(LCSA, n.d.)
[24 Jun 2024]

Long Covid Support AOTEAROA

REGISTER NOW AND BE COUNTED

About Long Covid Support Aotearoa

Those of us who became sick from the first small wave of Covid-19 to hit Aotearoa in early 2020 were still unwell by August 2020. We were desperate for answers, and began to connect via a Facebook group that became Long Covid Support Aotearoa (LCSA).

The beginning of the LCSA website | Te tīmatanga o te paetukutuku LCSA

In May 2023, LCSA expanded from the Facebook Rōpū | group and launched this website. It aims to provide a central repository of information from patients. It's written by patients, for patients, and fact-checked by medical professionals. We continuously update the site with new research and findings. Readers can expect to hear empathetic voices, distilled through input from the broader support group. People have explained their individual experiences with the many and varied symptoms, including diagnosis and management.

You are not alone | Kāhore koe e mokemoke

The Rōpū | group had the comforting tagline of "You are not alone". In that spirit, a small number of us started sharing our stories of Covid-19's lingering impact on our health. The group's numbers rose as more people caught the virus and didn't return to their former levels of health. For some, it triggered autoimmune issues or made pre-existing conditions flare up. For many, it unearthed inequities in healthcare access and exposed gaps in how NZ's medical system diagnoses and treats chronic conditions.

The early stages | Ngā taumata tōmua

In the first two years, our Rōpū | group only had a small number of people. This made it more difficult to get authorities or medical professionals to see or hear us. It became clear that little to no help was available. Many of us experienced gaslighting, where medical professionals didn't believe us; they said we were experiencing a psychological condition, not a physiological one. Whānau and friends struggled to relate to our experiences, which only heightened our feeling of isolation. Many of us were pushed out of the workforce, as we became unable to carry out activities at normal levels.

Where to go for help

- Visit FAQs
- About Long Covid
- Long Covid Symptoms
- Contact us

How could we make this better?

Is anything missing, something unclear or incorrect? Let us know how we can improve the information on this page.

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Walking their dog along the beach is an impossible activity for many Long Covidians. Photograph: Lotte Hawley

As more waves of Covid-19 swept through Aotearoa, we saw a sharp increase in Kowheori Roa | Long Covid numbers. Many thousands of people sought out the Tautoko | support of those with similar lived experiences. Our Rōpū | group provided crucial empathy and compassion about living with Long Covid to the 'newly diagnosed'. Not everyone had an official diagnosis, but many had realised their symptoms and exposure matched others' experiences of Long Covid. Often, people felt scared and didn't know what to expect or who to turn to.

We have come a long way in the understanding and acceptance of Long Covid within our health system. And not a moment too soon: this illness affects an estimated 10–20% of people who catch Covid-19. But the combination of pressure on our medical community and the lack of diagnostic tools has meant that while individuals may now receive a formal diagnosis, it comes with little to no treatment plan.

Why did we create Long Covid Support Aotearoa? | He aha mātou i whakatū ai i a Long Covid Support Aotearoa?

The Rōpū | group aims to fill the void this situation can create. By pooling our resources and knitting our stories together, we have been able to identify common themes and experiences. We know about pathways to recommend that a patient consider, treatments to try and advice to best heed. While everyone has a slightly different experience, and a person's lifestyle and life stage also affects recovery, this information from other patients can be validating and empowering.

> *The support group has been patient-led since its inception. Volunteers from the medical community provide vital support, in fighting disinformation and keeping our members safe.*

If a problem shared is a problem halved, then the Tautoko | support Rōpū | group acts as a vital lifeline for patients. We may not have all the cures or know how to make the disease disappear magically, but we can offer a safe space, free from fear, judgement and ridicule. Newly joined members echo this sentiment, saying how relieved they feel to have found out about Long Covid Support Aotearoa. Knowing people suffering similar issues can go a long way towards combating the stigma, minimisation and gaslighting many suffer.

Conditions for joining the LCSA support group

There are only a few specific conditions for joining the Facebook support group. A member must:

- be based in Aotearoa, New Zealand (or be a NZ citizen off-shore)
- have developed Kowheori Roa | Long Covid as a result of the virus itself, though they don't need to have a medical diagnosis
- agree to the rules of engagement, which are provided when people join the Facebook group.

Long Covid Support Aotearoa (LCSA)

LCSA is a non-profit organisation led by a large Rōpū | group of volunteers. We have secured sponsorship, which has enabled the Rōpū | group to fairly pay individuals who provide professional services to us, and to pay for technology to run the support group.

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