NAA Neuro Survey Insights Report

Experiences, Gaps and Priorities for Neurological Care and Research in Australia

EXECUTIVE SUMMARY

NEUROLOGICAL ALLIANCE AUSTRALIA

www.neurologicalalliance.org.au

About Neurological Alliance Australia

Neurological Alliance Australia is a national alliance of around 50 not-for-profit organisations representing the interests and needs of millions of Australians living with neurological and neuromuscular conditions as well as their carers and families. A list of member organisations is on page 7.

The Alliance advocates on shared priorities to improve quality of life, strengthen access to timely and appropriate care and support, and increase investment in neurological research, treatment and better models of care.

Acknowledgement of Support

Neurological Alliance Australia gratefully acknowledges and thanks the individuals and organisations that supported and contributed to the inaugural NAA Neuro Service Gaps and Innovation Survey including:

- people with lived experience, carers and NAA members who contributed to the co-design and development of the survey
- NAA members, health and community organisations, Federal Parliamentarians, clinicians, researchers and other partners who promoted the survey through their networks
- the 3,805 survey participants who generously gave their time to share their experiences and perspectives
- MS Australia for its support and contribution throughout the initiative
- Biogen Australia Pty Ltd, Novartis Pharmaceuticals Australia Pty Limited, Pharmacor Pty Ltd, Roche Products Pty Ltd, and UCB Australia Pty Ltd for their financial support. *

* Financial supporters had no role in the survey design or methodology, data collection, analysis or interpretation of responses, or the development of the findings and recommendations presented in this report.

Executive summary

Neurological care in Australia is fragmented, delayed, and inconsistently meeting the needs of those it is designed to support.

Opening

Neurological and neuromuscular conditions have a significant and sustained impact on individuals, families, and the healthcare system. The *Neuro Service Gaps and Innovation Survey* report highlights widespread challenges in accessing timely, coordinated, and affordable care across Australia, alongside gaps in research investment, innovation, and the translation of evidence into practice.

Despite advances in treatment and growing recognition of neurological and neuromuscular conditions, many people continue to experience a system that is difficult to access, fragmented in delivery, and inconsistent in meeting their needs. Respondents reported experiencing delays in receiving timely diagnosis and treatment, challenges navigating complex systems, and gaps in access to appropriate care and support, alongside limited awareness of, and participation in, research and innovation opportunities.

For many, outcomes depend not only on clinical need, but on geographic location, condition type, proficiency with the English language, level of health literacy, and an individual's ability to advocate for themselves or coordinate their own care. These findings, together with identified gaps in research investment, translation, and innovation pathways, point to many systemic barriers to how support for people with neurological and neuromuscular conditions is organised and delivered, with important implications for quality of care, health outcomes, and equity of access.

Who took part

The survey captured responses from 3,805 Australians, including people living with neurological and neuromuscular conditions, carers, health professionals, researchers, advocacy organisations, industry representatives, service providers, and policymakers. Respondents were represented across all states and territories and included both metropolitan and regional communities. The respondent gender profile was female at 77.3%, male at 21.2% and Other/prefer not to say at 1.4%.

Connection to neurological conditions

RESPONDENT GROUPS	NUMBER OF PEOPLE
People living with a neurological or neuromuscular condition	2,895
Current or past carers and/or family members	655
Health professionals	147
Advocacy and/or patient organisations	37
Researchers	28
Pharmaceutical Industry representatives	20
Service providers	12
Policymakers	11
TOTAL	**3805**

Numbers reflect total respondents. Completion rates are provided in the main report.

