

# Treating Long COVID in Scotland

June 2021

# Contents

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|  |           |
|--|-----------|
| Foreword   | <b>3</b>  |
| Introduction                                     | <b>4</b>  |
| Key recommendations                              | <b>5</b>  |
| What we know about long COVID                    | <b>6</b>  |
| Individual experiences of living with long COVID | <b>9</b>  |
| Action to treat long COVID across the UK         | <b>11</b> |
| How we can treat long COVID in Scotland          | <b>13</b> |
| Conclusion                                       | <b>15</b> |
| Endnotes   | <b>16</b> |



# Foreword

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As a GP, I see the devastation that the coronavirus pandemic has inflicted upon Scotland. The pandemic has affected everybody, from directly contracting COVID or seeing their loved ones contract it to indirect effects, such as the mental and financial pressures of the lockdown.

I see increased numbers of patients with mental health deterioration which is throughout all the age groups, and we do not know the long-term impact on our young children. I am also seeing a large cohort of patients who are presenting with a myriad of symptoms after contracting COVID that have simply persisted.

Long COVID has been a particularly devastating diagnosis as it is affecting fit, young healthy people and it seriously debilitates them.

At the moment there is simply nowhere for these patients to go and get the help they need. I have had people crying ask me when this will get better, why there is nowhere for them to go and seek further help. I feel helpless talking to them and wish that there was something I could have done.

So, publishing this paper is the first step in my campaign to get the Scottish Government to treat long COVID with the seriousness it warrants. We need to see a properly resourced strategy to deliver long COVID treatment through an app-based service and a network of specialist clinics. This will ensure that long COVID patients are given the support they deserve, while taking pressure away from other parts of the NHS.

Making a difference for patients and speaking up for the NHS is exactly the reason I stood to become an MSP. We need to give long COVID the recognition and funding it deserves in Scotland.



**Dr Sandesh Gulhane MSP**

# Introduction

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Long COVID has largely been the forgotten part of the coronavirus pandemic in Scotland. This is despite the disease affecting tens of thousands of our people, with thousands potentially left unable to work for months due to chronic fatigue and other conditions, despite being previously healthy.

This is devastating for the individuals who experience it, but it also has profound implications for our public services and economy. 3% of those who work in our health service across the UK have said that they have suffered or are suffering from the disease. 1.7% of the Scottish population generally have also said that they have or are experiencing from it. While more research is needed, these figures suggest that long COVID could be having a deeply damaging effect on our NHS and our economic recovery from the pandemic.

While other parts of the UK and other countries across the world have adopted strategies to deal with the disease, no such plan exists in Scotland. We are not funding specific support for patients with long COVID, which means that their treatment is falling upon the rest of the NHS.

That is why, as we build Scotland's real alternative, we are publishing our first policy paper in this parliamentary term on long COVID, to raise awareness of the extent of this disease and what we should be doing to tackle it. We need to see the Scottish Government give the disease recognition and patients the support and treatment they deserve.

# Key recommendations

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- **Publish a clear long COVID strategy.** The Scottish Government needs to publish a strategy on tackling long COVID, to set an approach across our health and other public services for supporting people with the disease.
- **Create a specific long COVID care fund.** The Scottish Government and NHS Scotland should set aside a clear ring-fenced funding pot for treating long COVID patients. An investment of £34 million delivered 83 clinics in England and the costs associated with app delivery have been in the hundreds of thousands rather than millions.
- **Work with health services and research institutions across the UK to discover more about the disease.** Long COVID is a challenge faced across the UK and so all four nations should be working together to tackle it. This should seek to establish more accurate data for the extent of long COVID in Scotland and the most severe cases of the disease. As long COVID is still a relatively new disease, our understanding will evolve with emerging research.
- **Invest in a network of specialist clinics.** NHS Scotland should deliver a network of specialist long COVID treatment centres which can help the worst cases and support rehabilitation across the whole health service. These should have a good geographic spread, given the difficulty of long COVID patients in traveling. As part of these clinics, the NHS should look to establishment multi-disciplinary teams, who can break down the treatment of the different symptoms that make up long COVID.
- **Adopt an app-based treatment service.** Given the volume of potential long COVID patients and their wide range of symptoms, an app-based service is needed to help patients access a range of specialist services. This is likely to reduce pressures on other parts of the NHS.

