

# Long COVID in Victoria

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An editorial in the *Medical Journal of Australia* in early 2023 stated that “Long COVID is precisely the kind of challenge the current Australian health system finds most difficult: a non-fatal chronic condition manifested as complex combinations of symptoms, without a simple diagnostic test or definitive pharmacotherapy”.<sup>1</sup> Achieving equitable access to supportive health care is challenging because the best models of care are multidisciplinary and coordinated by primary care. These involve medical assessment and coordination, allied health interventions and psychological support, each of which often incur significant out-of-pocket expenses. Thus, long COVID represents a sustained and multiplied disadvantage, with lower socio-economic, cultural, and linguistically diverse groups experiencing the least access to care.<sup>2</sup> In this issue of the *MJA*, we publish the supplement *The impact of long COVID in Victoria 2020–2023*. This collection of seven articles investigates the health and financial burdens of long COVID in Victoria, discusses the biological mechanisms at play, and explores models of care for this complex condition.

The 2022–23 parliamentary inquiry into long COVID, *Sick and tired, casting a long shadow*, recognised the need to provide coordinated care for people with long COVID, provided largely in the community but with targeted support from specialists on a case by case basis.<sup>3</sup> The “long shadow” includes a small but significant impact for the Australian economy, with an estimated health care cost per person affected in Victoria equivalent to the average Victorian wage, as Angeles and colleagues<sup>4</sup> report in this supplement on long COVID. Another modelling study for the whole Australian population estimated that 1.2–5.4% of the population had symptoms of long COVID during 2022–2023, with 0.7–3.4% to still be affected in December 2024. The total labour loss was estimated at \$9.6 billion, or 0.5% of gross domestic product, with the greatest impact in people aged 30–49 years.<sup>5</sup>

The lived experience of a consumer with long COVID within this supplement reminds us that the above estimates are not just numbers, but represent the lives of many real people: “Together, my husband and I have lost contact with friends, stopped social activities, and resigned from local community groups ... We struggled to maintain our previous home, but, most importantly, we struggled to care for ourselves, which has had an impact on our self-worth”.<sup>6</sup>

The term long COVID was first introduced by people with the condition. It has received support from those with lived experience, and stood the test of time, despite some reluctance to accept its use by some — referring to it as “a term used commonly in the community”.<sup>7</sup> In this editorial, and throughout the supplement, the terms long COVID, post-coronavirus disease 2019 (COVID-19) condition, and post-acute sequelae of COVID-19 (PASC) are used interchangeably. The seven articles published in this supplement on the impact of long COVID in Victoria were first presented as part of the Victorian long COVID conference in September 2023.<sup>8</sup> The World Health Organization’s definition of long COVID has been used: “the continuation or development

of new symptoms 3 months after the initial [severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2)] infection, with these symptoms lasting for at least 2 months with no other explanation”.<sup>9</sup>

The Global Burden of Disease Long COVID study reported that 15.1% of 1.2 million survivors who had an acute infection in 2020 and 2021 still experienced long-lasting symptoms one year later.<sup>10</sup> The Victorian long COVID health survey, presented in this supplement,<sup>11</sup> invited participation not only from people who had experienced an acute COVID-19 infection between 2020 and 2022, but also a control group of close contacts who had been exposed but not knowingly infected during the same period. The survey found that, at time of assessment, 39.1% of respondents who had had COVID-19 reported at least one new persistent symptom compared with 20.8% of controls. Combining persistent symptoms with incomplete recovery resulted in 14.2% of respondents (95% confidence interval [CI], 13.4–15.0%) being classified as having long COVID. Based on these results, an estimated 756 000 adult Victorians (95% CI, 714 000–799 000) may have been experiencing long COVID at the time of the survey.<sup>11</sup>

For people with long COVID, about one in five (22.6%; 95% CI, 20.0–25.2%) experienced a moderate to severe impact to their usual activities. This suggests about 173 000 adult Victorians (95% CI, 149 000–196 000) may have been experiencing a more severe form of long COVID, one that has substantially affected their daily life. Risk factors for persistent symptoms and incomplete recovery in Victoria included acute severity, female gender, age 40–49 years, chronic illness and a history of anxiety or depression.<sup>11</sup> The proportion of people experiencing long COVID in Victoria fell with the introduction of vaccination and emergence of less virulent SARS-CoV-2 variants over the first three years of the COVID-19 pandemic. However, the burden of disease has grown, given the much larger number of Omicron variant infections since the easing of social restrictions and the transition to Victorians “living with COVID” from December 2021. Multiple national surveys from around the world have confirmed similarly high rates of PASC or long COVID.