Conditions represented

FIGURE 1A: PEOPLE LIVING WITH A NEUROLOGICAL OR NEUROMUSCULAR CONDITION

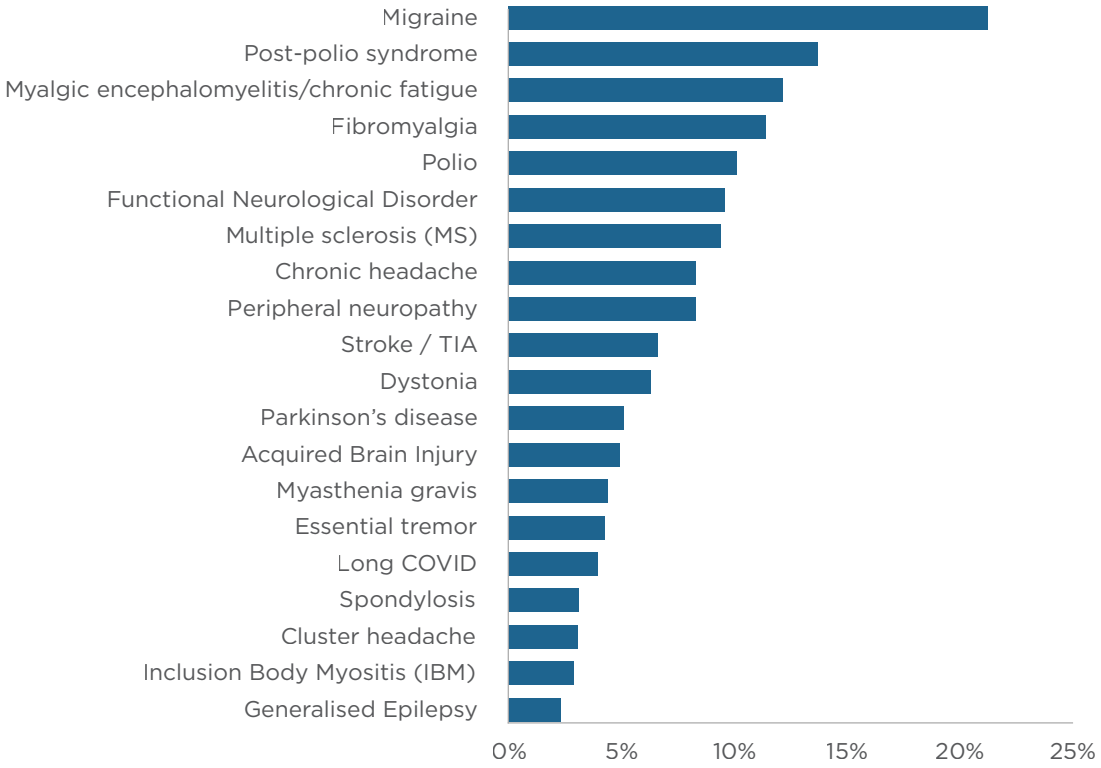
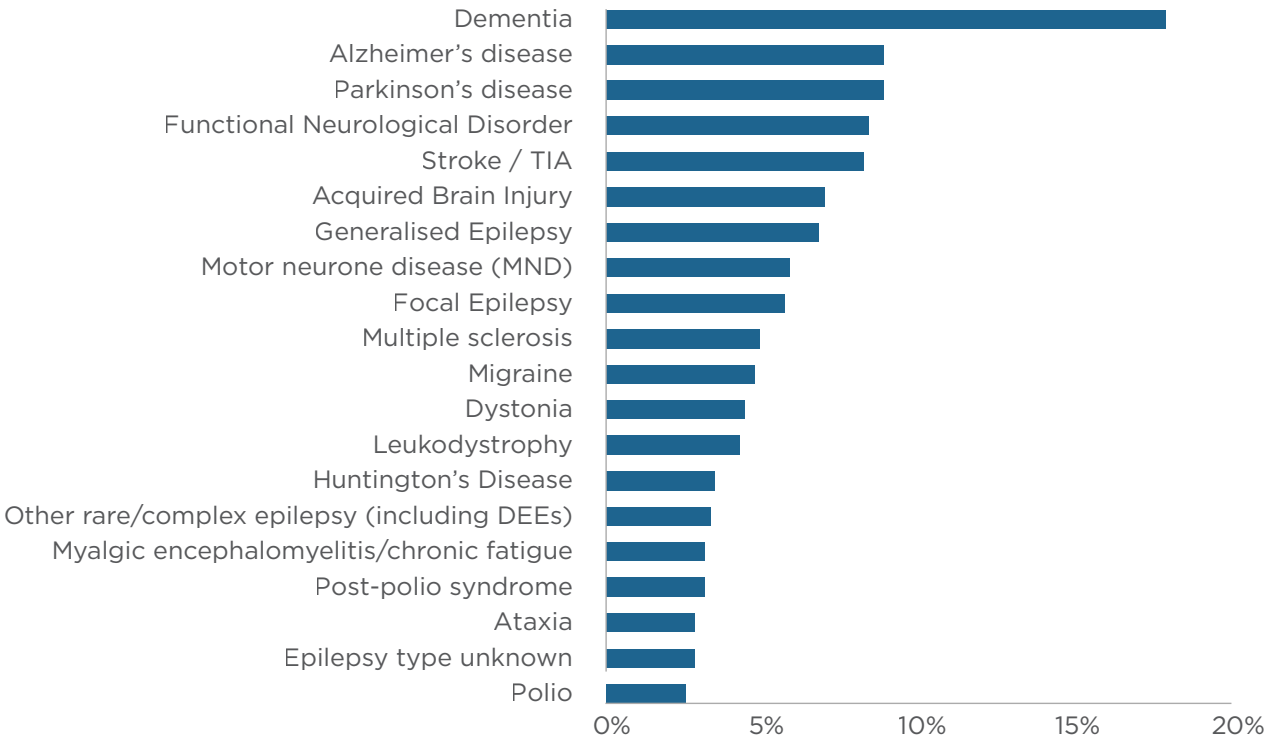