# What we know about long COVID

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## *What is long COVID?*

Long COVID as a disease is not simply one condition. It has been defined by the National Institute for Health and Care Excellence (NICE) as “the signs and symptoms that developed during or after an infection consistent with COVID-19 which continue for more than 12 weeks and is not explained by an alternative diagnosis”. There are many alternative names which are used when speaking about long COVID and these include: long-tail COVID, post-acute COVID, post-COVID, and long-haul COVID, and people with long COVID may refer to themselves as long haulers.

The most common symptoms are fatigue, shortness of breath, and brain fog but long COVID presents a varied list of symptoms which can interact with each other:

- Fatigue
- Problems with concentration
- Dizziness
- Depression and anxiety
- High temperature, cough, headaches, sore throat, changes to sense of smell or taste
- Breathlessness
- Insomnia
- Pins and needles
- Tinnitus, earaches
- Rashes
- Chest pain or tightness
- Heart palpitations
- Joint pain
- Feeling sick, diarrhoea, stomach aches, loss of appetite [1]

The epidemiology of long COVID is not defined adequately due to the multiple organ system pathophysiology in the medium and long-term. [2] The research so far has been focusing upon symptoms not organ dysfunction and we are faced with large differences in the estimate of the incidence and prevalence of long COVID.

What we are seeing is a varied range of organ dysfunction with patients having features of mast dysfunction, immunological dysfunction, neurological diagnosis and dysautonomia. The problem we are presented with is that common long COVID symptoms (fatigue, brain fog, shortness of breath, gastrointestinal disturbance) have many different differential diagnosis spread through multiple specialties. [3]

A virus causing residual problems is not a new phenomenon in medicine but long COVID has such a varied range of symptoms it does not fit well with other post viral fatigue syndromes. We also know that a number of cases resolve spontaneously by 8 to 12 weeks. [4] As long COVID is a new phenomenon, there is still comparatively little research into the disease and as such we do not know what the causes are.

The NICE definition is relatively new and research that has been conducted so far did not have a universally defined period, after testing positive for COVID-19, at which an individual can be said to be suffering from long



COVID. King's College London in their research into the extent of long COVID defined it as symptoms that last beyond 8 weeks. [5] The ONS in their study took long COVID as being any symptoms continuing past 4 weeks. [6]

*How many people are suffering from long COVID in Scotland?*

Given the breadth of symptoms associated with long COVID, the lack of an exact timeframe and our evolving understanding of both COVID-19 and its potential long-term effects, it remains unclear how many people are at risk or have been affected by it. King's College London's research suggested that 1 in 20 people who get COVID-19 suffer from long term symptoms.

The National Institute for Health Research (NIHR) suggest that 1 in 10 people experience at least one symptom after 12 weeks. However, their research found that this rises to between 50 and 89% of those who were admitted to hospital with COVID-19 after two months. There are also some suggestions that long COVID appears to affect patients with higher pre-COVID fitness levels, children and women more frequently compared with acute COVID-19. [7]

This was corroborated by ONS research, who found that symptom prevalence 12 weeks after testing positive for coronavirus was higher in women than men. Overall, they found that over 1 million people across the UK reported experiencing long COVID, with 650,000 saying that this had affected their day-to-day activities and 192,000 reporting that it had affected their lives a lot. For Scotland alone, they estimated that 87,000 people, 1.7% of the population has experienced long COVID.

The evidence that we have suggests that the severity of the acute phase does not relate to the severity of which a patient suffers

from long COVID. NIHR survey data found significant rates of long COVID beyond six months in people who had not been hospitalised during the acute phase.

What we do know is that long COVID can have severe impacts on people's quality of life. The NIHR found that 80% of respondents to their survey said that long COVID had affected their ability to work, 71% that it was affecting their family life, 39% said that it was affecting their ability to care for dependents and 36% said that it was affecting their family finances. [8]

*The importance of tackling long COVID to our public services and economy.*

As with other effects of coronavirus on our society and economy, the impact of long COVID will take years to be fully understood. However, it is clear that long COVID is forcing many people to make major adjustments to their life, including their ability to work. This could have dramatic consequences for our economy and public services, as a substantial number of people have to change their working habits or stop altogether for a prolonged period because of their condition.

Prevalence of long COVID among people who work in our health and social care sectors is nearly double the prevalence among the population of a whole. Against a rate in the general population of 1.58% the ONS found the rate among health workers as 3.05% and in social care was 2.75%. They also found higher rates in retail (2.43%), teaching and education (2.40%) and the civil service and local government (2.39%). This suggests that those public services and economic sectors that have been at the forefront of responding to the pandemic have been the most at risk of suffering from acute COVID-19 and therefore also long COVID.



