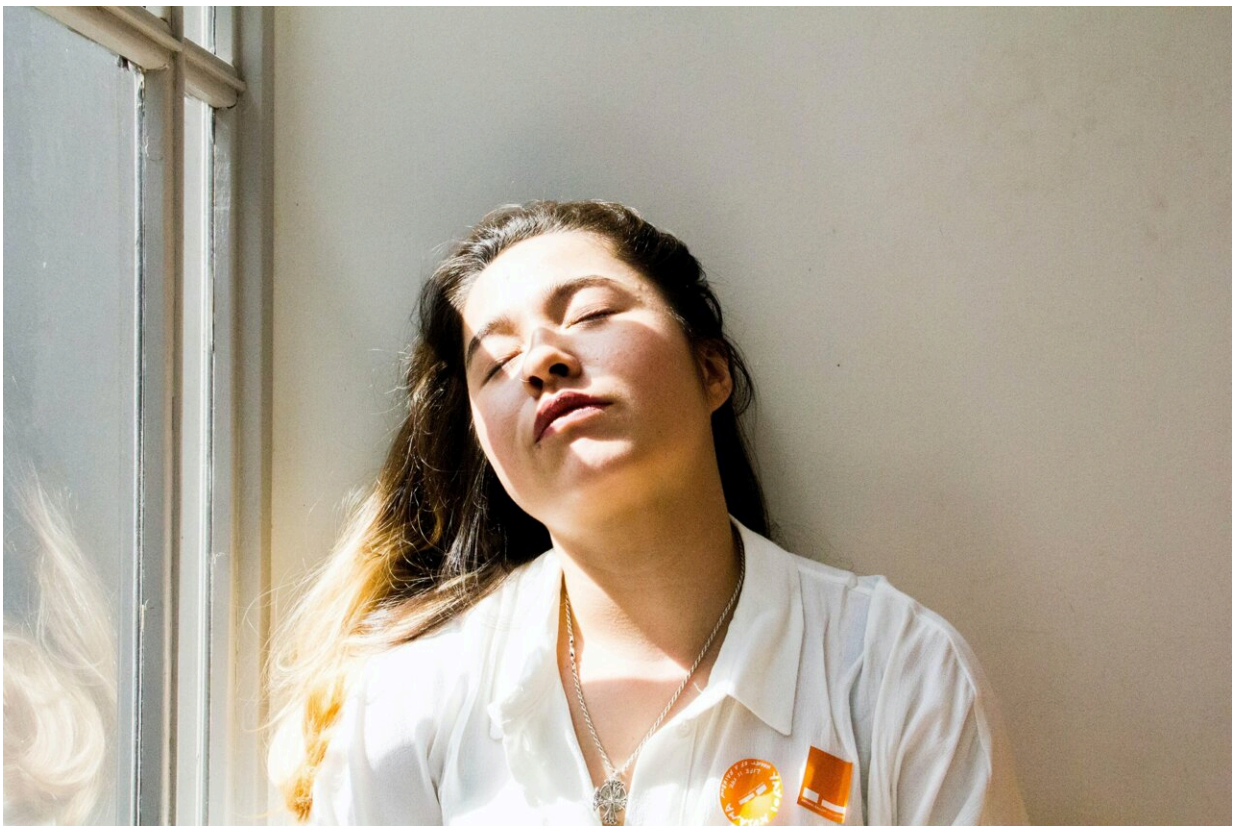
'Post-viral malaise': Why avoiding the term 'long-COVID' doesn't change anything for those affected

March 28 2024, by Associate Professor Joanne Macdonald, Dr Derek Sarovich, Associate Professor Erin Price



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Queenslanders were recently asked to stop using the term "long

COVID." Instead, Queensland's Chief Health Officer, Dr John Gerrard, suggested the condition affecting 3% of residents should be called "post-viral malaise," due to concerns of creating unnecessary fear and hypervigilance.

