

Join the Swedish COVID Association

A patient association for people affected by COVID-19 and long COVID

The Swedish COVID Association is a non-profit association representing people affected by COVID-19 and long COVID, and their relatives. We are working to promote research and knowledge about all of the medical and social consequences of SARS-CoV-2, and for adequate care for this group of patients. We want everyone who has experienced a COVID-19 infection to be able to return to a good life with the possibility to, for example, spend time with their loved ones, work, study and participate in society in various ways. To enable this, more research into long-term complications from COVID-19, among other things, is necessary.

Please support us by **becoming a member!** Everyone is welcome in the association, and you don't need to be personally affected to join. The membership fee of SEK 100 is a voluntary payment. You are cordially invited to Swish us an optional amount.



Use Swish to gift us an optional amount:

123 217 81 35

Open your Swish app and scan the QR code.

Our aims

The state of knowledge about long COVID is still limited, and the knowledge that exists is not adequately disseminated within healthcare. Many patients struggle to receive the support from healthcare and society that is needed.

We are therefore promoting:

- The establishment of multidisciplinary long COVID clinics with research contacts in all regions, thus ensuring effective learning and the best possible care.
- The establishment of a national center of excellence for long COVID, with the mission of monitoring knowledge advances and spreading knowledge of long COVID.
- That Funding agencies increase research grants, specifically focused on long-term complications from COVID-19.
- Regulatory changes in the medical insurance system.
- That authorities estimate how many people are suffering from long COVID. This is needed to be aware of the initiatives that are needed and the amount of resources that have to be allocated.

What is long COVID?

Long COVID is an umbrella term for a range of different conditions and symptoms caused by a SARS CoV-2 infection. WHO defines post COVID condition as follows:

Long COVID occurs in individuals with a history of probable or confirmed SARS CoV-2 infection, usually three months from the onset of COVID-19 with symptoms that last for at least two months and cannot be explained by an alternative diagnosis. Common symptoms include fatigue, shortness of breath, cognitive dysfunction among others, and generally have an impact on everyday functioning. Symptoms may arise following initial recovery from an acute COVID-19 episode or persist from the initial illness. Symptoms may also fluctuate or relapse over time.

Scientists still don't know why certain people develop long-term illness or who is at risk for developing long COVID. What we do know is that a large group of people worldwide develop long COVID and that most of them were previously completely young and healthy. Children can also develop long COVID. In the UK, the Office for National Statistics has estimated that 10% of all of those infected have symptoms that last 12 weeks or more.

Considerable research is being conducted into long COVID. We currently don't know with exact certainty what the symptoms are caused by, but there are theories that suggest causes such as autoimmune reactions, virus residue, micro-clots or damage to various organs. The causes might not be the same for all patients.



Being seriously ill, being able to see how the patient association is working hard to promote care and research – when I myself don't have the energy – has been a light in the darkness.

– Member

Symptom

People suffering from long COVID can have symptoms that are long-term and debilitating. Since several of the body's organic systems are often impacted, long COVID tends to be called a multi-systemic condition.

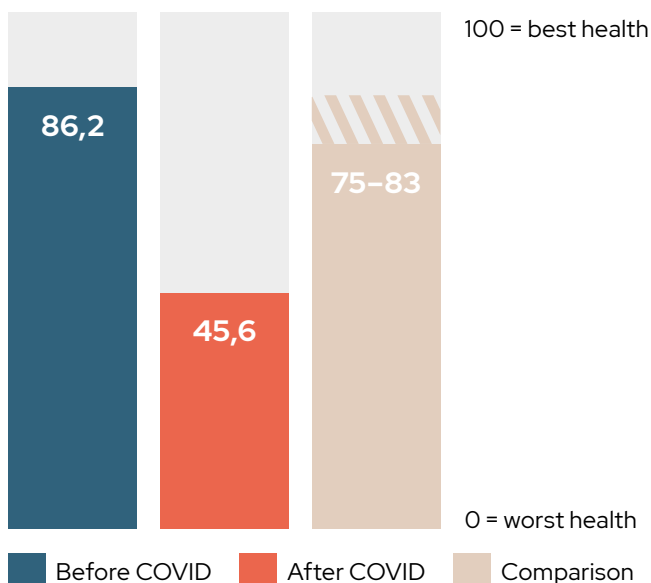
The most common symptoms include:

- Fatigue (extreme tiredness)
- Aches/pain
- Shortness of breath
- Forgetfulness and concentration difficulties
- Headache
- Sleeping disorders
- Chest pain
- Abdominal pain
- Palpitations and heart rate above the normal resting rate (tachycardia)
- Sore throat
- Night sweats
- Fever or fever sensation

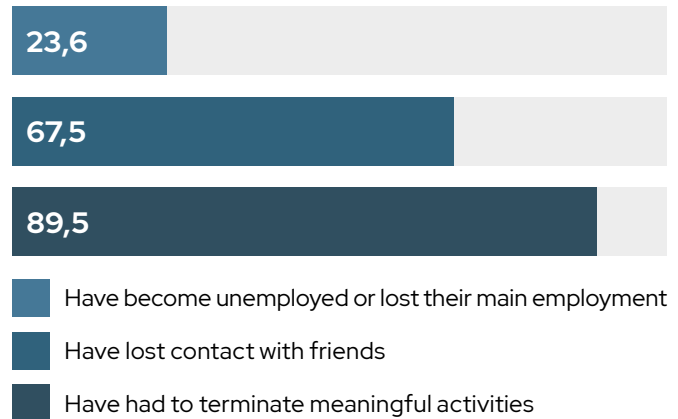
Research shows that even those who had experienced a mild initial COVID-19 infection can have sustained damage to their heart, brain and lungs, which means that it is not necessary to have been hospitalised in order to suffer from long COVID. For several of those affected, the symptoms may arise in flares.

Members' health has been affected severely by COVID-19

The bars in the chart show that the self-reported health before and after COVID-19 has almost halved at group level. The normal mean value in population studies ranges from 75 to 83%.



This is how our members responded when we asked what they had lost because of their long COVID



Do you want to know more?

The Swedish COVID Association

You can find more information about our work and become a member by visiting our website covidforeningen.se (in Swedish). You can also follow us on social media.



Doctor to Doctor

A group of doctors suffering from long COVID have created a website on which they share their knowledge with healthcare services. The contents are targeted at doctors who meet patients with long-term conditions.

Feel free to advise your doctor about this website (in Swedish) langtidscovid.se

Swedish Heart Lung Foundation

The Swedish Heart Lung Foundation, in cooperation with the Royal Swedish Academy of Sciences, Riksförbundet Hjärt-Lung and the Swedish COVID Association, has arranged a knowledge webinar about long COVID. Visit the Swedish Heart Lung Foundation's website to view this webinar and read the scientists' answers to questions about long COVID: hjart-lungfonden.se/postcovid/ (in Swedish).