

Scotland's Long COVID Service

September 2021

Foreword

While most people's symptoms of COVID-19 resolve within a few weeks, some people experience persisting or new symptoms after their initial infection with the virus.

There remains much we do not yet know about long COVID, including the underlying causes, why some people are affected and others not, and importantly, exactly how long these effects can be expected to last for any one individual. However, there is much we do know about how people affected can be well supported.

In a situation involving uncertainty, supporting people to make informed choices about their care and treatment options, based on what matters most to them, is key.

Providing clear information at the right time can help people to feel more in control of their condition, and live their lives better, on their terms.

Our response to long COVID depends on having a range of well integrated sources of support, given the wide spectrum of needs that people affected can sometimes have.

This range of support is already being delivered by our NHS, social care and third sector across Scotland. We have an approach in place that will strengthen the range of support available within the primary care setting, providing a person-centred response with referrals to secondary care where necessary.

However, there remains more to be done and this paper sets out the key elements that underpin our approach to care and support for people with long COVID. It also underlines our commitment to making sure our NHS is resourced to respond innovatively to the needs of people with the condition.

Through our £10 million long COVID Support Fund we will provide Boards with the resource they require to respond in a flexible and tailored manner to the needs of people with long COVID. The fund will support local services to develop and deliver the best models of care appropriate for their populations, which could include strengthening and improving the co-ordination of existing services, or establishing dedicated services (including 'long COVID clinics' if appropriate).

In navigating new and uncertain territory, it is right to chart a direction of travel and update that route in the light of evidence as it continues to emerge. As such, our approach is flexible and subject to ongoing review, to ensure that care and support is consistently person-centred, clinically effective and safe, for every person with long COVID, all of the time.

A handwritten signature in black ink, appearing to read 'H. Yousaf'.

Humza Yousaf MSP
Cabinet Secretary for Health and Social Care



Long COVID

Long COVID relates to people who have “signs and symptoms that develop during or after an infection that is consistent with COVID-19, which continue for more than four weeks and are not explained by an alternative diagnosis”¹.

This is an umbrella term which covers a range of different symptoms. These can overlap, change over time and can affect different systems within the body. Some of the common symptoms include, but are not limited to; fatigue, persisting high temperature, breathlessness, cognitive impairment, generalised pain, and mental health problems.

It is important to recognise that these symptoms can have a significant impact on people’s quality of life and are not limited to people who were seriously unwell or hospitalised with, or as a result of, COVID-19. In addition, we recognise that many people living with long COVID may not have had access to community testing for COVID-19 at the time of their initial infection.

Our response

Long COVID can be associated with a wide range of symptoms affecting many systems in the body. We know that for some people affected, this can at times present challenges in interacting with different systems and services. We recognise that there is a need to support navigation of care, to ensure that this experience is as straightforward and effective as possible.

This paper sets out our approach and commitments to supporting the health and wellbeing of people with long COVID. Our approach is based on maximising and improving co-ordination of the broad range of existing services across our health and social care system and third sector that are relevant to the spectrum of symptoms that people are experiencing.

Our approach is based on four key elements:

1. Supported self-management
2. Primary care and community-based support
3. Rehabilitation support
4. Secondary care investigation and support

