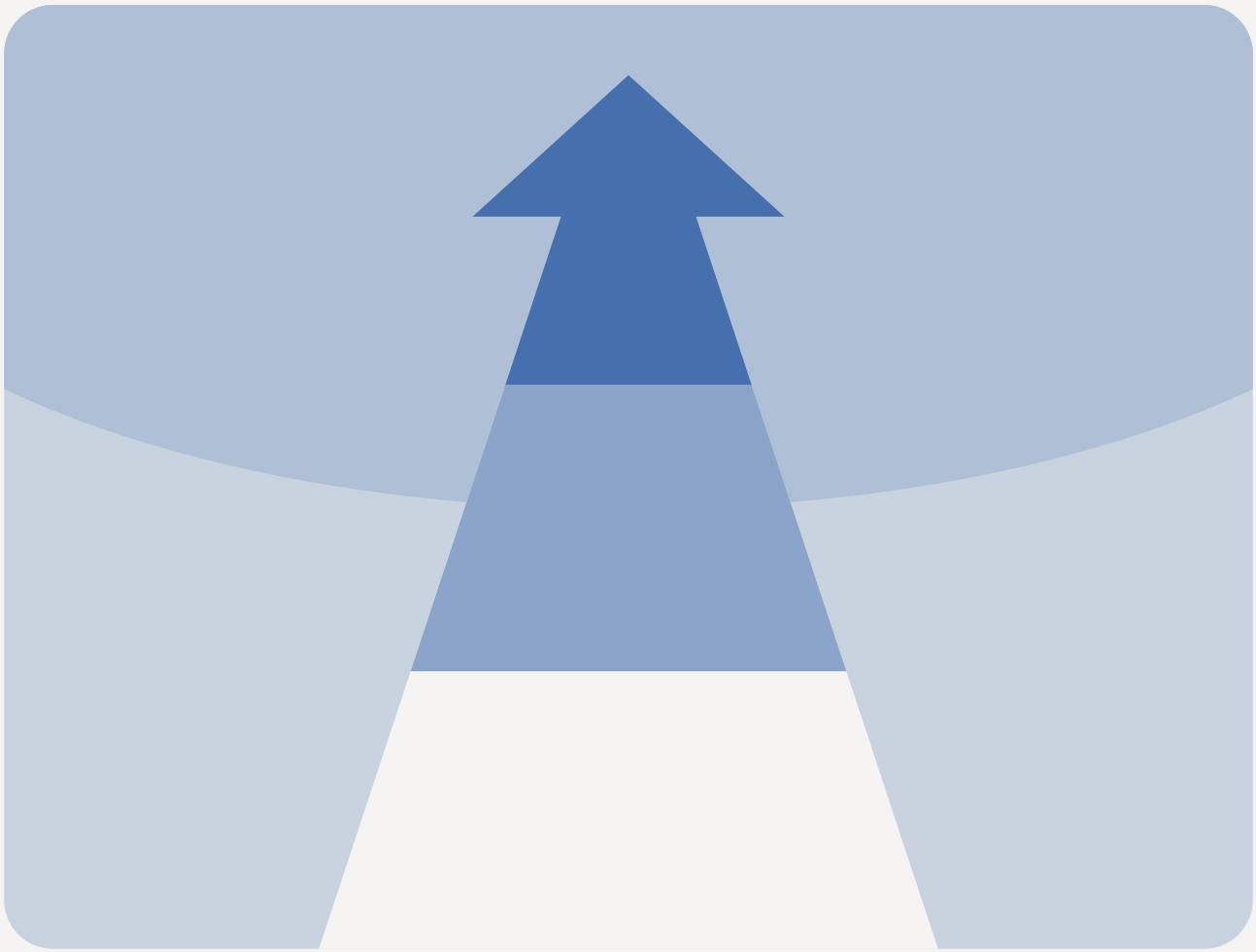
Similarly, our app sends alert messages when people are at risk of doing too much. Aside from the technicalities of ensuring these alerts are delivered at the correct time, equally important is the wording of the message itself. In our experience, messaging needs to be easy to understand but not condescending while also being aware of the experiences of the intended recipients. We also need a lot of different messages that meet these criteria, as participants tend to disengage when they repeatedly receive the same message. It turns out that this is not easy to do well, especially for a team of researchers who do not have Long Covid.

