

# 'A living hell': the serious and persistent symptoms of 'long COVID'

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By [Melissa Cunningham](#)  
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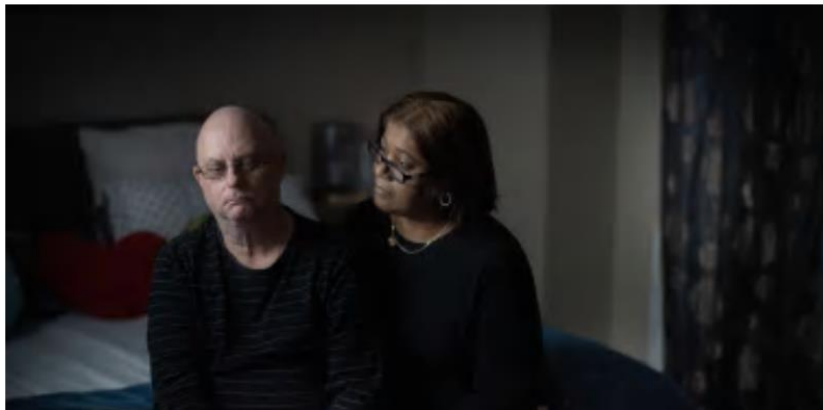


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It has been more than 100 days since Garry Keeping caught coronavirus and still his hands shake uncontrollably.

Walking less than 100 metres to the end of his street leaves the Derrimut father of two breathless and bedridden for days. But it is the constant “brain fog” that frustrates him the most.



Garry Keeping, with his wife Kamal, was diagnosed with COVID on July 18. Three months later he is still experiencing lingering effects, including hand tremors, forgetfulness and fatigue. EDDIE JIM

“I can’t even dial a number into the phone,” said the 57-year-old, who developed a tremor in both his hands after being infected with the virus in July.

“I’ll see the numbers right in front me, but they get all up muddled in my head. I am too terrified to get behind the wheel because I am worried sick I’ll black out while driving. It’s been a living hell.”

Mr Keeping is one of thousands of people all over the world who caught SARS-CoV-2 months ago and survived it, yet are stuck in their homes. No longer contagious, but still gasping for breath, they have been dubbed the 'long-haulers' and the persistence of their strange and often debilitating symptoms is perplexing doctors globally.

### **What is long COVID?**

"Long COVID" is not an official medical term, but it is used to describe people still suffering symptoms of the virus longer than the official World Health Organisation's recognised two-week period.

Shortness of breath, brain fog, racing heart, loss of taste and smell, fluid on the lungs, whittled away muscles. Flashbacks, confusion and scarring or inflammation of the lungs, heart, kidneys and liver. These are just some of the lingering effects.

But what is especially striking is that doctors are also seeing increasing numbers of young people, who despite not being severely ill with the virus initially, are struggling to shake off relentless waves of debilitating symptoms. Others who have been on the brink of death with the virus have escaped with minimal lung damage.

A recent study by the Centres for Disease Control and Prevention found more than 35 per cent of people who tested positive for coronavirus still had symptoms three weeks later.

While coronavirus has long been deemed most dangerous to the elderly and immunocompromised, the study found about 20 per cent of respondents aged 18 to 34, who did not have prior chronic

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to recover.

Anuj Kandel used to run each day and spent his nights riding his bicycle around Melbourne's northern suburbs delivering meals for Uber Eats.

Since testing positive to the virus on September 1, the 22-year-old international student from Nepal has been unable to work and spends hours a day in bed.

His persistent dry cough makes his chest ache and throat burn and he suffers from crushing fatigue.

"It is just a constant tiredness," he said. "I was a very fit and active person and now even doing the simplest things like walking from my bedroom to the kitchen exhausts me."

Cohealth general practitioner Catherine Orr has treated more than 100 young people infected with coronavirus.

Many like Mr Kandel were international students without their own GP with the Melbourne not-for-profit community health organisation providing free healthcare and linking them up to social support services.

Most follow the classic pathway: mild or no symptoms for about five days before recovering from the virus, but there is a troubling cohort.

"What we are also seeing in this pandemic is that young people who are not particularly sick in the beginning can sometimes be left with months and months of shortness of breath and fatigue," Dr Orr said.

"It is quite remarkable really because this is despite being fit and healthy with no previous lung problems."

Dr Orr is calling for more research, better monitoring and medical support for those experiencing long COVID, with some young people languishing in their bedrooms for up to a month despite no longer being infectious.

“This virus isn’t going anywhere so we need to recognise that some people may be left with some permanent disability, despite not initially having a really nasty respiratory illness,” she said.

