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Blueprint for a National Action Plan for Neurological Conditions 2025-2031

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Blueprint for a National Action Plan for Neurological Conditions 2025-2031

Call to Action for Australia's Governments to improve Neurological Health

Neurological conditions are among the fastest-growing health challenges of our time impacting seven million Australians, their families, and our economy. Yet right now, Australia lacks a national, coordinated response.

The consequences are clear: delayed diagnosis, fragmented services, inequitable access to care, and rising health, social and economic costs.

With government leadership, we can change the trajectory.

To support the Australian Government, the Neurological Alliance Australia has created this Blueprint for a National Action Plan for Neurological Conditions. The Alliance's determination is to ensure:

- people with neurological conditions are diagnosed earlier and can access the care when and where they need it.
- families at risk of genetic neurological conditions have access to preventive options and support
- Australia's health system equipped with a strong, well-resourced neurological workforce
- researchers have the national data they need to unlock new treatments and drive innovation
- communities are empowered through access to prevention strategies which improve brain health and reduce disease burden.

To achieve these outcomes requires leadership, commitment and investment by the Australian and State/Territory governments with clear goals, measurable targets and accountability. The Neurological Alliance Australia emphasises there is an urgent need for investment in data, research, prevention, early intervention, and equitable access to genetic screening.

The development and implementation of a National Action Plan for Neurological Conditions will establish a framework to guide the Australian and State/Territory governments in addressing key priorities through a nationally coordinated response. It will also create a structured approach to coherently align condition-specific initiatives with government responsibilities including the Intersectoral Global Action Plan on Epilepsy and other Neurological Disorders (IGAP) 2022-2031 which requires evidence of an operational national plan or framework to address neurological disorders .

It will support government reform priorities across health, disability, aged care, workforce participation, innovation and technology. It is consistent with the themes of the Government's 13 August 2025 Health, Disability and Ageing Economic Reform Roundtable.

The Blueprint outlines a transformational roadmap for a fair, equitable, sustainable, and integrated system that ensures people with neurological conditions have equal access to care, therapies, and support when and where they need it.

Why governments must act now

Governments must act now, before the human and economic costs grow even higher. This is not just a health issue. It is an issue of fairness, of national productivity and of ensuring a future where every Australian can live well regardless of their neurological condition.

Investing in this Blueprint is both a **public health imperative** and **sound economic policy** which will:

- reduce avoidable hospitalisations and emergency care costs for unmanaged neurological conditions, saving the health system billions annually
- achieve up to **$3.9 billion savings per year** through improved treatment options resulting in lower hospitalisation and better long-term care[1]
- generate up to **$500m savings per year** through integrated care models, including neuro hubs and nationally funded centres of expertise and in-home support
- boost workforce participation through development and implementation of a national Neurological Support Package (including respite, peer networks, financial support) that will enable thousands of carers to return to paid work, delivering up to **$4 return on investment for every $1 invested**[2]
- advance treatments and diagnostics via a Neurological Research Mission under the Medical Research Future Fund which would drive innovation in treatments, diagnostics, and neuro-prevention, from gene therapy to AI-enabled tools, with research return up to **$4 per $1 invested**[3]
- establish a **National Neurological Data Repository** hosted by the Australian Institute of Health and Welfare to improve planning, resource allocation and outcomes.

Independent economic analysis[4] extrapolating the Economist Impact 2022 report on *Mitigating the Global Impact of Neurological Disorders*[5], suggests that prevention, better treatment, and rehabilitation investment across just the main 11 neurological conditions could result in savings of $7 billion annually, or $42 billion over the life of the National Action Plan through reduced healthcare costs, increased productivity, and enhanced wellbeing.

The risk of inaction

Without decisive action, annual health system costs would continue soaring, further straining already stretched health, disability, and aged care systems. Poor data, misdiagnosis, and fragmented care pathways mask the true scale of the crisis.

In addition to the national economic impact which currently exceeds $140 billion annually[6], projected to rise sharply with population growth, an ageing population, improved diagnostics, and post-COVID-19 secondary impacts.

