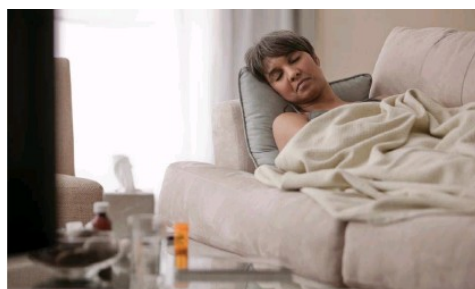


- COVID-19 / Virus

Long Covid: what we know about it and how best to treat it

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Much has been written about long Covid. Sufferers describe troubling ongoing symptoms on social media that persist for weeks after infection. Meanwhile, research to find a cause continues and multiple theories have emerged.



So what do we now know about long Covid, the risk of getting it and how best to treat it? Guardian Australia spoke to the leading physicians working with long Covid patients, including in long Covid and post-Covid clinics, to better understand the latest evidence.

What is long Covid?

Though the World Health Organization (WHO), the National Institute of Health Research in the UK and National Institute of Health (NIH) in the US all have definitions of long Covid, they're all slightly different and quite vague.

The WHO defines post-Covid or long Covid as occurring in people still experiencing symptoms three months after their initial Covid-19 infection, when those symptoms can't be explained by an alternative diagnosis. The NIH says the symptoms are "wide-ranging ... including shortness of breath, fatigue, fever, headaches, brain fog and other neurological problems" and acknowledges many of these symptoms are similar to those of other diseases and conditions.

How is long Covid diagnosed?

Dr Megan Rees, a respiratory physician at the Royal Melbourne hospital's post-Covid clinic, says there is no diagnostic test yet available for long Covid and this means other illnesses need to be ruled out first. A team of experts work together to make sure something else isn't going on, such as another respiratory illness or an underlying heart condition.

"Sometimes when people first come in, they feel they have symptoms that may lead to them having a chronic long Covid condition, but we try to have a recovery mindset here, rather than assuming people have long Covid from the outset," Rees says.

"We pitch our clinic as a post-Covid clinic rather than a long Covid clinic, because you won't necessarily be someone who is diagnosed with long Covid at the end of these assessments."

People are often reassured by the multidisciplinary approach of the clinic and when they hear most patients improve over time and recover, she says.

Rees says people admitted to hospital with Covid-19 sometimes received corticosteroids and symptoms of this can include anxiety and poor sleep. Being on machines and a longterm stay in intensive care can also leave people with fatigue and muscle weakness. Sometimes ongoing symptoms are due to the toll on the body of being in hospital rather than being due to long Covid, she says.

Associate Prof Anthony Byrne, a thoracic physician at the long Covid and post-Covid clinic at Sydney's St Vincent's hospital, says lethargy and fatigue are among the most common symptoms people present with at the clinic.

"But there are 100 medical causes of lethargy and fatigue, such as undiagnosed sleep apnea, undiagnosed diabetes, depression and anxiety, so there are many conditions that need to be considered and then excluded before giving a patient a label of long Covid," he says.

This correct diagnosis is important because if a different condition is causing the symptoms, it might be treatable in a different way.

How likely is it someone will get long Covid?

Being vaccinated and boosted seems to protect against long Covid. Estimates of those with Covid who will develop long Covid range from 5% to 30%, but applying this prevalence to the general population is problematic.

Some long Covid studies recruited patients before vaccinations were available and those patients would have been infected with earlier, more severe strains of the virus. The prevalence of long Covid in this group can't be applied to

vaccinated patients infected with Omicron more recently.

Not all long Covid studies are well designed, with a control group. A control group comprises people who are similar to the participants being studied, except they do not have the condition in question.

Dr Kate Gregorevic, a geriatrician and internal medicine physician, says this control group is really important when looking at common long Covid symptoms such as fatigue, which is present in about 20% of the population anyway. By comparing the long Covid group with a control group, you can see if a symptom really is more common after Covid than would be expected in the general population.

Some long Covid studies also use a large range of symptoms, from fatigue to gastrointestinal disturbance, shortness of breath and brain fog. These symptoms also range in severity, and Gregorevic says this lack of specificity will identify more people to study, but depending on the way the study is designed, this larger size does not always mean the study findings are stronger or that all of those participants have symptoms caused by long Covid.

Sometimes studies ask participants to self-report their symptoms and while these studies can be useful, they can also have strong limitations, with questions around bias and validity.

“It is always important to remember that correlation is not causation,” Gregorevic says. She is concerned that some long Covid study findings are not being put into context. “I’ve seen scary headlines that are not backed up by data from a study.

“Some of those headlines will give really high estimates of rates of long Covid but not mention that this refers to a study of people admitted to hospital, including ICU. Extrapolating data from people sick enough to end up in hospital to someone who has a mild illness is completely wrong.”

What has Australian research found?

Prof Gail Matthews from the Kirby Institute is a lead investigator on the Adapt study examining patients for long Covid, which has been running since mid 2020.

