

First-ever national neurological survey reveals Australians facing widespread barriers to care

13 August 2026: Australia's first national survey of people affected by neurological conditions has revealed widespread gaps in coordinated care, leaving many people without the timely, equitable and effective care and support they need.

The inaugural Neurological Alliance Australia (NAA) Neuro Survey gathered the experiences and perspectives of 3,805 Australians, providing the first national picture of the challenges faced by people affected by neurological conditions.

Key findings include:

- fewer than four in ten (39%) described their care as coordinated
- more than half (51%) of respondents experienced difficulty accessing neurological care
- nearly one in three (30%) waited more than four years for a diagnosis
- nearly half (48%) delayed or skipped healthcare because of cost
- just one in ten (9%) said they felt fully supported by their healthcare team.

NAA Chair Rohan Greenland said the survey shows people living with neurological conditions are being let down at multiple points across the health system.

"A person may wait years for a diagnosis, struggle to find an appropriate specialist, pay high out-of-pocket costs for consultations and tests, and then be left to coordinate complex care across multiple services.

"For someone living with a progressive, fluctuating or complex neurological condition, a delay in one part of the system can severely impact their health, independence, employment, family and future care needs," Mr Greenland said.

James Dunn, who lives with myalgic encephalomyelitis (ME/CFS, also known as chronic fatigue syndrome) and postural orthostatic tachycardia syndrome (POTS), said the survey reflected many of the challenges he has experienced.

Before his diagnosis, James spent years building his legal career before co-founding a national consulting business but was forced to abandon his career to focus on managing his health.

"Living with a complex neurological condition isn't just about managing the condition itself. It's about navigating a complex healthcare system, dozens of appointments, specialists, tests and treatments, sometimes outside your state or territory, while carrying significant ongoing costs, and often without the coordinated care and support you need.

"No matter what neurological condition people are living with, too many of us are facing the same barriers to getting the timely, effective and affordable care and support we need," Mr Dunn said.

The findings are consistent with broader Australian evidence showing that people living with long-term and complex health conditions continue to face significant barriers across the health system.

Mr Greenland said the survey provides the first national evidence that many of these challenges are shared regardless of diagnosis.

"For the first time, we've brought together the experiences of people across Australia's neurological community. The survey doesn't just identify the problems. It shows us where governments need to focus their efforts."

The findings point to priorities for action, including improving access to earlier diagnosis and specialist care, establishing coordinated models of care across health, disability and aged care services, increasing investment in neurological research, building the workforce needed to meet growing demand, and ensuring equitable access to care regardless of where someone lives or their neurological condition.

NAA is calling on all Australian governments to work alongside people with lived experience, carers, clinicians, researchers and community organisations to develop and implement a National Action Plan for Neurological Conditions, supported by state and territory plans.

Mr Greenland said despite neurological conditions affecting millions of Australians, there is still no nationally coordinated approach bringing together diagnosis, care, research, workforce development and long-term support.

"These survey findings provide a roadmap for change, and it's encouraging that work to develop neurological plans is already underway in some states.

"We now need governments across Australia to work with the neurological sector to develop and implement a National Action Plan that builds on this work and gives Australians living with neurological conditions a fair opportunity to receive timely, coordinated and affordable care," Mr Greenland said.

Read the full NAA Neuro Survey report: <https://neurologicalalliance.org.au/media>

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