



Pre-budget submission for the 2025-26 Federal Budget

January 2025

Rohan Greenland
Chair

Anne Wilson
Deputy Chair

***The Neurological Alliance Australia** is an alliance of 35 not-for-profit peak organisations representing adults and children living with progressive neurological or neuromuscular diseases or neurological disorders in Australia. The Alliance was established to promote improved quality of life for people living with these conditions and increased funding to support research.*

- *Overseas studies indicate as many as 1 in 3 people live with a neurological condition, the leading cause of illness and disability worldwide¹*
- *We estimate that 1 in 4 Australians live with neurological or neuro-muscular conditions, or neurological disorders, with an annual impact on the Australian economy of over \$100 billion²*
- *These conditions represent around 14% of NDIS participants³*
- *According to the AIHW Australian Burden of Disease Study 2023, neurological conditions are one of the five leading disease groups causing burden in 2023⁴*
- *To read more about the work of the Alliance, its members and our six pressing areas of need, please visit: <https://neurologicalalliance.org.au/count-us-in/>*

¹Retrieved from: <https://www.who.int/news/item/14-03-2024-over-1-in-3-people-affected-by-neurological-conditions--the-leading-cause-of-illness-and-disability-worldwide>

² Based on an aggregation of data from organisations who have commissioned prevalence and/or economic impact studies

³ Based on an aggregation of neurological 'primary disability groups' in the NDIS quarterly reports

<https://www.ndis.gov.au/about-us/publications/quarterly-reports>

⁴ Retrieved from Australian Burden of Disease Study 2023, About - Australian Institute of Health and Welfare (aihw.gov.au)

Introduction

The Neurological Alliance Australia (NAA) is pleased to provide a pre-Budget submission to the Australian Government for the 2025-2026 Budget.

Neurological and neuromuscular conditions and disorders have a devastating impact on those diagnosed, their families, friends and loved ones.

These conditions are on the rise in Australia and worldwide, yet despite being recognised as one of the nation's top disease burdens, neurological conditions remain under-recognised and underfunded.

The urgent unmet needs for people living with neurological and neuromuscular disorders and conditions in Australia are:

- Better treatments, prevention and ultimately, cures for these diseases - cures could well be within reach.
- Improved support for the management and care of people affected by neurological and neuromuscular conditions and disorders - through systemic improvements to the health care, disability care and aged care sectors.

This submission focusses on key areas to address these urgent unmet needs.

Summary of recommendations:

Recommendation 1

That a new Neurological Mission of \$300 million over ten years be established within the Medical Research Future Fund.

Recommendation 2

That the NDIS be strengthened by addressing barriers to access, improving education and training of NDIA staff about neurological conditions and progressing the work of the Neurological, Palliative Care and Rare Conditions Working Group.

Recommendation 3

That the Department of Health allocate an additional \$550,000 for the Australian Institute of Health and Welfare to progress the initial scoping work leading to the establishment of a national neurological data set.

Recommendation 4

That harmonised and unified national Assistive Technology access be established to meet the needs of people with disability who do not qualify for the NDIS.

Recommendation 5

That recommendation 6 of the Review of the National Strategic Framework for Chronic Conditions regarding sustainable and transparent funding tied to outcomes be addressed in the 2025/26 Federal Budget.

1. Establish a new Neurological Mission within the Medical Research Future Fund

The establishment of a new Neurological Mission of \$300 million over ten years within the MRFF will provide a focus for research investment, innovation and activity and bring us closer to better treatments, prevention and ultimately, cures for the diseases represented by the NAA.

The MRFF website states, “Missions challenge current ways of thinking. They allow researchers to be bold and change the face of medicine.”

The members of the NAA believe that neurological conditions:

- are an area of national priority (i.e. through the number of people impacted – estimated to be 1 in 4 Australians; the impact on Australia’s economy (estimated at over \$100 billion annually), and identification of where significant gains could be made to improve health and quality of life and reduce costs in the health, aged care and disability care sectors), that are currently only partially addressed through existing missions
- Show strong alignment with the MRFF Strategy and Priorities
- Show strong opportunities for return on investment i.e. investing in research where big achievements could be gained in the short, medium and long term, and investing in research that positions Australia as a global research leader.

