



---

# Pre-budget submission for the 2023-24 Federal Budget

---

January 2023

**Rohan Greenland**  
**Chair**

**David Ali**  
**Deputy Chair**

**The Neurological Alliance Australia is** an alliance of 15 not-for-profit peak or national patient 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. Members of the Alliance are: Dementia Australia, Brain Injury Australia, Emerge Australia, Huntington's Australia, Motor Neurone Disease (MND) Australia, MJD Foundation, MS Australia, Muscular Dystrophy Australia, Muscular Dystrophy Foundation Australia, Parkinson's Australia, Spinal Muscular Atrophy Australia, Leukodystrophy Australia, the Childhood Dementia Initiative, the Mito Foundation and Polio Australia.

Some NAA members are providers under the NDIS, offering support coordination, allied health and/or other supports. Most members provide information and navigation services funded through separate sources such as fundraising and philanthropy

**The Neurological Alliance Australia represents** nearly 2 million Australians living with the conditions represented by the members of the Alliance with an annual impact on the Australian economy of over \$50 billion.

## Introduction

The Neurological Alliance Australia (NAA) is pleased to provide a pre-Budget submission to the Australian Government for the 2023-2024 Budget. This submission focusses on four key areas that will impact people affected by the conditions represented by the members of the NAA.

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 - through systemic improvements to the health care, disability care and aged care sectors.

## Summary of recommendations:

1. **That the Department of Health work with the Neurological Alliance Australia to establish a new Neurological Mission within the Medical Research Future Fund**
2. **That a representative of the Neurological Alliance Australia be included on the existing NDIA Industry Chief Executives Forum.**
3. **That a Neurological Advisory Group be established within the NDIA, similar to the Autism Advisory Group.**
4. **That the Department of Health allocate \$550,000 for the Australian Institute of Health and Welfare to address the current neurological data gaps and opportunities, including:**
  - **\$400,000 for a scoping study leading to the development of a minimum data set for neurological and neuromuscular conditions in Australia.**
  - **\$150,000 for a data report on neurological conditions in Australia that would report the latest available data.**
5. **That a single National Assistive Technology Program be established to meet the needs of people with disability who do not qualify for the NDIS.**

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

**The establishment of a new Neurological Mission 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.**

Medical Research Future Fund (MRFF) activities are based on **areas of national priority** identified by an expert advisory board and widespread consultation. Activities put patients at the core and focus on translating research into practice so that all Australians can benefit.

The \$6.3 billion MRFF second 10-year Investment Plan outlines the Australian Government's plans for the use of MRFF funding from 2022-23 to 2031-32. This Plan contains 21 initiatives under 4 themes: Patients, **Research Missions**, Researchers and Research Translation.

MRFF Research Missions are “large programs of work that bring together key researchers, health professionals, stakeholders, industry partners and patients to tackle big health challenges”<sup>1</sup>. They:

- enable key players to work together and exchange insights that lead to better research
- position Australia as a global research leader
- promote new evidence-based approaches to disease management
- create new jobs and business growth

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

The establishment of a Neurological Mission will build on and complement the existing eight missions under the MRFF, these are:

- Australian Brain Cancer Mission
- Cardiovascular Health Mission
- Dementia, Ageing and Aged Care Mission
- Genomics Health Futures Mission
- Indigenous Health Research Fund
- Million Minds Mental Health Research Mission
- Stem Cell Therapies Mission
- Traumatic Brain Injury Mission

Each mission has an Expert Advisory Panel, a Roadmap, an Implementation Plan and attracts significant funding.

The members of the NAA believe that neurological conditions:

- are an area of national priority (i.e. through the number of people impacted [nearly 2 million plus family members, carers and friends], the impact on Australia's economy [estimated at over \$50 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.

---

<sup>1</sup> <https://www.health.gov.au/initiatives-and-programs/medical-research-future-fund/mrff-research-themes/research-missions>

The NAA is seeking an increase in MRF funding to create a new neurological mission to address neurological conditions rather than seeking funding repurposed from existing missions.

### **Recommendation 1**

**That the Department of Health work with the Neurological Alliance Australia to establish a new Neurological Mission within the Medical Research Future Fund.**

## **2. Improving the neurological voice within the NDIA**

**Nearly 2 million Australians live with neurological disorders or progressive, degenerative neurological or neuromuscular conditions. The NAA is calling for the neurological voice to be incorporated into the advisory and consultative structure of the NDIS/NDIA, to ensure fair representation and better support for our community.**

This could be achieved by NAA representation on the NDIA Chief Executives Forum and through the establishment of a neurological advisory group.