Bold intervention must be taken now. The Neurological Alliance Australia calls on the Australian Government to acknowledge both the impact of neurological conditions and the lack of focus to date. This Blueprint sets out a system that is:

- preventative and proactive – driving early intervention and effective therapies
- inclusive and lifelong – ensuring support even for conditions that are not yet preventable or curable
- data-driven and person-centred – aligned with IGAP and national frameworks and policies
- innovative and economically sound – supporting Australian science, technology, and smarter care delivery.

The Neurological Alliance Australia **calls** on the Australian Government to:

- **endorse** this Blueprint as a foundation for coordinated action and investment, noting that the Blueprint has been designed as a living document to evolve and remain responsive and relevant to policy shifts, new evidence, emerging opportunities, and challenges
- **fund** a fully-resourced National Action Plan for Neurological Conditions 2025–2031, inclusive of IGAP obligation
- **mandate** the Department of Health, Disability and Ageing to commence development of the National Action Plan as a priority in collaboration with State and Territory governments, the Neurological Alliance Australia, and other stakeholders
- **embed** neurological health as a national priority across all current and future reform frameworks and funding agreements.

The Neurological Alliance Australia and its partners stand ready to work with the Australian and State/Territory governments to co-produce and co-implement the National Action Plan for Neurological Conditions. Together we can:

- build a stronger, more inclusive health system for people with neurological conditions
- reduce costs to the health system and to the broader economy through more integrated care
- accelerate breakthroughs in effective treatments, innovations and technologies
- enhance the quality of life for seven million Australians and their carers and families.

Governments must act now, before the human and economic costs grow even higher. This is not just a health issue. It is an issue of fairness, of national productivity and of ensuring a future where every Australian can live well regardless of their neurological condition.

Neurological Alliance Australia
04 September 2025

The detail

Blueprint for a National Action Plan for Neurological Conditions 2025-2031

Purpose

Neurological and neuromuscular conditions affect an estimated seven million Australians across the life course and account for one-fifth of the nation's total burden of disease.

Without decisive, coordinated action, the human, social and economic costs will escalate beyond the capacity of Australia's health, disability and aged care systems.

This Blueprint sets out a National Action Plan for Neurological Conditions 2025-2031 (that aligns with the World Health Organization *Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders 2022-2031),* designed for endorsement and implementation by the Australian Government in partnership with State and Territory governments and the Neurological Alliance Australia (NAA), including people with lived experience of neurological and neuromuscular conditions.

This Blueprint provides the Australian Government with a framework for the development and implementation of a National Action Plan for Neurological Conditions that aims to:

- reduce disease burden through prevention, brain health across the life course, early diagnosis, early intervention strategies, faster access to treatments and equitable and relevant lifelong care coordination
- close critical gaps in services, supports, and access to care
- uphold and protect the rights of children and young people, adults and older Australians living with neurological and neuromuscular conditions, as well as their carers and families
- accelerate research and innovation in next generation therapies and assistive technologies
- accelerate data-informed policy and action
- fulfill Australia's commitments to act on neurological conditions which are currently tracking below global recommendations.

This Blueprint is conceived as a living document. Government endorsement provides a foundation for coordinated action and investment; however, its design recognises the need for ongoing adaptability. This will enable the Blueprint to be continually updated to incorporate government policy shifts and related administrative changes, emerging evidence, and stakeholder feedback. This approach ensures that the Blueprint maintains its relevance and effectiveness over time while preserving continuity in its long-term strategic direction, leading to the development and implementation of a National Action Plan for Neurological Conditions.

Vision

Every Australian with a neurological condition enjoys the highest quality of life through timely, equitable access to world-leading care, effective treatments, research and innovation.

About the NAA

The Neurological Alliance Australia (NAA) is a collective of over 40 not-for-profit peak organisations representing children and adults living with neurological conditions and neuromuscular conditions across Australia. Our members represent the needs of approximately seven million Australians including children and young people, adults and older Australians, First Nations communities, those living in rural and remote areas and people from culturally diverse backgrounds.