FIGURE 1B: CARERS OR FAMILY OF PEOPLE LIVING WITH THIS NEUROLOGICAL OR NEUROMUSCULAR CONDITION



A wide range of neurological and neuromuscular conditions were represented in the survey, with several participants reporting having more than one condition. The figures show the most frequently reported conditions among people living with a neurological and neuromuscular condition (Figure 1A); and carers or family of people living with a neurological and neuromuscular condition (Figure 1B).

Key findings

The findings reveal consistent gaps across neurological care, support, research and innovation. They reinforce persistent challenges in early diagnosis, accessing timely and affordable treatment and care, navigating fragmented systems, and coordinating services. The findings also highlight workforce constraints, inequities in access, and gaps in research awareness, participation and translation into practice.

Access to care

1 in 2 people report difficulty accessing neurological care

Over half of respondents (51.1%) reported that accessing neurological medical care in their area is somewhat or very difficult, with barriers including specialist availability, long wait times, and challenges navigating referral pathways.

Delayed diagnosis

Nearly 1 in 3 wait more than four years for a diagnosis

A substantial proportion of respondents experienced prolonged diagnostic pathways, with nearly 30% reporting waiting more than four years to receive a diagnosis for their neurological condition.

Cost barriers

Almost half delay or skip care due to cost

Nearly half of respondents (47.5%) reported delaying or skipping care due to cost, reflecting the financial burden associated with accessing healthcare, including specialist consultations, tests, and treatment.

Fragmented care

Only 4 in 10 people report their care is coordinated

Coordination of care remains a significant challenge, with only 38.7% of respondents describing their care as coordinated, while a comparable proportion reported fragmented care.

Carer impact

Nearly 1 in 2 carers provide 36+ hours of care per week

Carers reported substantial caregiving responsibilities, with 46.7% providing 36 hours or more of care per week, highlighting the significant reliance on informal and largely unpaid care.

Support experience

Over 9 in 10 people do not feel fully supported by their healthcare team

Support from healthcare teams was inconsistent, with only 9.4% of respondents reporting they felt fully supported, while many reported only partial or inadequate support.

Research and innovation

Nearly 1 in 2 people are unaware of research opportunities

Awareness of research opportunities is limited, with nearly half of respondents (45.3%) reporting no awareness and a further 37.4% only somewhat aware.