The ONS also found that prevalence was more than three times as high among people who were already suffering from a disability or health condition that limited their activity “a lot” (4.18%) than among people with no health condition (1.29%). In addition, they found that the rate was substantially higher among the most deprived quintile (2.06%) over the least deprived (1.27%).

For the whole of the UK, the ONS estimated that 72,000 people had ongoing symptoms for more than 12 months after they had first had acute COVID-19 and that this had reduced their ability to undertake day-to-day activities. This suggests that long COVID could be making tens of thousands of people across the UK either unable to work or severely restricted in what employment they can undertake. This could include thousands here in Scotland. **[9]**

Given the wide-ranging impacts, in terms of the number of people affected, how severely it can reduce people’s quality of life and how it can damage our essential public services and economy, it is important that the NHS and the Scottish Government makes tackling long COVID and offering the right, properly resourced support to patients a priority.

# Individual experiences of living with long COVID

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In this section, we will be looking at the actual lived experience of people who have suffered from long COVID. While statistics can show the extent of the impact of this disease on the country as a whole, the personal stories show just how terribly long COVID can overturn an individual or family's life.

While we have heard of the experiences of long COVID sufferers, we recommend the work of the UK Parliament's All-Party Group on Coronavirus for those who want to hear the personal stories. We have taken these sections from their transcripts:

*All-Party Group on Coronavirus - Oral Evidence Session 13 – 12 January 2021*

**Dr Nathalie MacDermott (clinical doctor sub-specialising in paediatric infectious):**

"I've never tested positive for the virus but I had all of the symptoms and I had all of the symptoms all over again and at the end of that time I developed neuropathic pain, so nerve pain in my feet and slight weakness in my legs. It wasn't really clear what was going on at the time but I couldn't walk very well....now I can only walk about 200 metres without some form of assistance. I can walk a bit further with crutches but the damage has affected my bladder and bowel as well so I get recurrent urinary tract infections and I also get a lot of pain in my arms and I'm getting weakness in my grip now as well."

**Geraint Jones (advanced pharmacist specialising in HIV and home care):**

"I had chronic diarrhoea and abdominal pain

which would last seven, eight hours a day at one point and this lasted for 14-15 weeks, still to the point now where I experience four to five loose motions a day. The pain is still there as a background pain. It does get more trying on times than others but I've also been left with like the brain fog that people explain where I can't seem to recall the most basic of words or phrases or I put mugs in the fridge when I go to make a cup of tea. I've got tinnitus in my one ear which is quite distracting when trying to communicate with others. Palpitations at rest which is quite painful to the point of not knowing whether to go to A&E with a quite sharp stabbing chest pain."

**Dr Linn Järte (anaesthetist):**

"At the start of my Long Covid even just taking a couple of steps would make me feel absolutely horrendous, it felt as if my whole body was just filled with lead but at the same time I had this sort of painful burning sensation and it also made my heart rate shoot through the roof and I had painful pins and needles throughout my arms and legs and I got recurrent sinusitis. And the more I tried to do anything the worse all of these symptoms got, so it would lead to what we call setbacks. So after having done anything at all, anything as basic as having a shower or cooking food for myself I would become even worse. So, this left me bed-bound then for many months." [10]

**Sammie McFarland (founder of Long Covid Kids):**

“[daughter 14 years old] she started clutching her chest and complaining of heart pain and she went very pale and very floppy and almost didn’t make it back into the house to be able to get to her bed. And then she stayed there for pretty much the next seven months. Unfortunately, all of her meals needed to be taken in bed, she didn’t have the energy to sit up, she couldn’t hold her head up, she was too weak. She had to use the walls and us to support her to get to the toilet, she would fall off the toilet because she didn’t have the energy to sit on the toilet. She was unable to do any simple tasks, so showering sort of went out of the window and really her days were just spent in bed for the majority of time between March and August..”

**Fran Simpson (founding member of Long Covid SOS)**

“[five year old son] He went on to have varying symptoms, so he sort of got a bit better and then he got worse again and his has fluctuated up until now. So, he has things like blurring vision, he gets headaches, he’s nauseous most days, he has fatigue frequently so if he does anything you know he has fatigue... My daughter who was nine at the time, she became ill about a week after I was ill and hers was much worse, she started with a sore throat, earache and then she was ill for six weeks with various, she was really fatigued, she was really pale, she stopped eating, she couldn’t eat anything she felt so sick, she was dizzy, she nearly fell on the stairs one day as I was helping her down, she collapsed. She was either on the sofa or the bed for about six weeks. And she has since had rashes, she’s nauseous most days, she has terrible anxiety and moods, OCD. She’s had some cognitive changes, I would say she finds any kind of work hard and she’s really quite a bright girl.”