The NAA members bring expertise spanning lived experience, care, research, policy and advocacy. The Alliance has been working collaboratively with a broad range of stakeholders – including people with lived experience, non-Alliance peak bodies, researchers, clinicians, the pharmaceutical industry and others – to develop this Blueprint.

The NAA commits to a mutually beneficial, long-term partnership with the Federal and State/Territory governments to co-lead the development, implementation and evaluation of the National Action Plan, to ensure there are meaningful health, social and economic improvements to the lives of Australians living with neurological conditions, as well as their carers and families.

Defining 'Neurological Conditions'

We acknowledge the complexity and diversity of lived experience, especially within rare diseases, and we use the term 'neurological conditions' to be inclusive of all relevant conditions.

Throughout this Blueprint the term 'neurological conditions' is used as a shorthand to encompass a broad and diverse population of individuals living with conditions that primarily affect the brain, spinal cord, peripheral nerves and/or muscles. This includes:

- neurological conditions that predominantly affect the central or peripheral nervous system
- neuromuscular conditions where the primary impact lies in the connection between nerve and muscle function, often with overlapping neurological features
- many rare or complex multi-system conditions that may not fit neatly into traditional categories, but which have a predominantly neurological impact on people's lives.

Why Australia must act now on Neurological Conditions

The Australian and State/Territory governments need to take urgent and strategic action to recognise, prioritise and support people with neurological conditions. The impacts of these conditions on individuals and their families can be varied and multiple. For instance, some conditions may result in a person being unable to live independently, other conditions may affect one's ability to sustain employment, communicate, or mobilise, while some may be progressive and life-limiting.

Despite their growing prevalence, neurological conditions have not received the same attention or investment as other disease groups. This systemic oversight is contributing to increasing disability, preventable hospitalisations, and unsustainable costs across the health, aged care, and disability sectors.

Scale of the challenge

Many neurological conditions remain under-recognised and under-prioritised in national health planning. Services are often limited, fragmented, and not embedded within national health policy or strategic frameworks—leaving major gaps in care and equity.

In Australia, an estimated seven million people live with neurological conditions. This number is expected to rise sharply in the coming decade due to population ageing, improved diagnostic capabilities and environmental factors. Neurological conditions are now the leading cause of ill health and disability worldwide. The overall amount of disability, illness and premature death (known as disability-adjusted life years, DALYs) caused by neurological conditions has increased by 18 per cent since 1990[7]

The Australian Institute of Health and Welfare Australian Burden of Disease data[8] ranks neurological conditions among the top five disease groups contributing to overall burden, with the impact increasing from 2023 to 2024. Neurological conditions constitute 20.5 per cent of Australia's total disability adjusted life years (DALYs), almost double the global average. Their rising prevalence places immense strain on Australian health systems, economies and families.

The national economic impact exceeds $140 billion annually, and is projected to rise sharply with population growth, an ageing population, improved diagnostics and post-COVID-19 secondary impacts.

In the absence of comprehensive Australian data there is clear evidence that globally, neurological conditions are now the leading cause of disability and the second leading cause of death, with robust international evidence indicating both rising prevalence and burden.

Systemic Gaps

Australia currently lacks:

1. a cohesive plan for coordinated action to address neurological conditions with national goals and targets to measure progress on:
    a. reducing burden of disease
    b. improving quality of life
    c. reducing mortality.
2. a comprehensive national neurological dataset for neurological conditions leading to considerable gaps in knowledge which limits research opportunities
3. adequate targeted investment in neurological research
4. coordinated prevention and early diagnosis and intervention programs
5. a strategy to address key challenges facing the neurological workforce
6. prevention strategies to improve neurological health which is valued, promoted and protected across the life course
7. accessible and comprehensive reproductive genetic carrier screening which offers families with an increased risk of having a child with a neurological genetic condition options for prevention and early intervention.

These absences result in fragmented services, delayed diagnoses, inequitable access to care and increased health, social and economic cost.

> *“A multi-disciplinary service that brings together medical and allied health in one place with appointments on a single day is so far from our reality.”* - Gillian lives with mitochondrial disease and has two children with mito.