Again, we turned to people with lived experience for help. In this case, we asked the ME/CFS community, a group that have experience using pacing to manage their symptoms, to tell us what they wished they had known when they started pacing. The result was overwhelming, and we received hundreds of tips and hints to help with the realities of pacing day-to-day. These co-produced ideas now form the basis of our alert messages. They are more varied, more practical, and critically, far more authentic than our research team would have been able to produce. These characteristics mean they are more likely to be understood and acted upon by the recipients, which in turn increases the likelihood of the intervention being beneficial. It also means the research funding is more likely to return some benefit for the investment.

Both of these examples demonstrate why good public patient involvement benefits everyone. In our case, the support has improved our research by providing a context for the questions we should ask and ensuring that we focus on problems that are important to those living with the condition. In the case of our alerts, not only are the messages better, public patient involvement has made us aware of new approaches to working that will benefit future research.

Public patient involvement informed research is not new and has been increasing in importance for over a decade. Nevertheless, ensuring that those with the condition can contribute to the design and development of research remains critically important to address real-world problems with high quality, challenge-led research.

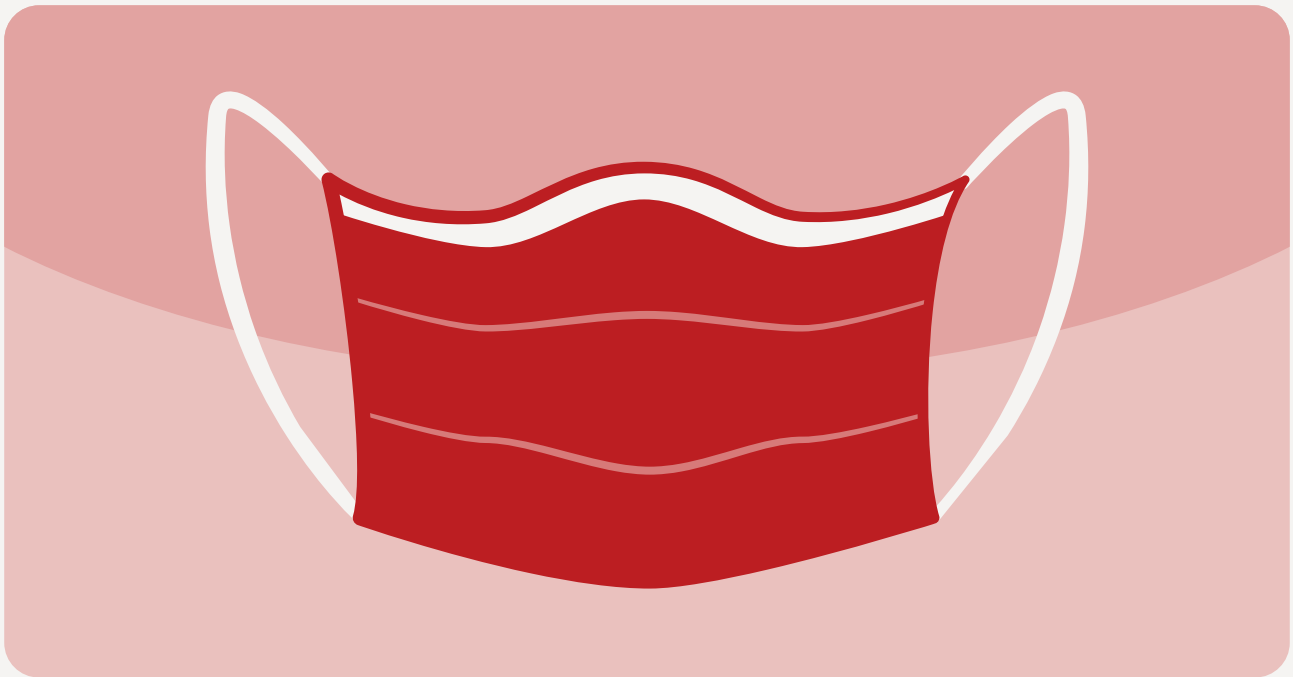
For more information on the pacing project, or to get involved, visit the project website.[10]