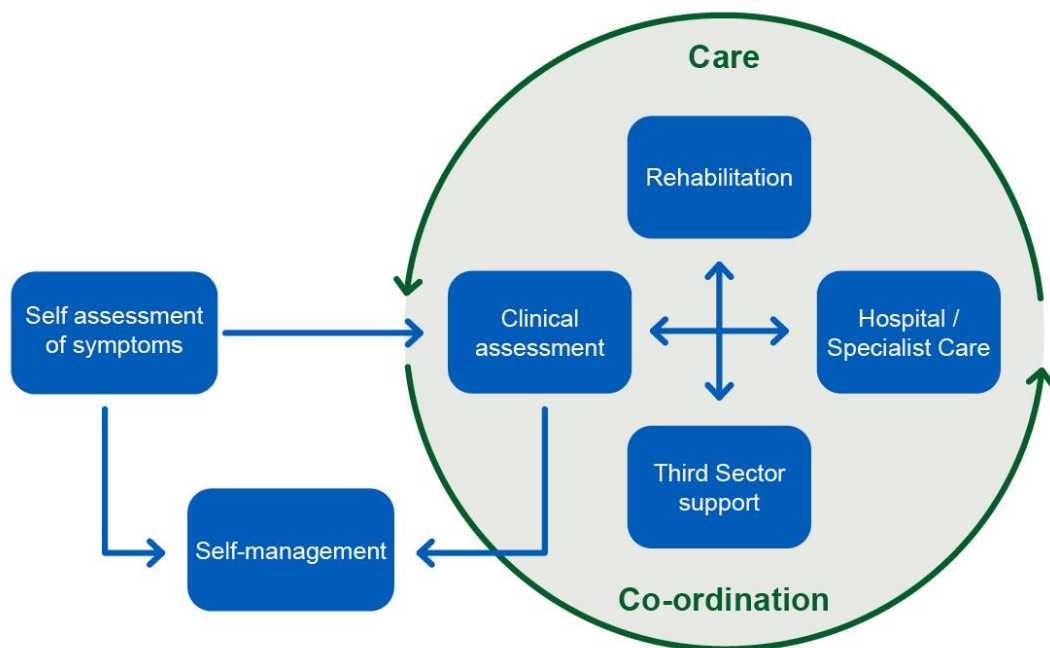
¹ [Managing the long-term effects of COVID-19 \(sign.ac.uk\)](https://www.sign.ac.uk/)

What people with long COVID can expect from NHS Scotland

Long COVID can affect each person in different ways and at different times. As such, people might require different levels of support and resources in order to achieve their personal outcomes.

There are a range of sources of help and support in place across our health and social care services and the third sector to make sure that people get a person-centred response targeted to their needs.

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Supported self-management

For many people, recovery from COVID-19 can be self-managed by using the right information, advice and support. This is about making sure people have access to information and resources and are equipped with the right tools to help them participate as actively as possible and enjoy the life they choose.

What you can expect:

- Clear, accessible information is available on [NHS Inform](#), which provides details about the condition, steps you can take to self-manage your symptoms, and advice on when to contact a healthcare professional for further support.
- People with long COVID can access Chest, Heart and Stroke Scotland's 'long COVID Support Service' by calling 0808 801 0899 (free from landlines and mobiles), emailing adviceline@chss.org.uk or texting NURSE to 66777. This service has been funded by the Scottish Government to enable people with long COVID to speak to Nurses who are trained in managing some of the most common long COVID symptoms, such as breathlessness and fatigue.

Our commitments

- We will work with NHS 24 to increase the range of self-management information available on NHS inform and make it more easily accessible for people with long COVID, by the end of 2021.
- We will work with NHS 24 and third sector partners to develop resources that help people with long COVID to access information on local community-based services which can support their health and wellbeing.
- We have committed £40,000 to deliver a targeted long COVID marketing campaign in conjunction with community pharmacies across Scotland.
- We will develop and distribute a communications toolkit for primary care teams, NHS Boards and other partners. The toolkit will include key messages, campaign assets and relevant information on long COVID ensuring clarity and consistency of information available.
- We will continue to support Chest, Heart and Stroke Scotland to raise awareness of their 'long COVID Support Service' and ensure that this resource can be easily accessed by those who wish to do so.
- We will continue to support long COVID needs as they emerge with the technologies appropriate to the person and the circumstances, including digital technologies and mobile apps where appropriate.

Primary care and community-based support

For many people, their first point of contact with healthcare services will be the healthcare team based in their local GP surgery.

Primary care teams have expertise in managing uncertainty and are experienced at assessing people with a variety of symptoms and conditions, as can be the case with long COVID.

As part of their local communities and often with an extended knowledge of the person over a long period of time, primary care teams are ideally placed to provide holistic, person-centred care which focuses on what matters to the person.