Researchers tracking patient recovery are also warning that the long-term effects of COVID-19 pose a more severe public health threat than the pandemic's death toll, foreshadowing a [significant surge of people battling lasting illnesses and disabilities.](#)



Dr Catherine Orr has treated more than 100 patients with COVID-19. JUSTIN MCMANUS

Mr Kandel suspects he caught the virus from his sister who was working in aged care in Melbourne in the height of the second wave of infections. She recovered from the virus within days.

Mr Keeping’s entire family was also infected. His wife Kamal, who has epilepsy, spent five days in hospital, but has since recovered. His two children, Liam, 21, and Lillian, 15, recovered within a week.

Mr Keeping, who is a diabetic, which puts him at heightened risk of severe infection, had to be resuscitated by doctors.

“My kidneys took a real hit and they reckon I’ve got pretty severe lung damage,” Mr Keeping said.

Australian infectious diseases expert Robert Booy said our genetics play a critical role in how our body fights the virus. More than half of those infected shrug the virus off like a common cold, with only 10 to 20 per cent requiring medical care.

“The way we respond to the virus is driven by our immune system,” Professor Booy said.

“Particular genetic types over-respond to the infection in a damaging and dangerous way to their own body explaining why a minority of people have unpleasant symptoms in the longer term.”

Professor Booy said other infectious pathogens like Epstein-Barr virus, which causes glandular fever, often plagued otherwise healthy young people in the months after infection.

These symptoms, sometimes called post-viral fatigue syndrome have also been documented in sufferers of many viral diseases including influenza and SARS.

"It commonly gives you an acute infection with a fever, a very sore throat and cough and then you can get prolonged symptoms of various types including chronic fatigue syndrome," Professor Booy said.

"We don't yet know the outcome of long COVID because it's only been around such a short time. But there is every reason to be confident that a large proportion of people will recover in six to 12 months."

For those who are elderly or endure severe complications from the virus, troubling residual symptoms may persist for years or even the rest of their lives.

Mr Keeping has searing pain in his back, which radiates down his arms and legs. He has had to learn to walk again and does physio classes on Zoom each week to build up his strength.

He worries he will never be able to return to his old life or play cricket in the backyard with his son.

"Feeling like this every day eats away at you," he said. "Most days I just feel really scared. It has robbed me of my joy."

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Western Health consultant geriatrician Shiu Lai, who works in a rehabilitation ward for elderly Victorians recovering from coronavirus, said the lingering maladies of the virus were lasting longer than she could have ever imagined.

“These patients have managed to survive COVID, but it’s now day 100 down the track and they are still quite symptomatic with significant shortness of breath, a chronic cough and fatigue,” Dr Lai said.

“They are extremely slow to progress with their therapy and potentially there is a chance they may not ever get back to the same level of function they were.”

Dr Lai is also concerned about the psychological ramifications of the virus. Some of her patients remain in an acutely confused state and battle bouts of delirium long after being diagnosed with the virus.

“They are very anxious because they have been sick for so long,” she said. “Only more time and research will tell us what recovery truly looks like.”

With nowhere else to turn, thousands of ‘long haulers’ have turned to online groups sharing medical histories with strangers mirroring their experiences in other countries.

“How do you get your head to stop hurting?” a young woman, based in the United States, asks [the Survivor Corps Facebook group](#), a network of tens of thousands of COVID-19 survivors. “Will this ever end?”

Gail Matthews, head of infectious diseases at St Vincent's Hospital in NSW and Associate Professor at the Kirby Institute, is leading an Australian-first study examining the effects COVID-19 infection on pulmonary and cardiac function, neurocognitive impact, quality of life, mental health, smell recovery and immune function.

“It is clear from global reports and what we are observing locally that there is a subset of individuals who have a prolonged recovery after COVID-19,” Professor Matthews said.

“The true prevalence and which individuals this affects is as yet unclear, but it is not clearly linked to traditional risk factors for acute infection of older age or comorbidities.”

Emerging research also suggests women aged 50 to 60 were at heightened risk of developing long COVID. Older age and experiencing five or more symptoms within the first week of illness has also been linked to heightened risk of lasting health problems.

The extent to which this overlaps with myalgic encephalomyelitis (ME), a profoundly stigmatised and widely misunderstood condition, also known as chronic fatigue syndrome, is also being investigated.

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The National Institute for Health Research in the United Kingdom also [released a report](#) which suggests that “long COVID” may not be a single syndrome, but up to four different ones, that can be experienced simultaneously. People with lasting organ damage, those with post-viral fatigue and those with fluctuating symptoms that move around the body.