Instead of "Living with COVID", we need to be thinking about "Living well with COVID"

Sara Redmond, Chief Officer, the Health and Social Care Alliance Scotland (the ALLIANCE)

The announcement that Scotland's COVID-19 restrictions were lifting was welcomed by many people. However, as we adjust to "Living with COVID", our approach cannot leave people behind. For many disabled people, people living with long term conditions, and unpaid carers, the prospect of a life without restrictions was a terrifying vision of a life without protections. For people who were previously advised to shield due to the risk to their lives, the shadow does not feel lifted. People living with Long Covid feel frustration and fear that they will not return to the life they had before. And many more feel that the lessons from the pandemic have not been learned and will be repeated.



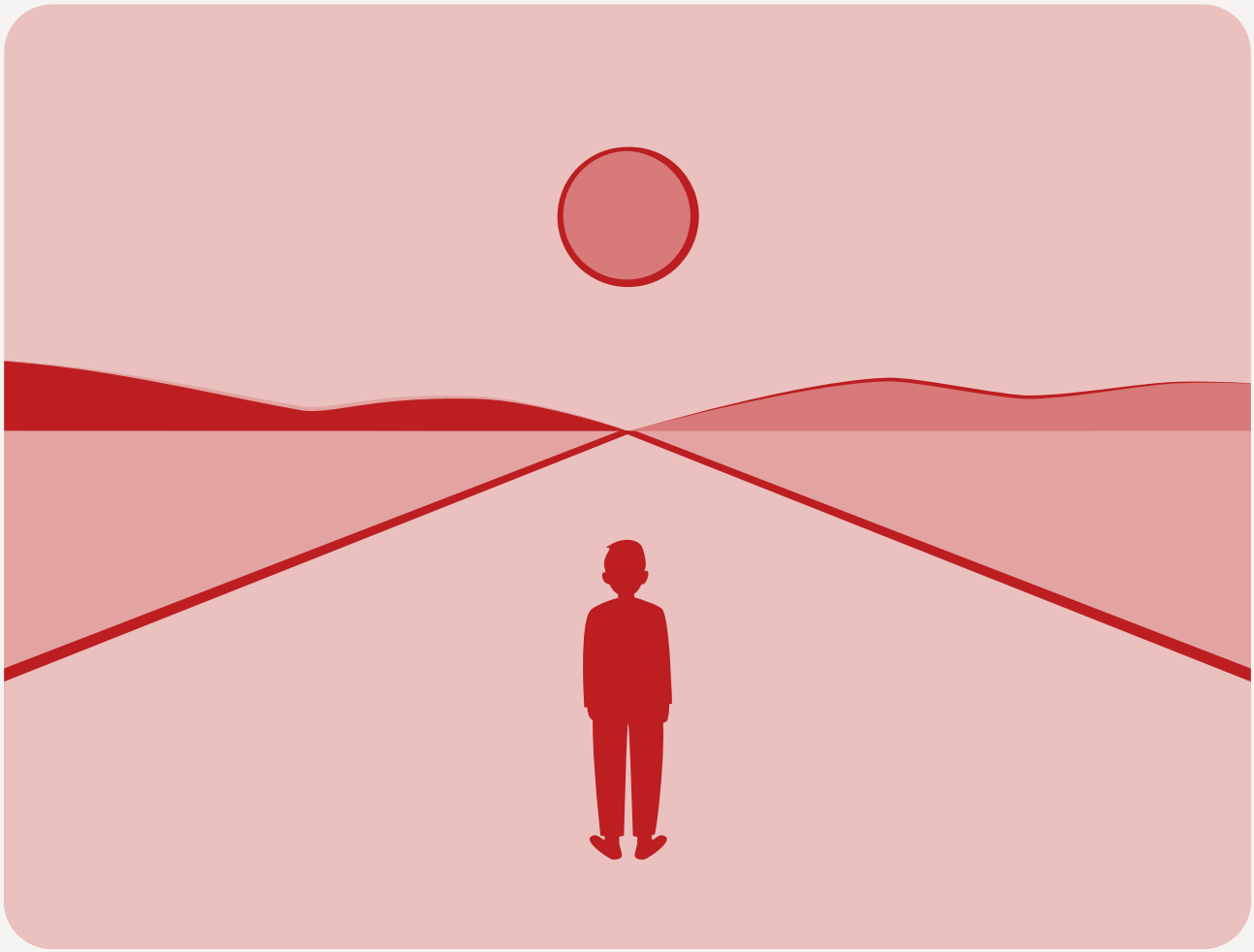
Instead of "Living with COVID", we need to be thinking about "Living *well* with COVID".