What you can expect:

- An assessment of your symptoms by a member of your local primary care team. Within this assessment, your healthcare professional may;
 - Take a medical history and ask you about your symptoms.
 - Conduct a physical examination to assess your symptoms.
 - Carry out tests to investigate your symptoms. This will also help them rule out other conditions which may be causing these.
- After your assessment, you will be able to discuss and agree what further information, assessment, support or rehabilitation you may need or benefit from, and how this will be delivered. This will vary depending on your own individual circumstances and needs. It could include;
 - Advice on steps that you can take to help you feel more in control by self-managing your symptoms.
 - Advice on third sector services which can help support your health and wellbeing as a result of the long-term effects of COVID-19.
 - Further support from primary care, community and mental health services, including rehabilitation.
 - Referral to investigation and assessment delivered in secondary care settings where necessary.

Our commitments

- We have established a £10 million ‘Long COVID Support Fund’ to strengthen local NHS services and care pathways for people with long COVID. This will:
 - Bolster the capacity of existing NHS services which are providing support to people with long COVID.
 - Support NHS Boards to develop and deliver a care co-ordination service model across the whole care pathway.
 - Ensure NHS Scotland is resourced to respond appropriately to emerging needs in relation to long COVID in line with the latest clinical evidence, including around staff training and education needs, equipment and other resources.
- We have established an expert group to identify the capacity needs of NHS Boards and staff in delivering safe, effective and person-centred support for people with long COVID.

- We will continue to support future updates of the SIGN Guideline and encourage clinicians to use the Implementation Support Note which provides key direction on identifying, assessing and supporting people with long COVID as required in line with clinical evidence.
- Through our Primary Care Improvement Fund, we will continue to support and expand the range of professional roles in primary care that play a key role in the provision of services that can support people with long COVID.

Rehabilitation support

When the long-term effects of COVID-19 are significantly impacting on a person's day to day functioning, rehabilitation can provide support that is focussed on goals that are important to the person.

Rehabilitation can focus on a number of areas including,

- mobility and getting around
- managing daily activities
- management of fatigue
- swallowing or dietary problems
- getting back to work

What people can expect:

- An assessment of your abilities.
- A discussion with your rehab therapist to agree goals that are both important to you and that are realistic and achievable.
- A focus on physical health and/or mental health aspects of recovery.
- A rehabilitation plan based on your goals.
- This plan should be delivered as much as possible within a primary care setting. Where referral to specialist services is required there will be clear pathways to do this and clear communication with services, through your care co-ordinator.
- Review and monitoring of goals, within a time period agreed between you and your rehab therapist.

Our commitments

- We will build our understanding of current rehab services being delivered across NHS Boards in Scotland, including ICU/Critical Care, primary care & community care (exit out of and entry into services).
- From this work, and underpinned by the priorities set out within the 'Framework for Supporting People through Recovery and Rehabilitation during and after the COVID-19 Pandemic', we will develop and implement a programme of work to deliver a 'Once for Scotland' rehabilitation pathway that will ensure everyone who requires rehabilitation will be able to access it.

Michelle's story

"I tested positive for COVID in October 2020, and by November I went to the Doctor because I wasn't getting back to normal. They did various blood tests and different things, which were fine, and they asked me if I wanted to go and see the Occupational Therapist based within the practice for a rounded approach to getting back to full health again.

I agreed, and I am glad I did because she has been an amazing help in my journey. I was able to get advice on how to manage my time and how to adapt to having to take a step back from my usual routine.

I've learned to listen to my body to manage my energy – the way that the Occupational Therapist described it was to think about it like a battery that has only got a limited amount of life in it. I wouldn't say I am yet quite back to 100%, but she has helped me to manage getting to where I am just now."

* July 2021 – source NHS Lanarkshire Primary Care Occupational Therapy service.

Secondary care services

In some cases, a person's initial assessment within primary care may indicate that further investigation and assessment delivered in a specific speciality clinic or hospital setting is required.

We know that for some people, interacting with different systems and services can be challenging. We recognise that there is a need to support navigation of services, and we are committed to supporting NHS Boards to deliver a service that ensures a person's experience is as straightforward and effective as possible.

What you can expect:

- Following a shared decision between you and your GP or care co-ordinator, you may be referred for further investigation and assessment in secondary care.
- You will be provided with information on the potential benefits, harms and limitations of any investigations, to help you make an informed decision.
- Absence of a positive SARS-CoV-2 test (lateral flow, PCR, antigen or antibody) will not exclude you from referral for further investigations or secondary care input where required.
- You may be referred to different specialities, or for more than one type of investigation, depending on your needs. One role of your care co-ordinator is to support this process and act as a central point of contact for you during this process.
- Both you and your care co-ordinator will be informed of results and planned follow-up care.