We need a Mission, or risk healthcare and disability support crises including rising costs, overwhelmed health systems, and growing inequities.

Recommendation 1

That a new Neurological Mission of \$300 million over ten years be established within the Medical Research Future Fund.

2. Improve the neurological voice within the NDIA

There are approximately 1 in 4 Australians⁵ living with neurological or neuromuscular conditions or neurological disorders with an annual impact on the Australian economy of over \$100 billion⁶.

These conditions represent around 14% of NDIS participants⁷. They are generally poorly understood by the NDIA; this affects access, and the quality of assessment and care received.

Advocacy by individual NAA member organisations can bring about important improvements such as the example below from MND Australia. Working with

⁵ Based on an aggregation of data from organisations who have commissioned prevalence studies

⁶ Based on an aggregation of data from organisations who have commissioned economic impact studies

⁷ Based on an aggregation of neurological ‘primary disability groups’ in the NDIS quarterly reports <https://www.ndis.gov.au/about-us/publications/quarterly-reports>

the NDIS as an alliance has the potential to bring about further improvements on a greater scale.

Advocacy wins - changes to NDIS access for people living with motor neurone disease (MND)

MND Australia is the national peak body of state organisations that support those living with and impacted by motor neurone disease.

The strength that comes through our federation of State MND Associations led to the recent introduction of MND being added to the 'priority pathway' in the NDIS.

MND was added to the priority eligibility decisions within the NDIS Guidelines in 2024. This priority pathway enables a decision outcome within 2 to 5 business days. For people diagnosed with MND, the process of applying for an initial NDIS plan and making plan revisions is now faster and more seamless for people with MND as of 1 July 2024.

A Neurological, Palliative Care and Rare Conditions Working Group (NPRG)⁸ has been established within the NDIA to provide strategic advice to the NDIA regarding aspects of the NDIS that impact people living with neurological or neuromuscular conditions or neurological disorders, such as barriers to access, assessment, planning and budgeting.

The Working Group has made considerable progress since it was established in May 2024, but more work needs to be done. It will be important that funding continues to ensure this work is progressed.

Recommendation 2

That the NDIS be strengthened by addressing barriers to access, improving education and training of NDIA staff about neurological conditions and progressing the work of the Neurological, Palliative Care and Rare Conditions Working Group.

3. Establish a national neurological data set

Most NAA members experience considerable data gaps. This data is a key foundation for building a platform for planning and prioritising health policies and evaluating intervention programs and initiatives.

The AIHW's Neuro Conditions Expert Advisory Group has commenced initial scoping for a neurological conditions data set through an initial allocation of funds from the Department of Health and Aged Care; we need this work to progress so that a comprehensive data set is established and regularly updated.

⁸ <https://www.ndis.gov.au/about-us/reference-group-updates/neurodegenerative-palliative-care-and-rare-diseases-advisory-group>

Notably, the recent World Health Organisation (WHO) Global Action Plan on Epilepsy and Other Neurological Conditions 2022-31⁹ includes a focus on data and information systems, with a list of actions for Member States to routinely identify, collate and report on neurological conditions.

In light of this ‘call to action’ from WHO and the significant data gap for neurological conditions in Australia, the NAA is very keen to progress work with the AIHW to address this gap so that a comprehensive data set is established and regularly updated.

Recommendation 3

That the Department of Health allocate an additional \$550,000 for the Australian Institute of Health and Welfare to progress the initial scoping work leading to the establishment of a national neurological data set.

4. Establish harmonised, unified national Assistive Technology access

Assistive technology (AT) plays a critical role in the lives of people with disability of all ages by facilitating independence and participation in everyday activities.

The NDIS is able to provide scheme participants with fully funded access to assistive technology, but the situation for those who are excluded from the scheme is very different. Older people with disability bear the brunt of this arrangement, as the age cut-off for eligibility for the NDIS is 65.

People with disability who are excluded from the NDIS are commonly required to wait well over a year to access funding for AT. They are forced to self-fund part or all of the equipment they need, often at considerable expense and in some cases, they simply go without.

Provision of AT keeps people living their lives better – in work and at home, resulting in less demand on support systems within the health, disability and aged care sectors.