Priority populations for action

There are several population groups with particular challenges which need to be addressed, such as:

Women

Neurological conditions significantly impact women's health and wellbeing in Australia, both directly through disease burden and indirectly via social, economic and carer roles.

Women have a higher prevalence for several neurological conditions such as multiple sclerosis and myalgic encephalomyelitis/chronic fatigue syndrome (around three in four people diagnosed), migraine (two to three times more likely than men), dementia, stroke (more likely to have worse long-term outcomes) and some rare neurological diseases for example neuromyelitis optica spectrum disorder (66 to 88 per cent are women). Certain types of epilepsy are more prevalent in women, and they also face unique challenges arising from the interactions between epilepsy, seizures, and hormonal changes. Furthermore, mental health burden such as depression is commonly comorbid with neurological disorders and is more prevalent among women.

Women living outside major cities often face challenges accessing specialist neurological care, leading to poorer outcomes. Carer and social burdens including reduced workforce participation often affect women disproportionately.

Women often face a longer journey to diagnosis because of bias in assessing symptoms.

> *"I went to a neurologist in Perth only to be told, "lots of women your age can't get up off the floor, lots of people have high creatine kinase levels, I don't think there is anything wrong with you."* – Tracey, eventually diagnosed with Myositis

First Nations and remote communities

Neurological conditions have a disproportionately severe impact on First Nations peoples influenced by a combination of higher risk factors limited healthcare access, and social determinants of health.

Indigenous Australians have a higher prevalence and earlier onset of stroke (on average 10 to 15 years earlier than non-Indigenous Australians) due to higher rates of risk factors, dementia rates up to five times higher than the non-Indigenous population with earlier onset as early as 45 years, higher rates of epilepsy due to meningitis and head injuries, as well as Machado–Joseph Disease.

Remote communities often lack specialist neurological services as well as other health workers. Lack of culturally appropriate care contributes to mistrust in health systems, under-diagnosis, and treatment gaps. The financial cost of treatment, medications and travel for specialist care is disproportionately high.

There is a critical lack of detailed, disaggregated data on neurological conditions in Indigenous Australians. And most neurological research in Australia has not adequately included or addressed Indigenous populations, resulting in under-served health needs.

> *A man newly diagnosed with symptomatic Huntington's Disease, initially living in a tent in remote WA, faced health, housing, legal, and mental health challenges. After moving to Perth for specialist care, a relationship breakdown left him homeless and suicidal, highlighting the complex needs of people with Huntington's Disease in rural and remote areas.* Huntington's Australia

Children and Young People

Neurological conditions can be present at birth or acquired later in life. Some are genetic, resulting from inherited faulty genes from one or both parents, or by spontaneous mutations at conception as seen in conditions such as Duchenne muscular dystrophy, Spinal Muscular Atrophy and many forms of epilepsy. Others may result from environmental factors such as head injury or infection. In some cases the cause is unknown.

These conditions can have a profound and lifelong impact on children and young people in Australia, impacting their development and limiting their ability to participate in social, economic and civic functions of our society.

Children reach developmental milestones in a predicted pattern and each milestone builds upon the last. For the children supported by NAA members, what matters most is not necessarily keeping pace with peers but rather that they are progressing through milestones that are adapted to their specific diagnosis. Every child deserves the opportunity to grow, develop and experience movement even though we know these abilities may decline over time.

Children require timely access to assistive technology and therapies, enabling them to explore their environment, to learn and develop through play-based therapy. Any delay in receiving support results in loss of precious time which can never be reclaimed. Families also need additional support to ensure essential therapies are not overlooked due to the demands of daily life.

The parents of several NAA members are often coping with the grief of losing the future they had imagined for their 'healthy' child as well as loss of independence due to caring duties. To ensure optimal support for the child it is essential parents receive support to manage their own psychosocial wellbeing.

These children and young people need a more coordinated, equitable and family-centred approach with early diagnosis, sustained and integrated care models, which is informed by stronger data collection and analysis.