With the state's confirmed COVID-19 cumulative case numbers sitting at 1,759,431 infections as of January 1, 2024, that means up to 52,783 Queenslanders may have become debilitated for at least 12 months after their initial infection.

If the same percentage is observed in other states and territories, that means from Australia's 11.8 million reported COVID-19 cases, as many as 355,000 Australians may have, or are, suffering from debilitating, ongoing moderate to severe functional impairment from their past SARS-CoV-2 infections.

However, many COVID-19 cases have gone unreported, with an estimated 8 in 10 people likely to have contracted the disease nationwide.

This would mean a staggering 600,000 Australians could be suffering from post-viral symptoms including brain fog, headaches, sleeping difficulties, joint pain, palpitations, loss of smell, gut issues, shortness of breath, chest pain, anxiety, depression, dizziness, and tiredness up to 12 months post infection.

Gerard says that even if we stop calling it "long COVID," it doesn't change the fact that so many people are affected by a condition that, like an autoimmune disease, needs better recognition and ongoing clinical management. Instead of debating terminology, we should instead be concentrating on helping people struggling with this debilitating condition.

Other illnesses that fall under 'post-viral malaise'

Dr. Gerrard also said that an additional 4% of Queenslanders with flu or other respiratory illnesses similarly suffered from "post-viral malaise."

This statement brings much-needed recognition for the many others who suffer similar long-term impairment from non-COVID viral infections.

Recent studies have shown significant overlap between long COVID and other chronic illnesses such as myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), mast cell activation syndrome (MCAS), and postural orthostatic tachycardia syndrome (POTS). It is estimated that between 30 and 80% of long COVID sufferers have experienced POTS, and many long COVID symptoms mirror those seen in POTS or MCAS.

Studies estimate between 0.4 to 1% of the Australian population have ME/CFS, and an estimated 0.8% have POTS, meaning an estimated additional 100,000 to 250,000 ME/CFS and 200,000 POTS sufferers could be recognized alongside long COVID sufferers.

In addition, although a less understood disease, up to 17% of people are thought to have MCAS. As this chronic, debilitating condition often remains undiagnosed for decades, and has significant symptom overlap with long COVID, we have potentially only just reached the tip of the iceberg with the true "post-viral malaise" burden.

Taken together, there are about between 455,000 to 850,000 Australians that need specialized care due to ongoing debilitating illness triggered by viral infections.

Can we change how we support patients and prevent more cases?

Would changing the terminology allow us to direct more resources to provide dedicated treatment to Australians suffering from these long-term debilitating conditions?

Some states and territories in Australia still have clinics dedicated to long COVID rehabilitation. These clinics are critical for providing affordable access to the range of respiratory, cardiovascular, neurological, gastrointestinal, and other specialists needed to support patient rehabilitation towards this multi-organ disease.

However, many of these clinics are now being closed. Instead, we need to accelerate expansion of these clinics to all states and territories, and to ensure inclusiveness for all patients suffering from "post-viral malaise" such as long COVID, ME/CFS, POTS, and MCAS.

Longer-term, investment in preventing SARS-CoV-2 and other viral illnesses beyond vaccination strategies may bee needed.

For instance, by investing in improving indoor air quality, we could significantly reduce the number of bacterial and viral respiratory infections in the population. By providing hospital and aged care staff and patients with N-95/P2 respirator masks that are scientifically demonstrated to prevent spread when worn properly and consistently, the burden of infection in vulnerable and sick populations could significantly be reduced.

Since ending COVID-19 restrictions in Queensland, the State's death toll from the virus has risen from seven to 3375. This death toll is almost 500% higher than Queensland's road death toll, which led to 576 deaths over the same period.

In February 2024, the Queensland Government announced a $500 million investment in road safety treatments. By these numbers,

Queensland alone should also be providing a $3 billion investment towards improving COVID safety.

Provided by University of the Sunshine Coast