"Living well with COVID" would mean more support for disabled people, people living with long term conditions, and unpaid carers. At the height of the pandemic, 4,061 people in Scotland were advised to shield by the Chief Medical Officer – although many people who did not receive a shielding letter also chose to shield. Despite the official end of shielding, many people are continuing to protect themselves from social contact, keeping away from the potential of infection. They are far from reassured that it is safe to remove protections or that the government is considering them when making decisions. We need to listen to those with lived experience, and design support and permanent protections to allow them to live well again.

"Living well with COVID" should also mean improving support for people with Long Covid. Long Covid is a new long term condition which – so far – has no cure, and has left people with a wide variety of symptoms, including breathlessness, brain fog and heart problems. People living with Long Covid have faced disbelief from medical professionals, the loss of employment, and barriers to accessing state support services. It is imperative that we adopt a whole system, person centred approach, which prioritises peoples' experience and the vital work of the third sector. It also means making sure that employers' practices, social security, and social care systems are adequate and responsive to Long Covid.

The lessons from COVID-19 have been hard-earned, and we cannot lose sight of them. We must work hard to continue to keep people's experiences at the centre.

A version of this article first featured in The Scotsman.[11]



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9 PEM is a contested term, and for a good reason. Researchers are slowly adopting better names such as post-exertional neuroimmune exhaustion (PENE). However, it remains the most commonly used term, so it is included here.

10 University of the West of Scotland, "Pacing Project: Introduction" (2022). Available at: https://pacing.uws-projects.co.uk/

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About the ALLIANCE

The Health and Social Care Alliance Scotland (the ALLIANCE) is the national third sector intermediary for a range of health and social care organisations. We have a growing membership of over 3,000 national and local third sector organisations, associates in the statutory and private sectors, disabled people, people living with long term conditions and unpaid carers. Many NHS Boards, Health and Social Care Partnerships, Medical Practices, Third Sector Interfaces, Libraries and Access Panels are also members.

The ALLIANCE is a strategic partner of the Scottish Government and has close working relationships, several of which are underpinned by Memorandum of Understanding, with many national NHS Boards, academic institutions and key organisations spanning health, social care, housing and digital technology.

Our vision is for a Scotland where people of all ages who are disabled or living with long term conditions, and unpaid carers, have a strong voice and enjoy their right to live well, as equal and active citizens, free from discrimination, with support and services that put them at the centre.

The ALLIANCE has three core aims. We seek to:

- Ensure people are at the centre, that their voices, expertise and rights drive policy and sit at the heart of design, delivery and improvement of support and services.
- Support transformational change, towards approaches that work with individual and community assets, helping people to stay well, supporting human rights, self management, co-production and independent living.
- Champion and support the third sector as a vital strategic and delivery partner and foster better cross-sector understanding and partnership.

ALLIANCE
HEALTH AND SOCIAL CARE
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