> *"When my daughter, Angelina, was diagnosed with a rare neurological condition caused by a CASK gene mutation, our world changed forever. There are no days at the park, walks along the beach or dance lessons. Instead, our days and weeks are filled with intensive therapies, medical appointments and hospital admissions. I'm haunted by the thought of what would happen to Angelina if one of us died, or the unthinkable possibility of her dying before us which is a very real possibility. These anxieties pervade every aspect of my life, keeping me in a constant state of apprehension and emotional stress. Having a support system in place is vital for parents like us."* – Giovi M.

People living with a neurological rare disease

Up to two million Australians are living with a rare disease and 75 per cent of rare diseases have neurological symptoms. The number of known rare neurological conditions is increasing and, according to the European Reference Network for Rare Neurological Diseases (ERN-RND), 60 per cent of those affected are still undiagnosed. Many of these diseases can be life threatening and cause severe symptoms and disability. Only five per cent of rare diseases have effective treatments.

People living with rare neurological disorders currently have wide-ranging and complex unmet needs. These include a longer pathway to diagnosis, fragmented care, limited access to specialist clinicians and services and slower access to innovative treatments. Awareness of rare neurological diseases and the needs of patients is poor within the health system.

> *"Adrenoleukodystrophy has been cruel and unfair for Mateo, aged four. No child deserves to go through what Mateo has suffered. Research and newborn screening are imperative for babies to prevent children like Mateo developing severe disability. Had newborn screening and support been available when Mateo was born, he wouldn't be facing a lifetime of severe disability."* – Michelle E

There are systemic oversights in relation to governmental action for neurological conditions including inadequate national data collection, inconsistent diagnostic classification (especially in cases with comorbidities) and widespread under-reporting. These shortcomings suggest that governments are significantly underestimating the urgency and importance of addressing neurological health.

There is also a powerful opportunity to have an integrated health, ageing and disability system that is proactive, inclusive, economically sound and person-centred for people with neurological conditions. This Blueprint provides the framework.

Consequences of inaction

If governments across Australia do not take any urgent action including comprehensive, system-wide reform:

- neurological conditions will overwhelm existing systems as demand exponentially outstrips capacity
- service gaps and health inequities will widen
- economic costs as the burden on carers and families will continue to rise
- human rights and equity issues will remain unaddressed
- opportunities for collaborative research and innovation will be lost.

Australians with neurological conditions will continue to experience increased disability, poorer quality of life and higher rates of hospitalisation. This will cause significantly greater costs across the health, disability, and aged care systems.

In 2025, the total estimated economic burden of the top 11 neurological disorders in Australia is projected to reach approximately $137.26 billion per year[9]. This highlights the significant and sustained financial strain neurological conditions place on the Australian health system, aged care sector, disability services, and broader economy each year.

Extrapolating from the Economist Impact 2022 report on *Mitigating the Global Impact of Neurological Disorders*[10] which concludes that scaling up prevention, treatment, and rehabilitation for the top 10 neurological conditions could save USD $4 trillion by 2030 across 11 countries (excluding Australia), health economists engaged by the NAA concluded that the development of the National Action Plan could potentially result in:

- treatment savings potential: ≈ $3.9 billion per year
- rehabilitation savings potential: ≈ $3.1 billion per year
- together, scaling up rehabilitation and treatment could save up to $7 billion per year

through reduced healthcare costs, increased productivity, and enhanced wellbeing. This relates only to the top 11 neurological conditions.

The cost of doing nothing is immense in terms of health system costs. This is in addition to the national economic impact which exceeds $140 billion annually. This figure is projected to rise sharply with population growth, an ageing population, improved diagnostics and post COVID-19 secondary impacts.

The Opportunities

There is a strategic opportunity for the Australian Government to act now – capturing significant economic and social value while addressing a critical health priority. There is also a powerful opportunity to have an integrated health, ageing and disability system. The next decade presents many opportunities with breakthroughs in treatments including gene therapies, neuro-technologies, digital health, and preventative strategies. A co-produced future-focused plan, aligned with economic modelling, timeline commitments and integrated data and research will enable Australian and State/Territory governments and the community to deliver transformative, sustainable change for people with neurological conditions.

