

Long COVID should make us rethink disability, and the way we offer support to those with 'invisible conditions'

August 1 2022, by Marie-Claire Seeley



Credit: AI-generated image ([disclaimer](#))

Australia has only a handful of specialists familiar with managing what happens when the nervous system can't properly regulate the body, as sometimes occurs with long COVID. While [long COVID clinics](#) are being set up, there are no government-funded clinics for this type of

nervous system dysfunction and private waiting lists are now long.

From the outset, long-COVID sufferers faced the same prejudice experienced by patients before them who sought assistance through Centrelink and the National Disability Insurance Scheme for the effects of [post-infection conditions](#).

Disability insurance schemes worldwide are driven by definitions and checklists that allow non-medical workforces to assess and approve candidates for [support services](#). But those with "invisible illness" rarely meet these criteria.

If we are to manage the tidal wave of impairment and [disability](#) bearing down on us, policymakers must heed the warnings that have been sounding for the past two years. We'll need to rethink disability and support.

First warnings

In November 2020, [data](#) later published in *The Lancet* were presented to the Chinese Academy of Medical Sciences. The researchers warned of [persistent symptoms](#) after COVID, including fatigue, cognitive dysfunction, palpitations, chest pain, depression, insomnia and headache.

The colloquial term "long COVID" was soon coined. Varying iterations of the name followed (including "[COVID long haulers](#)" in the United States). Many clinicians use the more scientific descriptor, "[Post-acute sequelae of COVID-19](#)."

Long COVID is not a new phenomenon. Various post-infection illnesses have been documented in medical literature for decades.

And such conditions bear a striking resemblance to each other. First, an

individual is knowingly (or unknowingly) exposed to a pathogen (a virus, bacterium or other microorganism). An acute illness of varying degrees of severity ensues before a partial or complete recovery. But following "recovery," a broad range of symptoms emerge. And these lead to functional decline. In other words, they stop the sufferer from doing the daily activities they would normally be able to do.

Two of these conditions, [postural orthostatic tachycardia syndrome](#) and [myalgic encephalomyelitis or chronic fatigue syndrome](#), appear closely related. And their symptoms look a lot like long COVID too. Both seem to affect more women than men and additional immune problems are often present.

These similarities support the theory these illnesses result from a hyper-vigilant immune system. This creates an immune response that inadvertently causes damage to the fragile autonomic nervous system (which regulates the body's normal functions like heart rate and blood pressure) while attempting to rid the body of the invading pathogen.

However, there are a plethora of [other theories](#) and more investigation is needed.

An old stigma

Lack of understanding about these syndromes is reflective of the broad stigmas attached to them—the idea they are psychosomatic and involve the mind and body.

The origin of these stigmas can be traced to a [series of publications](#) in the latter half of the 20th century that addressed outbreaks of illnesses after exposure to unknown pathogens.

In 1970, the *British Medical Journal* published an [article](#) authored by two

psychiatrists who had reviewed the case notes of 198 patients from the Royal Free Hospital in North London, where an outbreak of an unknown pathogen had occurred 15 years prior. The authors determined the disease had no identifiable organic origin and was therefore likely to be caused by "epidemic hysteria." This conclusion was partly justified by the high proportion of women among those infected with the illness, the authors said.

Publication of this theory in a preeminent scientific medical journal gave credence to what became an enduring narrative. The result has been a chronic lack of interest and investment in these debilitating invisible illnesses, which can render people unable to work or participate in society.

Having a very difficult long COVID day. Spontaneous tears, aching and panting after a trip to the loo, confused by dialogue—so much rewinding of whatever this is I'm watching. I was triple vaxxed when I caught it in May. Mask up. You're not immune.

— Adam Richard (@adamrichard) [July 26, 2022](#)

A question of definition

The burden of these systemic failings now weighs heavy on a society faced with a worldwide tsunami of post-COVID conditions. And it goes some way to explaining the collective shrugging of shoulders by [health authorities](#) when it comes to providing answers for sufferers.

Estimates of how many people infected with COVID go on to develop long COVID vary from [5–40%](#). The large variance is a result of the initial absence of a consistent or unifying set of diagnostic criteria.

Recently the World Health Organization provided a [definition](#) of post-COVID conditions. It includes those with a history of likely or confirmed infection with SARS-CoV-2 (the virus that causes COVID) who experience lingering symptoms for longer than two months, which are unexplained by an alternative diagnosis.

Defining the illness allows clearer characterization of who is affected. Long COVID is now known to affect any age group and may be [unrelated](#) to initial infection severity. This evidence prompted the US Centers for Disease Control and Prevention to detail an [ominous warning](#) about post-COVID health problems that "can last weeks, months, or years."

Multiple case series and [observational studies](#) have now identified a high burden of [nervous system](#) dysfunction in long COVID patients. Several studies, including one [published](#) in the *Journal of the American College of Cardiology*, demonstrated up to 95% of long-COVID patients also meet the international criteria for postural orthostatic tachycardia syndrome. This [syndrome](#) can cause lightheadedness, brain fog, fatigue, headache, blurred vision, palpitations, tremor and nausea.

These [symptoms](#) often are often incompatible with carrying out normal daily tasks, which explains why [unemployment and disability](#) are high among postural orthostatic tachycardia syndrome patients, despite their young age.

The next wave

Back in March 2021, the American Autonomic Society released a [statement](#) warning of the rising presentations of patients to autonomic specialist referral centers with symptoms of post-COVID postural orthostatic tachycardia syndrome. Of particular concern was the insufficient number of physicians familiar with this type of dysfunction

to treat the condition.

This situation is mirrored in Australia where only a handful of specialists are familiar with managing such complex cases.

Contrary to popular medical opinion and widely held beliefs, [effective therapies](#) exist for underlying conditions like postural orthostatic tachycardia syndrome, which is prevalent in long COVID. Early intervention is key. Treatment needs to be fully explored and implemented before [disability support services](#) can be [sought](#).

Time to listen

Our health systems need to absolve themselves of past sins and pay attention to the overwhelming voice of the current sufferers of long COVID and those with other post-infection syndromes or invisible illnesses who have endured decades of medical neglect.

Treatment options need to be made available and multidisciplinary teams need to upskill to manage these conditions.

A redefining of what it is to be disabled needs to be explored. Most importantly, these definitions should not be tied to a single cause but to the manifestation of symptoms that culminate in the disability.

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