### **Representation on the NDIA Industry Chief Executives Forum**

The NDIA currently engages with NDIS provider peak bodies and provider representatives on improvements to the NDIS and the NDIA's processes and practices through the Industry Chief Executive Forum (ICE Forum)<sup>2</sup>. The ICE Forum provides an opportunity for two-way collaboration where the NDIA can test policies, practices and processes to improve the NDIS with ICE Forum members and to gather views and feedback on key issues from Forum members.

The Forum also gives members the opportunity to engage directly with the NDIA CEO. There is currently no neurological or neuromuscular voice in the ICE Forum.

### **Establishment of an advisory group**

The Autism Advisory Group<sup>3</sup> was established in 2018 to provide a strong voice on behalf of people who participate in the NDIS. The group includes autism experts, service providers and people with lived experience of autism and advises the NDIA on autism.

A similar advisory group representing the neurological and neuromuscular community would be of enormous benefit to the NDIA.

As previously stated, it is estimated that nearly 2 million Australians live with a progressive neurological or neuromuscular disease in Australia with an annual

<sup>2</sup> <https://www.ndis.gov.au/about-us/reference-group-updates/industry-chief-executive-forum>

<sup>3</sup> <https://www.ndis.gov.au/about-us/reference-group-updates/autism-advisory-group>

cost to the Australian economy of over \$50 billion. The NAA estimates that around 15% of NDIS Participants have a progressive neurological or neuromuscular condition.

The cost of individual packages for participants with neurological conditions is comparatively high. The annualised commitment for supports and average payments for people with MS according to the September 2022 NDIS Quarterly Report<sup>4</sup> is \$115,200 and for 'other neurological' primary disability type is \$148,600 (with Huntington's disease at \$212,000 and motor neurone disease at \$242,000 as stated in the Participants with a neurodegenerative condition, NDIS Report, 31 March 2021)<sup>5</sup>. This compared, for example, with an average of \$40,900 for Autism plans, \$20,300 for developmental delay, \$46,800 for visual impairment and \$99,300 'other physical' disabilities.

'Compared with the Scheme overall, the distribution of annualised committed supports is more concentrated at the higher cost bands for participants with a neurodegenerative condition.'

The poor experiences of participants living with neurological conditions is reflected in the higher number of complaints from this cohort. In March 2021, the rates of complaints were 13% for participants with Muscular Dystrophy and Motor Neurone Disease, 12% for Multiple Sclerosis, 10% for Huntington's Disease and 9% for Parkinson's Disease, compared with the overall Scheme rate of 5%.<sup>6</sup>

#### Establishing national, evidence-based, outcomes-focused care pathways

The Neurological Advisory Group will be best placed to provide the NDIA with advice and guidance regarding optimal, outcomes-focused care pathways for neurological and neuromuscular conditions that the NDIA's own clinical workforce is not large enough nor evenly distributed enough to achieve. This could include advice regarding the best way to ensure people living with neurological/neuromuscular conditions can receive evidence-based care more uniformly, including care from neurologists and specialist nurses.

This guidance should include prompts for when to re-engage health care such as reviewing relapse or exacerbation guidelines to better safeguard people rather than adopting the default to simply increase the provision of care. This might include, for example, examination of the UK reablement approach to reduce the focus on disability, with short duration "pulse" packages<sup>7</sup> and also examination of the UK NICE clinical guidelines<sup>8</sup> for applicability in the Australian context.

Other areas of advice to ensure people get the right care and support at the right time might include:

<sup>4</sup> NDIS Quarterly Report to disability ministers, September 2022

<sup>5</sup> NDIS Report: Participants with a neurodegenerative condition in the NDIS, March 2021, p44

<sup>6</sup> NDIS Report: Participants with a neurodegenerative condition in the NDIS, March 2021, p24

<sup>7</sup> Social Care Institute for Excellence (February 2020): *Role and principles of reablement*. Retrieved from: <https://www.scie.org.uk/reablement/what-is/principles-of-reablement>

<sup>8</sup> National Institute for Health and Care Excellence (June 2022). *MS in Adults: Management*. Retrieved from: <https://www.nice.org.uk/guidance/ng220>

- Establishing a network of telehealth expertise to assist care coordination and planning in areas of deficit
- Establishing a national approach to assistive technology to reduce inappropriate variations in access.
- Monitoring trends in modifiable lifestyle factors in young Australians in particular such as diet, obesity, smoking, alcohol consumption and exercise (keeping this cohort as active and engaged in employment is critical).

