

12 August 2021

Long Covid in Switzerland

Majority of Long Covid sufferers severely restricted in work, household, family and sport

In According to [estimates](#) by the Science Task Force and [studies](#), at least 200,000 people in Switzerland suffer from Long Covid. They include adults, adolescents and children who have still not fully recovered more than three months after their Covid-19 infection – in some cases they have been sick for one and a half years. A majority are substantially limited by debilitating symptoms in their mobility, work, family life, and leisure time. This is the result of a non-representative survey of 400 people conducted by the association Long Covid Switzerland. With the results of this survey, the association would like to contribute to a well-founded public discussion.

Long Covid Switzerland asked more than 400 people affected by persisting symptoms after a Covid-19 infection which symptoms bother them most and how they cope with them in everyday life. The survey was conducted in March and April 2021, one year after Switzerland reported its first cases. Most respondents are between 30 and 60 years old, but children and older people also took part in the survey. Two thirds had become infected during the second wave. A quarter had been infected before or during the first wave. Some of these people have already been sick for almost one and a half years – and still have no cure in sight.

The majority of those affected used to be fit and active

The survey showed that four out of five Long Covid sufferers were in great shape before the disease. A large majority of those affected today had no previous health problems. Due to the sometimes severe symptoms such as pathological exhaustion, pain and brain fog, only 11% of the respondents still considered themselves healthy. Three quarters of those affected suffer from pain or are in poor health. About half have limited mobility and the same number have developed anxiety or depression. Four out of five are restricted in household, family life, leisure and sports. About 43% have returned to work full time, 28% have had to greatly reduce their workload, and 20% are completely unable to work.

Debilitating diffuse symptoms

Three quarters have been suffering from Long Covid symptoms for more than three months, with almost a third of respondents having been ill for more than half a year at the time of the survey. Almost all suffer from fatigue, a pathological exhaustion that cannot be relieved even by sleep. This is almost always accompanied by exercise intolerance, which manifests itself in the fact that those affected quickly become exhausted during physical, cognitive/intellectual or psychological exertion and suffer from heart palpitations, shortness of breath, dizziness and/or pain. When overexerted

or overstimulated, many sufferers feel so sick for days that they are unable to put any strain on themselves and often develop fever or a raised temperature. A common neurological symptom is brain fog, a condition in which sensations and thought processes are impeded by a foggy or cotton-wool feeling. It includes various distressing cognitive deficits such as concentration difficulties, memory problems and word-finding problems. Almost all sufferers experience headaches, neck pain and pain in the muscles, joints and the chest. Respondents added over 150 symptoms that they felt were missing from the list of the suggested top 30 symptoms.

Treatment challenges and gaps

According to the survey, 90% of the respondents had never been hospitalised in the acute phase or later, and two thirds had not even visited an outpatient clinic for treatment of their Long Covid symptoms. Many affected people felt that their treating doctor meant to help, but often this was not possible due to a lack of knowledge and treatment options. Some felt that they were not taken seriously by the medical profession, which may be related to the challenges of diagnosing the condition with its diffuse and poorly delineated symptoms in addition to a lack of diagnostic tests and guidelines. Almost all respondents found themselves compelled to seek information through online self-help groups (81%) or scientific publications (61%). Only 34% obtained information from their GP and 26% sought information from the FOPH. Due to a lack of support, many sufferers experiment with a wide variety of treatment approaches from conventional medicine and alternative methods. Almost 100 different therapies were mentioned as helpful. These included pacing (57%), light exercise (50%) and medication for the various symptoms (41%). Only 13% were prescribed rehabilitation, which is worrying as early targeted rehabilitation increases the chances of preventing chronification.

Without significant previous illnesses

More than half of those affected did not suffer from any previous illness. Of the 23% of respondents who had a pre-existing condition, allergies were the most frequently mentioned. Four out of five felt in top shape before the disease, despite possible pre-existing conditions. After the illness, only one out of nine rated their state of health with 8 to 10 out of 10 points. The majority (52%) rated their health with only 3 to 5 points out of 10. Almost half of the respondents have problems with their mobility. Shortness of breath, circulatory problems, aches and pains, weakness and lack of energy are symptoms that hinder their mobility. Three quarters have pain or feel unwell. Half now suffer from psychological problems such as anxiety or depression.

A majority is impaired in everyday life

Most of the respondents were between 30 and 60 years old at the time of the survey, i.e. of working age. For half of those affected, the disease had led to drastic changes in their work situation. Either because they had to reduce their workload (28%) or because they were on full sick leave (20%). Almost half continue to work full time under more difficult conditions, and again at least half of them need more breaks. Almost all are also restricted in household and family life, half slightly, a quarter severely and 7% even need care. Many of those affected can no longer enjoy their leisure time. Active creative activities, but also reading or watching films are made difficult or impossible by the cognitive deficits. Physical activities are impaired in almost all cases. Only 4.4% of those surveyed can do sports without restrictions, as they did before the disease. Four out of five are limited, 22% slightly, 38% severely, and 25% can no longer do any sport

at all. Endurance sports are no longer possible for many of those affected, as the exercise intolerance no longer allow this.

Comment by Long Covid Switzerland

The survey showed that people suffering from Long Covid are severely affected by the sometimes debilitating symptoms in their daily lives. Since the survey, a lot has changed in the situation for those affected. Specialised multidisciplinary consultations have been set up at various clinics, rehabilitation clinics offer specialised programmes for Long Covid, and the medical profession now takes the complaints of those affected seriously for the most part. For many, however, the situation has also become more acute. Some sufferers have already lost their jobs or are forced to return to work despite their sickness because insurers do not recognise their disease. Long Covid has many overlaps with chronic fatigue syndrome (ME/CFS), a neuroimmunological disease. Both are poorly researched, difficult to diagnose and as yet untreatable.

Outlook

Those affected suffer severely and have to bear high health costs. What is still missing after almost one and a half years is quantification (prevalence in adults and children), recognition of the disease, guidelines for diagnosis and treatment, further training for professionals, research funding and support for those affected in therapy, rehabilitation, insurance and employment issues. Long Covid Switzerland hopes that these survey results will provide an insight into the precarious conditions in which many Long Covid sufferers currently find themselves.

Information:

On our website [Long Covid Switzerland](#) you will find graphics and additional information about our survey in a presentation.

About Long Covid Switzerland:

Long Covid Switzerland is an association officially founded in March 2021 with headquarters in Bern. As early as September 2020, *Chantal Britt* (52, communications specialist) and *Florence Isler* (43, art historian, Germanist and company owner) started a multilingual self-help group on Facebook to offer affected and interested people in Switzerland information about Long Covid and to exchange experiences. The group on Facebook now has over 1,700 members.

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