**Charlie Mountford-Hill (mother of five children with long Covid)**

“I look at all my children and none of them are the same children who they were before we got sick, before March I had children who were outside playing, doing sports everyday and now I have children who all look shattered, all need more sleep, Indie in the snow on Sunday kept having to stop to catch his breath. This is a child who plays in two different football teams and does all the after school sports that he can get his hands on and yet he can’t breathe properly still. And both me and my husband are still sick as well.” [11]

# Action to treat long COVID across the UK

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There are two mainstream models used for long COVID treatment across the UK. The first is an app-based treatment model, which offers advice to patients on their recovery and rehabilitation. In some cases, patients can access specialist services through the app on a wide range of NHS services and book virtual appointments.

The other is a dedicated network of clinics who offer care and support through face-to-face contact for treating long COVID. It should be noted that these are not mutually exclusive and that patients in some areas, such as large parts of the South of England, can access both services.

In other parts of the UK, the following action has been taken to tackle long COVID:

- In November 2020, NICE published guidance to support medical practitioners to identify and treat patients suffering from long COVID.
- Barts Health NHS Trust in London was the first to launch an app dedicated to supporting the treatment of long COVID in August 2020. The Living With Covid Recovery Programme is focused on breaking down and treating the individual symptoms of long COVID. This is currently being rolled out across England and the trials have shown that one health practitioner can remotely treat 122 patients in a single morning through it.<sup>[12]</sup>
- The NHS in England has also set up a network of dedicated long COVID treatment clinic. This has grown to 83 clinics being set up at a cost of £34 million. <sup>[13]</sup>

- In Wales, an NHS COVID recovery app was launched in January 2021, which provides advice to patients on their recovery from acute and long COVID. They have also given GP practices codes so that the extent of long COVID in Wales can be better recorded. The Welsh Government has delivered regular written statements on actions to treat long COVID. <sup>[14]</sup>

However, we believe that the most extensive response to long COVID anywhere in the UK is in Hertfordshire Community NHS Trust. They developed a post COVID-19 Rehabilitation Pathway delivered by a multidisciplinary team (MDT) which included: a community GP, pharmacists, physiotherapists, pulmonary rehabilitation, respiratory nurses, speech and language therapists, dietitians, occupational therapists, clinical psychologists, chronic fatigue and pain management. The MDT has worked closely with colleagues in social care, acute hospitals, mental health and the voluntary sector to deliver a holistic approach to each patient's care. <sup>[15]</sup>

Having spoken to the team who have set up this amazing long COVID clinic, we believe that this could form a model that Scotland could adopt. The treatment pathway begins when a patient is referred by their GP to the clinic after conducting routine investigations. The referral is triaged by the team and they consider both the medical, physical, cognitive issues facing the patient. The clinic GP is able to directly access investigations such as radiological and cardiological tests and they are able to directly refer into the clinics of hospital consultants



(such as respiratory and cardiology clinics) who have dedicated slots.

Once the hospital consultant has seen the patient, investigated and treated as much as they can, they refer the patient back to the clinic and the co-ordinating clinic GP will take over the Long-COVID care again. This is complemented by psychological and psychiatric support available along with physiotherapy and occupational therapy. Occupational therapists are key to supporting patients to get patients back to work. These patients are unable to perform a standard four week return to work phased return and need more bespoke help.

A lot of the work this clinic performs is over telephone and video consultation because their patients do not have the energy to be seen face to face. This is important for areas of low population density where it is not practical for patients to directly access clinical services in person, such as the Highlands and Islands.

The UK Government is also funding research into long COVID and its treatment. NIHR and UK Research and Innovation have awarded £18.5 million to four projects aimed at better understanding the causes, symptoms and treatment of long COVID. [16]

*The response of the Scottish Government to long COVID.*

While there will be instances where individual medical practitioners are supporting patients with long COVID and may be doing so well, the Scottish Government and NHS Scotland are not currently offering a system-wide response.

The Scottish Government has funded £2.5 million of research into nine university projects on long COVID. The Scottish Intercollegiate Guidelines Network (SIGN) was also a partner in the production of the NICE guidelines.

However, the last rehabilitation pathway that the Scottish Government produced was in August 2020 and that makes no reference to the treatment of long COVID specifically. [17] Across Scottish health boards there are no specific treatment services available for patients that are suffering from long COVID. There has also been no announcement of additional funding from the Scottish Government to begin to develop specific treatment services dedicated towards long COVID.