### **Recommendation 2**

**That a representative of the Neurological Alliance Australia be included on the existing NDIA Industry Chief Executives Forum.**

### **Recommendation 3**

**That a Neurological Advisory Group be established within the NDIA, similar to the Autism Advisory Group.**

## **3. Establishing a neurological data set within the AIHW**

**Most of the NAA member organisations experience considerable data gaps for their specific disease group.**

These peak bodies have, in the past, allocated scarce resources to the commissioning of consultants to provide basic demographic and economic impact data. This data is a key foundation for building a platform for planning and prioritising health policies and evaluating the effectiveness of intervention programs and initiatives. Many smaller peak bodies representing fewer patients and with less resources have to manage as best they can without accurate up-to-date data sets and reports or by extrapolating or making assumptions based on overseas studies.

Minimal data sets might include basic demographic information such as condition prevalence, incidence, hospitalisations, accidents and emergency presentations, contribution to deaths, burden of disease and economic impact. The Australian Institute of Health and Welfare (AIHW) is best placed to collect and report this information as it does for the other chronic conditions such as dementia<sup>9</sup> (in adults) and epilepsy<sup>10</sup>.

Taken as a whole, there appears to be significant gaps across the entire neurological disease group, with some clear exceptions where there has been strong investment in addressing gaps, for example, dementia in adults, for which

<sup>9</sup> <https://www.aihw.gov.au/reports/dementia/dementia-in-aus/contents/about>

<sup>10</sup> <https://www.aihw.gov.au/reports/chronic-disease/epilepsy-in-australia/contents/about>

we understand there is now a dedicated data centre (which excludes children with dementia) and epilepsy.

Notably, the recent World Health Organisation (WHO) Global Action Plan on Epilepsy and Other Neurological Conditions 2022-31<sup>11</sup> includes a focus on data and information systems, with a list of actions for Member States, namely:

Actions for Member States:

212. Integrate monitoring of neurological disorders into routine information systems and across all levels of care and identify, collate, routinely report and use core data, disaggregated by sex, age and other equity measures in order to improve neurological care service delivery, promotion and prevention strategies and provide an understanding of the social determinants of neurological disorders.
213. Analyse and publish data collected on the availability and evaluation of utilisation and coverage of services and effective treatments for neurological disorders to improve care and delivery of programmes.

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.

Representatives of the NAA met with the AIHW in November 2022 to discuss the current national neurological data gaps and opportunities for monitoring neurological conditions, with a view to improving health outcomes for people living with neurological conditions and inform evidence-based policy. The AIHW advised that there are two essential projects that must be undertaken to establish the current neurological data gaps and opportunities:

- A scoping study that comprises a short report reviewing and assessing Australian data sources for neurological conditions across the lifespan, including identifying gaps and opportunities for data improvements pertaining to the topics of interest; and
- A data report on neurological conditions in Australia that would report the latest available data.

The outcome of these projects can then help to guide the future monitoring of neurological conditions by the AIHW. The AIHW have recently undertaken a similar project with the creation of the National Centre for Monitoring Dementia (NCMD) which was established to undertake a range of data improvement activities. This included scoping data gaps and opportunities, a comprehensive data report and the implementing an ongoing monitoring and reporting program for dementia in Australia.

---

<sup>11</sup> <https://www.who.int/news/item/28-04-2022-draft-intersectoral-global-action-plan-on-epilepsy-and-other-neurological-disorders-2022-2031>

**Recommendation 4**

**That the Department of Health allocate \$550,000 for the Australian Institute of Health and Welfare to address the current neurological data gaps and opportunities, including:**

- \$400,000 for a scoping study leading to the development of a minimum data set for neurological and neuromuscular conditions in Australia.**
- \$150,000 for a data report on neurological conditions in Australia that would report the latest available data.**

#### **4. Assistive technology for older Australians**

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. Screen reading software, mobility aids, electronic communication devices and prosthetic aids are all examples of AT.

It is essential that older people with disability have access to the support they need to lead full and active lives. 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 Victoria<sup>12</sup> 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*”<sup>13</sup> demonstrated that current levels of unmet need would best be resolved through the establishment of a single national assistive technology and home modifications program. This would support all people with disability who are ineligible for the NDIS, irrespective of age.

<sup>12</sup> 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>

<sup>13</sup> 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>



## 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.**

The final report from the Royal Commission into Aged Care Quality and Safety addressed the needs of this cohort. It recommended that people with disability accessing support from the aged care system have access to assistive technology and home modifications equivalent to what would be available under the NDIS. 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. Dozens more charitable, NGO and philanthropic funding sources were uncovered. The eligibility criteria across the 109 Australian schemes we located were often historic in nature and are not fully aligned with AT provision guidelines or good practice standards.

### **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 5**

**That a single National Assistive Technology Program be established to meet the needs of people with disability who do not qualify for the NDIS.**

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

Andrew Giles  
Executive Officer  
Email: [Andrew.giles@neurologicalalliance.org.au](mailto:Andrew.giles@neurologicalalliance.org.au)