A case for reform – recommendations in brief

Across all stakeholder groups, there is strong alignment on priorities for reform.

Increase investment in neurological research

Increase investment in neurological research and strengthen pathways to translate research into diagnosis, treatment, and care, with a focus on unmet need and support real-world impact.

Improve access to diagnosis and specialist care

Improve access to timely diagnosis and specialist care, including neurologists, diagnostic testing, and multidisciplinary services, to reduce delays and improve outcomes for people with neurological conditions and their families.

Strengthen workforce capacity

Build neurological workforce capacity across neurology, allied health, and care services through investment in training, expansion, and improved distribution, particularly in regional and rural areas.

Establish coordinated models of care

Establish coordinated, integrated models of care across health, disability, and aged care systems to reduce fragmentation and improve continuity of care for people with neurological conditions. This includes acces to care coordination, navigation, rehabilitation and long-term support across the course of a person's condition.

Reduce inequities in access

Address geographic, age-based, and condition-related inequities to ensure equitable access to neurological care and support, regardless of location or eligibility.

Embed lived experience in system design

Embed lived experience and carer perspectives in research, policy, and service design to ensure systems reflect real-world needs and priorities.

Strengthen data and national coordination

Improve data systems, national coordination, and long-term planning to support decision-making, track outcomes, and align research, policy, and service delivery.

The full recommendations and supporting rationale are presented within the main report. While their order broadly reflects the prominence of issues in the survey findings, they should not be interpreted as ranked priorities. Each will require sustained and concurrent attention to achieve meaningful, system-wide improvement.

Across the recommendations, two cross-cutting imperatives are particularly clear: improving coordination and navigation across systems and reducing inequities in access to care and support.

Together, the findings demonstrate the need for a nationally coordinated approach to neurological care and research. Without action, delays, inequities, workforce shortages, and fragmented care will continue to limit outcomes for millions of Australians living with neurological and neuromuscular conditions, as well as their families and carers.

Neurological Alliance Australia, 13 August 2026

Current Organisational Members

- Australian NPC Disease Foundation (ANPDF)
- Brain Foundation
- Brain Injury Australia
- Cerebellar Ataxia Australia
- Childhood Dementia Initiative
- Cure CASK
- Dementia Australia
- Dystonia Network of Australia
- Emerge Australia (ME/CFS)
- Epilepsy Action Australia
- Epilepsy Australia
- Epilepsy Foundation
- FARA Australia
- FAST Australia (Angelman Syndrome)
- Fight Parkinson's
- FND Hope
- FSHD Global Research Foundation
- Fragile X Association of Australia
- Genetics Alliance Australia
- Huntington's Australia
- Homer Hack
- Klim Foundation
- Leukodystrophy Australia
- Meningitis Centre Australia
- Migraine Australia
- Mito Foundation
- Machado-Joseph Disease (MJD) Foundation
- Motor Neurone Disease Australia
- Multiple Sclerosis Australia
- Muscular Dystrophy Australia
- Muscular Dystrophy Foundation Australia
- Myasthenia Alliance Australia
- Myositis Association Australia
- Nerve Connection Foundation
- Neurological Alliance Queensland
- Neurological Council of WA
- Neuromuscular WA
- Palliative Care Australia
- Parkinson's Australia
- Polio Australia
- Post Polio Victoria
- Save Our Sons Duchenne Foundation
- SCN2A Australia
- Spinal Cord Injuries Australia
- Spinal CSF Leak Australia
- Spinal Muscular Atrophy Australia
- Stroke Foundation
- The Australian Young Onset Dementia Special Interest Group
- Tuberous Sclerosis Australia
- Young People in Nursing Homes National Alliance

Current Associate Members – individual researchers from:

- Macquarie University, NSW
- Murdoch Children's Research Institute, VIC
- Neuroscience Research Australia and Royal Prince Alfred Hospital, NSW
- Perron Institute for Neurological and Translational Science, WA

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