

Long tail of coronavirus can prolong suffering for months

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They call themselves "long-haulers", "long-tailers", or simply survivors.

Some have been sick almost as long as the new coronavirus is known to

have existed.

Six months after the virus began to scorch its way across the planet, it is becoming clear that COVID-19 causes far more symptoms than first suspected.

Thousands of people of all ages are staying sick for weeks or even months.

British forensic psychiatrist Jenny Judge began an odyssey of illness in March with a fever, cough, headache and breathing problems.

She has since experienced waves of other symptoms including a racing heart, scalding rashes and "COVID toes", which were itchy and ulcerated.

At one point she was so delirious she heard her dogs talking, and was not particularly surprised.

"Now I am going through a belly phase," she told AFP on day 111 of her ordeal.

More than 12 million COVID-19 cases have been recorded worldwide with more than 550,000 deaths. Some six million people are listed as "recovered".

But these figures do not tell the full story.

'They feel left out'

A study of 143 recovered [hospital patients](#) in Italy, published in the JAMA Network journal on Thursday, found that 87 percent were still suffering at least one symptom 60 days after falling ill.

Fatigue and breathing difficulties were most common.

This follows research published last week by the US Centers for Disease Control and Prevention that found of 350 people surveyed, about 60 percent of inpatients and around a third of outpatients were not back to health 14-21 days after testing positive.

People leaving hospital may need ongoing care for organ damage, injuries sustained in invasive oxygen therapy or post-traumatic stress.

But those who have coped with their illness at home often do not have an explanation for their continuing symptoms, and may face scepticism or outright disbelief from employers and doctors.

"I think these people feel very left out and that nobody's looking after them," said Tim Spector, Professor of Genetic Epidemiology at King's College London, who is behind a large-scale symptoms-tracking project.

"Some of them can have really debilitating fatigue."

Some 3.8 million people in the UK have logged on to the app since it was launched in March, while it also has more than 300,000 users in the US and 186,000 in Sweden.

Researchers think that up to one in 10 of them still have symptoms after 30 days and some remain unwell for months.

Spector, who estimates there may be a quarter of a million people in the UK with longer-term illness, receives around 10 emails a day from people who are still ill and who feel "no one is listening to them".

Part of the problem is the sheer variety of symptoms, many of which do not appear in official health advice.

"I used to be a rheumatologist and study very rare autoimmune diseases like lupus which can affect any part of the body and can present in different ways—but this is even more weird," he said, adding the app has identified 19 symptoms so far.

"You can have people just with skin problems. You can get people probably just with diarrhoea and chest pain. It's really very unusual."

'Might be you'

COVID support groups are attracting thousands of members on social media and hashtags are trending in languages including Japanese, French, English and German.

Many people posting in these groups say they have experienced disbelief from doctors or employers.

Those who became ill in March may face particular problems as testing was scarce and they may have no clear evidence that they were ever infected.

Judge said even though she is a doctor she has faced scepticism from staff at her local hospital, with one medic suggesting her high heart rate might be anxiety.

She believes this is partly because hospital doctors are only just coming into contact with patients whose initial symptoms were not considered serious enough for emergency treatment.

But the 48-year-old, who had no pre-existing conditions, said there could also be an element of denial at play.

"If you accept the person who looks just like you, who is a doctor, who

was taking all the precautions, is sick at a hundred plus days down the line—that might be you," she said.

'Sick and struggling'

The situation is improving with new studies launched and a growing number of people sharing their stories.

Paul Garner, a professor of infectious diseases at Liverpool School of Tropical Medicine, began a blog in the British Medical Journal out of frustration.

He had been ill for a month but the health advice he had read online said the illness lasted just two weeks.

The previously fit and healthy 64-year-old was tormented with blinding headaches, shortness of breath and a strange tingling in his arms and legs that he said is like the "fizziness" of Sichuan peppercorns.

At one point he thought he was losing consciousness: "I thought I was dying, that was how scary it was."

Garner said one of the hardest things about his illness has been the "muddling" in his head and mood swings.

"This doesn't happen to me, I don't get depressed," he said, adding he had sought advice from a rehabilitation consultant, who said depression was a possible side effect.

"I was just in tears, but it kind of helped me understand what was going on."

He endured several false dawns. On day 45, after he had felt better for a

few days, Garner decided he had finally shaken off the virus and tested the waters with a workout in his front room.

"Then bang! Monday: 'felt rotten all day, consequence of exercise'," he said, reading from his diary.

"It knocked me back a week."

With the help of literature for ME (myalgic encephalomyelitis) and [chronic fatigue](#), he devised a routine interspersing light physical or mental exertion with periods of rest.

Speaking to AFP on day 96 of his illness, Garner said he was gradually seeing improvement.

But he is concerned that vulnerable people may be pressured into trying to return to work before they are ready.

"Everybody's obsessed about the public health control. But what about the people that are sick and struggling and not knowing what's going on?" he said.

Risking it?

It is not yet clear whether long-lasting symptoms are caused by the virus itself or the body's overzealous immune reaction.

Spector said some of the long-haulers may still have traces of virus in their systems, although it is unclear whether they could still be infectious.

"There will soon be these rapid tests in airports, does that mean they will never be able to travel, because they'll be positive all the time?" he said.

Other diseases can cause prolonged "post-viral" effects.

A 2009 study of 233 people who had been treated in hospital for SARS, another coronavirus, found that four years after their illness 40 percent reported suffering from depression or chronic fatigue.

"The implication for rehabilitation and appropriate support for the SARS/COVID-19 victims is obvious," said Yun Kwok Wing, a professor at the Chinese University of Hong Kong who was one of the authors of that study.

As we learn more about the new [coronavirus](#), our perception of the risks of the disease may need to stretch beyond the likelihood of dying.

Young people are still most likely to get a mild version of the disease, but Judge said they should also be aware that if they do catch COVID-19 there is a chance they could be ill for months.

"It seems to be a kind of Russian roulette type thing, we don't yet know what's making some people get a longer illness," she said.

"There's a lot to learn still."

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