Added to the burden of long COVID symptomatology is that people with long COVID still report being told “it’s all in your head” and that, as Flannigan and Flannigan<sup>6</sup> reflect on their experience of long COVID, doctors do not know how to treat them. This has been acknowledged by some general practitioners in Victoria and New South Wales, as described in this supplement in a study of factors affecting general practitioners’ diagnosis of long COVID,<sup>12</sup> reporting challenges with diagnosis, a lack of specialist input and advice, and limited access to multidisciplinary models of care.

In Australia, the separate Commonwealth and state funding models under the National Health Reform Agreement are prone to creating barriers to more widespread adoption of, and access to, holistic primary care-based multidisciplinary clinics. Primary care clinics still rely upon specialist advice, often to exclude the other conditions necessary to confirm the diagnosis

of long COVID. Despite some Victorian long COVID hospital-based clinics being closed or reabsorbed, there is still a need to develop funding models to deliver genuinely multidisciplinary clinics with a strong allied health input, as reported by Wrench and colleagues in this supplement,<sup>13</sup> to support ongoing rehabilitation.<sup>14</sup>

Long COVID results in multisystem symptomatology and sequelae. Almost five years into the COVID-19 pandemic, there are still major gaps in our knowledge as to the pathophysiology, treatment and prognosis of long COVID. However, we have learned the virus binds with pulmonary and endothelial ACE2 (angiotensin-converting enzyme 2) receptors and thus has the capability of inducing viral mediated and/or inflammatory responses in every system of the body.<sup>15</sup> The underlying pathways driving these inflammatory responses are still being elucidated, and thus there are no evidence-based pharmacological therapies currently available.

During the 2020–2021 Victorian waves of COVID-19, the hospitalisation rates for patients who had had COVID-19 increased significantly for cardiovascular, neurological, respiratory, kidney and thrombotic conditions.<sup>16</sup> These increased hospital admission rates in the year following infection may be due to deterioration of pre-existing comorbid conditions as well as direct post-COVID-19 pathologies. There is corroborating international evidence that patients with long COVID who have underlying comorbid conditions such as obesity, diabetes or kidney disease are more likely to be admitted to hospital and that these conditions may deteriorate after having COVID-19.<sup>17</sup> Whether this is directly related to long COVID or also contributed to by lack of seeking or receiving medical care for their comorbid condition remains to be determined.

Post-COVID-19 neurological syndrome (PCNS) is common<sup>14</sup> and includes “brain fog”; cognitive and memory impairment; loss of smell and taste; disorders of equilibrium; speech and language difficulties, including forgetting words; sleep disturbance; extrapyramidal and movement disorders; and cerebrovascular thrombosis. It is too early in the COVID-19 pandemic to know what the longer term impact of a SARS-CoV-2 infection will be on rates of dementia and extrapyramidal conditions, although we do know that, following infection, the virus can be found in all tissues, including the brain, and that ongoing inflammation is detrimental to health and wellbeing. Post-COVID-19 mental health sequelae, as reported in the Victorian long COVID health survey in this supplement,<sup>11</sup> may also have some neurological and/or inflammatory component but, as the survey demonstrates, the causes are likely to be multifactorial and can emanate from a variety of system disturbances either in isolation or combined.

The Victorian long COVID health survey provides an enduring data asset that will continue to be of use to researchers and clinicians seeking to understand both the impact of long COVID and the opportunities to develop better models of multidisciplinary care for people who experience it.<sup>11</sup> This is particularly the case since a landmark proportion of respondents (74%) provided consent for their (de-identified) data to be linked with other datasets for further research, and 62% agreed to be contacted for future surveys. Interested researchers are invited to contact the Centre for Victorian Data Linkage in the Victorian Department of Health.

Although expanding the evidence base is an important enabler of providing better care for people with long COVID, the testimony

of consumers tells us that this alone is not enough. Researchers and clinicians must also listen with compassionate curiosity to people with lived experience of long COVID, believe their accounts of illness, and work across professional boundaries to provide the multidisciplinary support they need to recover and/or live with their condition.

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