Given the range of services available in other parts of the UK and their expansion in recent months, we believe that long COVID patients in Scotland are being left behind by the treatment services that are available.

# How we can treat long COVID in Scotland

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As we have noted, long COVID is already having a profound impact on tens of thousands of Scots, our economy and public services. It is time that the Scottish Government gave the disease the attention it deserves and gave medical practitioners the support they need to tackle it.

Fortunately, there are established models that already exist in other parts of the country, that we can follow and use. As we have detailed in other parts of the UK, there is already app-based treatment services and specialist clinics that we could rollout in Scotland.

Firstly, we believe that the Scottish Government needs to publish a strategy on tackling long COVID, to set an approach across our health and other public services for supporting people with the disease. This will look at how we deliver a patient centred approach to treatment but also at how we manage the impact of long COVID on our economy and public services. It will give the condition the recognition that it deserves in Scotland. This strategy has to be delivered; it cannot be a paper exercise. We believe that the Scottish Government should provide a regular update on the work that it is doing to tackle long COVID and to allow for scrutiny of its actions.

Then the Scottish Government and NHS Scotland should set aside a clear ring-fenced funding pot for treating long COVID patients. We note that an investment of £34 million delivered 83 clinics in England and the costs associated with app delivery have been in the hundreds of thousands rather than millions.

There will have been Barnett Consequentials to the Scottish Government of £3.3 million from this investment, but this should not be limit of our ambition. While the NHS is under resource pressures, particularly during the pandemic, the widespread impact of long COVID and its severity, in many cases, should mean that we treat it now as a priority.

Long COVID is also a challenge faced across the UK and so all four nations should be working together to tackle it. The Scottish Government should be coordinating research projects and funding for them with the other governments of the UK to have best effect. An early priority for additional research funding should be to seek to establish more accurate data for the extent of long COVID in Scotland and the most severe cases of the disease. This will better inform our response across the NHS and our other public services. As long COVID is still a relatively new disease, our understanding will evolve with emerging research, which is best conducted through long COVID clinics.

In addition, NHS Scotland should deliver a network of specialist long COVID treatment clinics, which can help the worst cases and support rehabilitation across the whole health service. These should have a good geographic spread, given the difficulty of long COVID patients in traveling and the low population density in parts of Scotland. As part of these clinics, the NHS should look to establishment multi-disciplinary teams, who can break down the treatment of the different symptoms that make up long COVID. We believe that the approach set out by Hertfordshire Community



NHS Trust represents the best model anywhere in the UK for bringing a holistic, multi-discipline approach to treating long COVID and should be replicated in Scotland.

Finally, NHS Scotland is already significantly behind its counterparts in other parts of the UK in the delivery of app-based treatment. Apps can allow medical practitioners to treat far more patients than they would through physical appointments. A large number of long COVID patients are going to be unable to travel due to their condition and there is also likely to be a high number of self-referrals. Given the volume of potential long COVID patients and their wide range of symptoms, an app-based service is likely to reduce pressures in other parts of the NHS. Models like the Living With app are already available and should be seriously considered.

Ultimately, though with a relatively new disease we should be prepared to adapt our approach based on ongoing research and best practice. The Scottish Government should therefore be alive to developments in treating long COVID both in the rest of the UK and in the rest of the world.

#### **Our recommendations:**

- **Publish a clear long COVID strategy.**
- **Create a specific long COVID care fund.**
- **Work with health services and research institutions across the UK to discover more about the disease.**
- **Invest in a network of specialist clinics.**
- **Adopt an app-based treatment service.**

# Conclusion

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As we begin to understand more about coronavirus and how it mutates, spreads and creates organ dysfunction, we will be able to create more nuanced treatment options, but we believe that the recommendations in this paper provide a start for tackling long COVID in Scotland.

The establishment of a network of long COVID clinics will enable us to discover the epidemiology of the disease which will allow us to create criteria for a diagnosis, help establish appropriate treatment strategies, coordinate public health policy and intervention and allow us to plan our resources. The clinics will give us a focus for our patients, placing them in a situation where they are able to be seen by the right person at the right time, with coordinated care treating mind and body.

We cannot afford to wait two to three years whilst research is undertaken, our patients simply cannot wait that long. General Practise is under tremendous strain and is on the verge of being completely overwhelmed. We cannot expect GP's to be able to adequately cope with long COVID patients and Long COVID patients cannot cope with the short appointment times and lack of significant investigations.

The Scottish Government needs to give long COVID treatment the focus and importance that it deserves, so that we can better help patients and the whole of Scotland to recover from the coronavirus pandemic.

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