A study commissioned by Council on the Ageing Victoria¹⁰ titled “*Establishing and costing a single national assistive technology and home modifications program to support people with disability who are not eligible for the NDIS*”¹¹ demonstrated that current levels of unmet need would best be resolved through

⁹ <https://www.who.int/news/item/28-04-2022-draft-intersectoral-global-action-plan-on-epilepsy-and-other-neurological-disorders-2022-2031>

¹⁰ Council on the Ageing (COTA) Victoria lead the Assistive Technology for All (ATFA) alliance of 65 peak organisations that have joined forces to advocate for a single assistive technology program to meet the needs of people with disability who are excluded from the NDIS. To read more, please visit:

<https://assistivetechforall.org.au>

¹¹ Layton, N., & Brusco, N. (2022). *The Australian assistive technology equity studies: Improving access to assistive technology for people with disability who are not eligible for the NDIS*. Monash University; COTA Victoria. <https://doi.org/10.26180/21113887>

the establishment of a single national assistive technology and home modifications program.

A single national assistive technology and home modifications funding program will support all people with disability who are ineligible for the NDIS, irrespective of age. A single national funding model will enable existing successful organisations that implement AT models to continue operating but access funding from one national pool of funds.

Key findings of the study

Two out of three older people with disability who are not eligible for the NDIS access support from the aged care system.

Currently the average spend on assistive technology and home modifications per person per year for NDIS participants is \$2,500, compared with just \$51 per person per year for aged care recipients.

Current schemes for providing assistive technology and home modifications (AT/HM) are fragmented and complex

109 separate AT/HM schemes were identified in the study.

Lack of equity across state/territory boundaries

Each state/territory has a flagship AT/HM Scheme. All have different eligibility criteria, different AT/HM in scope and different rationing methods e.g. subsidy rates.

Return on government investment

An annual investment of \$16 billion could ultimately save \$32 billion. For every dollar spent on assistive technology and home modifications, there is a conservative estimated two-fold return on investment relating to savings on the cost of paid carers, support and medical services. The timely provision of assistive technology and home modifications can also prevent or delay entry to residential care, the cost benefits of which are not included in this estimate.

Data in the study suggests that for every \$1.00 spent on high level assistive technology and/or home modifications, up to an additional \$1.98 is spent on organisational/administrative costs. Consolidating the 109 existing funding streams into one national program could create further cost efficiencies for Government by reducing the administrative burden associated with operating the existing multiple schemes.

Recommendation 4

That harmonised and unified national Assistive Technology access be established to meet the needs of people with disability who do not qualify for the NDIS.

5. Fund the National Strategic Framework for Chronic Conditions (NSFCC)

In 2017, the NSFCC was developed and launched by the Council of Australian Government (COAG) Health Council to provide high-level guidance to work towards a national response to chronic conditions that is effective and coordinated. The NSFCC recognises that many chronic conditions share similar principles for prevention and management.

In September 2023, the Australian Government Department of Health and Aged Care engaged Ernst & Young to conduct a review of the National Strategic Framework for Chronic Conditions, its related Action Plans (there are 11) and the National Asthma Strategy 2018.

The review report¹² was delivered to the Department in December 2023 and included seven key recommendations to inform the future refresh of the NSFC, including a key recommendation regarding funding:

“Recommendation 6: Implement a set of funding reforms.

This includes:

- *Embedding principles of sustainable funding in the NSFCC to focus on strategic long-term change and embedding the requirement for multisectoral collaboration.*
- *Increasing transparency surrounding funding processes.*
- *Ensuring that sustained / continued funding is tied to evidence of achieving agreed outcomes.”*

Critical to the successful implementation of the Framework is a commitment to implement these funding reforms to ensure its success.

Recommendation 5

That recommendation 6 of the Review of the National Strategic Framework for Chronic Conditions regarding sustainable and transparent funding tied to outcomes be addressed in the 2025/26 Federal Budget.

For more information about this submission and the work of the Neurological Alliance Australia please contact:

David Ali
Executive Officer
Email: david.ali@neurologicalalliance.org.au

¹² <https://www.health.gov.au/sites/default/files/2024-05/review-of-the-national-strategic-framework-for-chronic-conditions.pdf>