Our commitments

- We will support NHS Boards to develop and deliver a care co-ordination service model, which will enhance the way in which primary, community and secondary care services work together in order to meet the needs of people living with complex needs as a result of long COVID.
- We will support NHS Boards to establish a service model for the delivery of clear, consistent and co-ordinated pathways across primary and secondary care to ensure that the person is at the centre of decision making and the pathway.
- We will work with National Services Division to support NHS Boards to provide healthcare staff with a clear understanding of the services and infrastructure available in their areas to support investigations related to long COVID.
- We will encourage the use of the SIGN Decision Support platform, which provides healthcare professionals with an integrated point of access to evidence-based information on supporting people with long COVID.

Pamela's story

Pamela has a mild chest condition – bronchiectasis – which meant she had to shield at the start of the pandemic. After contracting the virus in September 2020 she was admitted to hospital where she ended up in intensive care and intubated for almost three months.

By the time she was transferred to a respiratory ward on Hogmanay, she could not move and ultimately went to a Physical Disability Rehabilitation Unit for intensive physiotherapy and Occupational Therapy.

She also received intervention and oxygen therapy in a respiratory ward, and returned home with long-term oxygen at the beginning of June 2021, where she receives ongoing care from a Community Rehabilitation Team to support her to regain her independence, function and mobility.

“This last year has been a challenge, when I’ve had to let other people take care of me. But I’m blown away by everything I’ve been given by the NHS. They are just amazing. Some of them visit me weekly, some are at the end of the phone, they deliver my oxygen and really look after me.”

* September 2021 – source NHS Greater Glasgow and Clyde

Evidence-based approach

We are committed to continually developing our understanding of the long-term effects of COVID-19, using all of the information sources available to us, in order to ensure people affected are able to access the most appropriate support and care.

We have already achieved a great deal in supporting people with long COVID and we are committed to doing more, ensuring our approach is evidence-based and providing a service where people can access the support they need as locally and quickly as possible.

Research is key in improving our understanding of the effects of long COVID on people's physical and mental health in Scotland, and that is why the Scottish Government has provided funding of £2.5 million to support 9 research projects.

These studies are examining various aspects including the frequency, nature and impact of long COVID in the Scottish population, the longer-term impact of COVID in people living with diabetes, assessing cognitive symptoms after COVID-19 infection, and evaluating emerging models of rehabilitation.

This research activity will add significantly to the growing evidence base in addition to research being conducted across the UK and internationally. We will maintain effective relationships with our partners across the UK, to support the sharing of research and practice developments as they continue to emerge.

Accurate data is a vitally important tool in our response, and we have worked with the Royal College of GPs Scotland to support primary care teams in the recording of long-term effects of COVID-19 within clinical information systems. This data, along with work being carried out by the University of Edinburgh and Public Health Scotland will help to inform our understanding of the number of people diagnosed with long COVID, and their use of health services.

Alongside clinical evidence and data, the experience of people living with long COVID is critical in informing our understanding of the condition. We have worked closely with the Health and Social Care Alliance Scotland (the ALLIANCE) to ensure that the views of people living with long term conditions, including long COVID, inform our approach as we remobilise health and social care services.

The third sector plays an invaluable role in supporting people to feel more equipped to deal with some of the day to day impacts of living with their conditions.

That is why we have invested over £460,000 to enable Chest Heart and Stroke Scotland to deliver its 'Long COVID Support Service' which further enhances the support being provided by NHS Scotland.

In addition, the Self-Management Fund, administered by the Health and Social Care Alliance Scotland (the ALLIANCE) on behalf of the Scottish Government is enabling the Thistle Foundation to develop their remote self-management programme, with a specific focus on supporting people living with long COVID.

There is still much to be done and this paper sets out our approach to supporting people with long COVID and our continued commitment to ensure each person experiencing long COVID receives the best support and care that is person-centred, equitable and accessible.



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