
Covid-19 – there isn't just healthy or dead

The Coronavirus has been spreading around the globe for almost a year. We count cases and we count deaths: more than 50 million people have been infected by now, and more than a million have died. But are all those who survive healthy? Unfortunately not.

Even months after the acute infection – the virus is not detectable anymore –, a fraction of patients still isn't back to normal. It's not entirely clear how large this fraction is; probably it is a two-digit number. On one hand, there are patients who suffer from visible damages to their lungs, or hearts, or kidneys. On the other hand, there are patients where no organ damage can be observed but who still have a range of symptoms, among them shortness of breath, headaches, an unusual fatigue, and so-called brain fog, i.e. difficulties to think clearly, to memorize things, or to concentrate even on simple tasks such as watching a movie. These long-term effects do not only affect people who had severe Covid-19 but also people who only suffered from mild symptoms during acute infection.

Long-lasting symptoms following viral infections are not rare and occur with other viral diseases as well. Luckily, most people recover eventually, and we hope that the same holds true for Covid-19 long-haulers. However, there is fear that in a small fraction of

people, the symptoms will become chronic. This fraction may be small, but think of the numbers: even a small fraction of 50 million people (+ all those who will still get infected in the future) is a very large number of people! For each of them, it is devastating.

One chronic disease that may be triggered by an infection with SARS-Cov-2 is Myalgic encephalomyelitis/Chronic fatigue syndrome (ME/CFS). ME/CFS is a severe disease that puts patients' lives at halt (see Box on the next page). A considerable fraction of patients who had SARS or MERS – diseases caused by two other Coronaviruses – were struck by ME/CFS subsequently. Even if only a small percentage of Covid-19 patients eventually develops ME/CFS, we expect to see an enormous rise in cases. Leaving aside the economic consequences and the costs for our healthcare systems, the human suffering this brings is tremendous.

Once more, this shows how important it is to comply to physical distancing and to avoid all unnecessary contact for the time being. By keeping the number of Coronavirus infections as low as possible, we also reduce the number of those who will never recover.

Dr. Hildegard Uecker

Additional resources:

- <https://www.nature.com/articles/d41586-020-02796-2>
- <https://health.ucdavis.edu/health-news/coronavirus/covid-19-long-hauler-patients-search-for-answers-and-help/2020/10>
- <https://www.health.harvard.edu/blog/the-tragedy-of-the-post-covid-long-haulers-2020101521173>

Myalgic encephalomyelitis/Chronic fatigue syndrome (ME/CFS)

ME/CFS is a disease that may develop following a viral or bacterial infection but that may also develop gradually without an apparent trigger and that can hit everyone. As the name says, patients suffer from chronic fatigue. But one shouldn't imagine this as needing a little more coffee than everyone else: it's a fatigue that makes normal life impossible. Every effort – in severe cases, this can just be walking from one end of the room to the other – makes it worse. Experts call this post-exertional malaise. Sleep isn't restful. But this is not all: patients also suffer from headaches, joint pains, and other flu-like symptoms. Many have difficulties concentrating and thinking clearly. Extreme sensitivity to light or sound may occur as well. For a diagnosis as ME/CFS, symptoms must persist for at least six months. The severity of the disease varies across patients. In the majority of cases (ca. 75%), people are left unable to go to work. In extreme cases, patients spent 24 hours a day in bed, sometimes in dark rooms, because all stimulation is too much.

Unfortunately, we know very little about the disease. There is no treatment to date. Why is this the case? Why don't we know more about a disease that is so devastating to patients and their families and that is not even rare (~ 20 million cases worldwide; ~ 2 million in the European Union)? Is it simply so difficult to understand the underlying causes and to develop cures? Maybe – but maybe not. We don't know how difficult it is compared to other diseases. Very little funding – much less than for cancer and many other diseases – is invested into research on ME/CFS although such research is urgently needed. No research means no knowledge and no knowledge means no cure.

Evelien van den Brink, a young woman who has been bedridden by ME/CFS for 20 years, directed a petition to the European parliament, asking to increase the funding for research on ME/CFS. EU citizens can sign [the petition](#) to support her request.

Additional resources:

- A blogpost about the disease by Dr. Pleuni Pennings:
<https://abetterscientist.wordpress.com/2020/11/12/this-week-i-learned-about-me-cfs/>
- An interview with Evelien van den Brink:
<https://europeanmecoalition.com/wp-content/uploads/2020/11/Interview-Vriendin-English-translation-October-2020.pdf>
- The speech that she gave in the EU parliament (starting at 2'10"):
<https://europeanmecoalition.com/speech>
- The link to the petition:
<https://www.europarl.europa.eu/petitions/en/petition/content/0204%252F2019/html/Petition-No-0204%252F2019-by-Evelien-Van-Den-Brink-%2528Dutch%2529-on-a-request-for-funding-for-biomedical-research-on-Myalgic-Encephalomyelitis>