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#longcovid

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The textbook on long-lasting COVID-19 is written by the patients themselves.

Photo: Einar Nilsen

In the classical board game of 'Snakes and Ladders' you can take a shortcut if you land on a square with a ladder. If you land on a snake, on the other hand, you must move some steps back. It was such a situation that Paul Garner, who is a professor of infectious diseases at the Liverpool School of Tropical Medicine, felt that he was in for some weeks after he had suffered a 'mild' case of COVID-19 (1). He could wake up one morning and find that he finally felt better, before suddenly feeling just as ill as before. Not only did he have symptoms that came and went, he also had strong emotional reactions and extreme exhaustion.

Stories like Garner's have gradually become so common that the patients and their condition have been given their own names: *long-haulers* and *long COVID*. There is good evidence that those who have been hospitalised with severe COVID-19 can develop sequelae and need rehabilitation for weeks and months (2). More surprisingly, even patients with mild illness – often young people – describe inexplicable, unexpected and confusing courses of illness.

The way in which patients who are ill, but with no objective findings, have been treated through the years does the medical profession little credit. Such diffuse conditions include fatigue and chronic pain. Unfortunately many such patients, especially women, have received inadequate care and not always undergone the examinations to which they were entitled. Typically, the patients have been told that their symptoms are psychological – even when they had other causes.

> ***«Patient activists have used social media platforms to place long COVID on the agenda»***

We should keep this in mind when we meet those who can teach us more about the after-effects of a SARS-CoV-2 infection, i.e. the patients themselves. Many of them have resorted to social media under the *longcovid* hashtag to share their experiences and give and receive support from fellow patients with chronic symptoms after a bout of COVID-19. This testifies to their compassion, commitment and willingness to help others. Perhaps it also testifies to a lack of follow-up and understanding on the part of the healthcare services. In support groups on Facebook, Slack and Reddit, members from all over the world post stories of employers who expect them to return to work, of sceptical doctors and of family members who believe that they no longer have COVID-19. It is therefore perhaps no surprise that people seek out other patients who listen to them, take them seriously and want to walk with them through the unknown realm of symptoms (3).

Suddenly being left with a body that no longer obeys you, having hitherto unknown sensations and noticing that your head cannot keep up is a scary experience. In an autoethnographic essay which is now being published in the Journal of the Norwegian Medical Association, Astrid K. Wahl describes her experience of chemotherapy for breast cancer (4). As a researcher on patient experiences and health-related quality of life, she considered herself prepared for what lay ahead. She was wrong. She also had to recognise that the questionnaires she had handed out to patients were far too simplistic to reflect the wave of ailments that were washing over her at unexpected times and with unpredictable intensity.

#apresJ20, LongCovidSOS and many other online campaigns and initiatives led by patients with persistent COVID-19 call for 'recognition, research, and rehabilitation' (5). Over time, several countries have introduced clinical guidelines for follow-up. For example, the British Medical Journal has presented a manual for general practitioners (6). It is worth noting that the patients themselves have contributed to the preparation of this manual. Similarly, the world's largest epidemiological study in real-time of symptoms following a SARS-CoV-2 infection is based on volunteers who register their symptoms in an app (7). To date, the COVID-19 Symptom Study has attracted more than four million users.

> ***«We are also witnessing a quiet revolution regarding what and who will shape the health services of the future»***

Last, but not least, patient activists have used social media platforms to place *long COVID* on the agenda, while the health services quite naturally have been mostly busy handling the sickest patients during the first phase of the pandemic. To quote Tedros Adhanom Ghebreyesus, general secretary of the World Health Organization (5): 'It appears that patients are writing the first textbook on long COVID.' If this is so, we are witnessing more than a pandemic the like of which the world has not seen for a century; we are also witnessing a quiet revolution regarding what and who will shape the health services of the future.

LITERATURE

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