In research from the study published in January, her team examined blood samples from people with and without long Covid. They found some participants with symptoms eight months after a Covid-19 infection had elevated levels of types of proteins that cells make in response to the presence of a virus.

These proteins generally disappear after an infection clears, but in patients with long Covid, the proteins were still present. The cause of this requires further study.

“But it gives biological plausibility to the symptoms of long Covid,” Matthews says.

The study involved 62 participants, including 31 control participants without long Covid. The study authors said the results now require validation in other long Covid cohorts.

“We are about to follow up these participants again at the two-year mark to see if they are starting to recover,” Matthews said. “But I can tell you that from the Adapt cohort of patients, it’s not just people who have been in hospital that have ongoing symptoms.”

Matthews says it is not possible to come up with a strong estimate of prevalence from studies conducted to date, including her own.

However, even a small percentage of people with Covid-19 developing long Covid will lead to significant numbers of people affected, given the high overall Covid-19 case numbers in the community. While the majority of these people will recover, this can take months or in very rare cases, years.

The National Covid-19 Clinical Evidence Taskforce recently published ‘frequently asked questions’ about long-Covid and post-Covid, which highlights what research has found and what remains unknown.

How is long Covid being treated?

There are two Covid clinics at Royal Melbourne hospital: one that assesses people and rules out alternative explanations, and an allied health rehabilitation program focused more on therapies, exercise physiology, diet, psychology and even treatments such as singing therapy to help people to use their voice and strengthen their lungs.

“We recognise that post-Covid symptoms can be debilitating, distressing and frustrating but we can work through this together and our clinic experience to date is that most patients make a steady gradual recovery, although the time course for that recovery varies considerably between patients.” Rees says. “We also find lots of people who have been very sick do get a lot of benefit from a reduced, graded exercise program.”

A difficulty with treatment is the cause of long Covid is still being studied. There may be different causes for different people. Some theories about the trigger include immune system activation, ongoing inflammation and other abnormalities including in the lungs.

Prof Steven Faux, the director of St Vincent’s hospital’s rehabilitation unit, says: “Somebody described treating long Covid as flying the aeroplane while we’re still building it.

“There are some common symptoms but there are also people presenting quite differently.

“For example, some people will present with fatigue or heart palpitations. Some people will present with brain fog and difficulty returning to work. Some people present with worsening mental illness. And some people present with deconditioning, so they present with breathlessness or cough and they need to be dealt with in a different manner.

“So we’re not coming up with one thing and once we fix that, it all goes away. It’s not like that at all.”

Faux says physicians are learning a lot, but the developing evidence about causes and treatments means “there is this sort of vacant space which is evidence-free, which is being filled with people who are enthusiastic about particular cures and treatments”.

“You often see these being shared on the Twittersphere,” he says.

He says this is similar to how now disproven treatments like ivermectin and hydroxychloroquine were initially being heavily promoted as cures for Covid-19 early on in the pandemic, when little was known about how to care for patients.

“I think people have to accept a level of uncertainty and to manage as best as they can within the limitations of the research,” Faux says. “I know that’s not what those with long Covid want to hear.”

The good news is, many others with long Covid manage and improve with an individualised program that fits within their needs and with what they can do.

“There is no reason not to expect improvement in most people,” Faux says.

Who is at risk of long Covid?

Byrne says while evidence is still growing about risk, and while some people who had only a mild Covid-19 illness are diagnosed with long Covid, generally “if you’re older, if you have certain comorbidities like diabetes, if you had acute symptoms initially, if you were in hospital ... all those things make you more likely to develop long Covid”.

Faux says the demographics and symptoms of those presenting with long Covid also differ by country, for reasons still being studied. In his clinic, he is also seeing high rates of people with pre-existing mental health conditions that are exacerbated after Covid-19 infection.

A study recently published in the Journal of the American Medical Association’s ‘Psychiatry’ journal also found the people at highest risk of long Covid seem to be those with more severe disease, especially those requiring hospitalisation, but more research is needed.

Can children get long Covid?

Associate Prof Shidan Tosif, a paediatrician at the Murdoch Children’s Research Institute, says there are similar issues with prevalence estimates in children as there are for adults. But based on patient numbers, long Covid “appears rarer” in children than adults, with numbers so low prevalence is hard to estimate. “We have had a small number of children, mostly older children above 10 years of age, who have experienced prolonged symptoms, which are lasting beyond three months, such as fatigue, abdominal pain and headaches.” Tosif says that while there are some children who experienced more severe symptoms affecting function, most children who have symptoms after three months “are doing well and improve over time”. He says a factor driving some parents is fear about long Covid, which he understands “would be concerning”. Tosif says it is important these parents feel comfortable seeing a doctor with their child and have their concerns taken seriously. “There is a tendency to seek out information online and try therapies that might not always be evidencebased or accurate,” he says. “I do urge those parents to see their GP for evaluation and support.”