

# Long Covid – What it is, the current situation and future possibilities.

## What is Long Covid?

'Long Covid' refers to prolonged and debilitating COVID-19 symptoms that persist at least 12 weeks after the acute phase of infection with SARS-CoV-2 and cannot be explained by any alternative diagnosis. Long Covid is said to occur after 4-5% of Covid-19 infections and it can affect children and adults. Symptoms may be diverse affecting most systems of the body. People experience a wide range of symptoms including fatigue, fever, cough, shortness of breath, cognitive dysfunction, chest pain, headache, joint or muscle pains, diarrhoea, stomach pains, rashes, and blood clots. There is often a relapsing and remitting pattern. There may be considerable impact on everyday functioning.

## Possible causes of Long Covid

It has been suggested that the persistence of viral infection and a dysfunction of the immune system may be responsible for tissue damage and the wide range of symptoms seen in Long Covid. Because Long Covid is not confined to those people who's acute Covid infection was severe, there are real concerns over the potential long-term impact of Covid, particularly in children.

## The scale of the problem

[The Office for National Statistics](#) estimates that 1.4 million people in the UK (as of 2<sup>nd</sup> July 2022) are living with Long Covid, which equates to nearly 150,000 people in Scotland. This figure, for no known reason, does not include children and teenagers under 18. Given that Long Covid tends to be misdiagnosed and uncounted, the true figures could be higher. In general, the incidence of Long Covid follows the pattern of the incidence of Covid cases nationally and regionally.

## Who is affected?

Continuing symptoms are more prevalent in women, people living in deprived areas and those with an existing health condition or disability. The Scottish profile however includes young previously healthy adults who were active and hard-working but who are now no longer able to work, study or live their lives to the full. There is a wide age span of men and women experiencing Long Covid. It has been suggested that Long Covid could be the largest mass disabling event since the 1st World War.

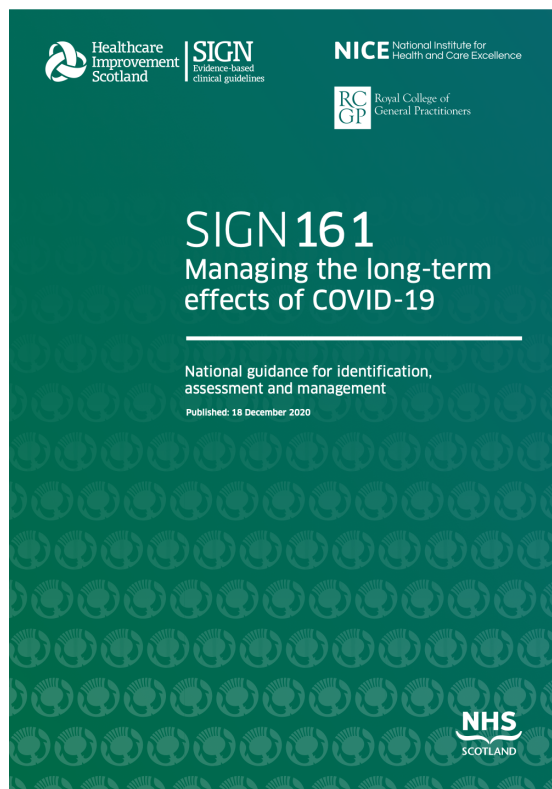
## Approaches to diagnosis, treatment and management

The challenges in accurately diagnosing Long Covid have been compounded by the pandemic's impact on health services. Many people who contracted Covid 19 in 2020,

in the first wave, were not able to access testing and sometimes were not able to see their GP or other Health Care Professionals. Long Covid was a new disease and when people did access health care after not recovering from an initial infection, they were met by a knowledge deficit amongst staff and sometimes dismissed as being anxious instead of physically ill.

In terms of developing effective treatment and consistent management of Long Covid these factors were compounded by the multisystem effects of the virus and what seem to be multiple pathophysiological processes often seen in one patient. This all makes for challenges in terms of ensuring patients are seen, diagnosed and offered treatment wherever and as soon as possible.

To try and address some of these health service challenges a [SIGN guideline](#) was developed in Scotland together with an implementation note, support online resources and a mobile app. The aim was to emphasise the importance of person-centred assessment and to exclude other causes of symptoms, then refer patients for further investigations when appropriate.



Following introduction of this guideline, the Scottish Government also published an [“Approach” paper](#) outlining “Scotland’s Long Covid Service”. This paper sought to offer a clear understanding of the services and infrastructure available locally to support investigations related to Long Covid. With an aim to develop a coordinated care pathway, a £10m Long Covid Support Fund was established with an allocation of £3m during 2022 - 2023. Each Health Board was required to develop and submit outline plans to bid for their funding allocation. First allocations of this funding have now been made to Health Boards. A Long Covid Strategy Network is now established to share good practice as the work moves on.

## Scotland's Long COVID Service

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Long Covid has been compared to other “post viral” chronic illnesses such as CFS and ME. There have been longstanding issues with treatment and management in these illnesses and this does not inspire confidence that a treatment solution for Long Covid to meet all patient needs will be found and utilised.

However, knowledge and understanding of Long Covid has developed considerably and continues to move at pace. Therapeutic advances have been and continue to be trialled nationally and internationally. What began as small-scale trials of medications that may have been used with success in other conditions – for instance, antihistamine drugs, glucocorticoids and anticoagulants - are now being tested in larger trials. Longer term monitoring of effects on patient outcomes is needed, together with further funded research to evaluate possible approaches to treatment.

### Current Key concerns for those living with Long Covid

Living with Long Covid is a daily struggle and there is a constant need for those with Long Covid to voice their experience and what they need in terms of treatment and care. This is exhausting. Long Covid Scotland advocates for those with Long Covid. We work in partnership with a range of stakeholders to ensure those needs are heard and hopefully met. This is a work in progress and much remains to be done.

[Long Covid Scotland](#) is looking for additional funding for Long Covid specific clinics with a clear pathway of treatment and support, including mental health support. We are seeking assurances that funding already allocated to Health Boards is specifically used for Long Covid. The quantum of resource must be increased given the scale of the problem now and in the future.

Additional effective biomedical research on treatment and cure for Long Covid is also required, along with funding for that research. Research and clinical pathways must progress together.

Long Covid has a cost for health, social care, employment, and benefits and therefore needs better coordination across sectors and a holistic approach from all stakeholders, especially the Scottish Government.

While there are clearly some good examples of people being supported by GP's health services and employers this is not a universal experience for people and there is clearly much more needed to be done. Public health messaging on Long Covid is poor and there is little currently being done to address this by public services, unions, and professional bodies despite the number of people living with long-covid growing in Scotland.

## References

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