The National Action Plan will be a strategic investment in reducing disease burden, improving equity and preparing for what lies ahead. Governments together with the NAA, its partners and those with lived experience will be able to position Australia to:

- deliver world-class integrated care through neuro hubs and nationally funded centres of expertise together with integrated care in hospitals and in the home
- capitalise on research missions with an overarching Neurological Research Mission under the Medical Research Future Fund (MRFF)
- embed neurological health care within existing reforms such as NDIS, disability, aged care, primary care and preventative health
- ensure neurological conditions are recognised as a priority disease group by all levels of government
- address the interface between health, disability and ageing systems to support smoother transitions – especially from paediatric to adult care
- strengthen and expand access to the neurological workforce.

> *"I'm really, really, really fortunate with my healthcare team…They all communicate with each other. They're really happy to do that. So, I've found a really great team in that respect."* – person with mitochondrial disease.

Alignment with National and Global Frameworks

The National Action Plan for Neurological Conditions complements and operationalises:

- World Health Organization's Intersectoral Global Action Plan on Epilepsy and other Neurological Disorders (IGAP) (2022-2031)
- World Health Organization's Global Action Plan on the Public Health Response to Dementia 2017 – 2025 *(recently extended to 2031*)
- World Health Assembly's 2025 resolution: Rare diseases: a global health priority for equity and inclusion
- United Nations Convention on the Rights of Persons with Disabilities
- National Strategic Framework for Chronic Conditions
- National Action Plan for the Health of Children and Young People 2020–2030
- National Preventive Health Strategy 2021–2030
- National Strategic Action Plan for Rare Diseases (2020)
- Australia's Disability Strategy 2021–2031
- National Dementia Action Plan (2024–2034)
- parallel existing and emerging strategies and action plans for National Health Genomics Policy Framework, Dementia, Parkinson's and others to ensure coherence and efficient use of resources.

The National Action Plan is likely to support and complement other policy reforms, for example the outcomes of the revised National Health Reform Agreement, details of Foundational Supports outside the NDIS (to be phased in from 2025-2026).

More specifically, the NAA recognises strong alignment with the WHO *Intersectoral Global Action Plan on Epilepsy and other Neurological Disorders* (IGAP) given it calls on Member States to:

- develop or update national neurological policies and frameworks
- improve access to care and services
- integrate neurological health into broader public health systems
- engage people with lived experience in design and implementation
- collect and report data to measure national progress.

The proposed National Action Plan will support the Australian Government's commitments to IGAP, noting that countries such as India, Italy, Germany, Norway, Poland, Scotland, Sweden, Switzerland and Uruguay have developed national action plans for neurological conditions and brain health plans and countries such as South Africa and Zambia have specific integrated neurological policies.

Guiding Principles

The development and implementation of the National Action Plan must rely on the following principles:

- people centred and rights-based
- equity, dignity and inclusion across age, gender, culture, geography and socio-economic situation
- evidence informed and outcomes focused
- co-produced with lived experience
- whole-of-government and intersectoral ensuring a coordinated response across jurisdictions.

National Action Plan Implementation Roadmap

Based on the development of other Blueprints and Action Plans, the NAA acknowledges that the development and implementation of the proposed National Action Plan is a long-term project which must be led by the Australian Government together with all State and Territory governments, the NAA and people with lived experience. All governments across Australia must be committed to developing and implementing the National Action Plan.

The NAA proposes a three-stage process over the next six years which is framed around the real, urgent need to inform Australian and State/Territory governments' policy, strategies and initiatives in neurological health, disability, aged care and research. And in doing so:

- address the unmet needs of the estimated seven million and growing number of Australians with neurological conditions plus their carers and families
- ensure people living with neurological conditions and their carers and families receive fair and equitable access to the services they require
- improve integration of the needs of the neurological community into current and future systems of support and care
- investment in collaborative research to better understand causes, mechanisms and progression, with a focus on disease-modifying therapies, health and social care and treatment of neurological conditions.

The proposed three-stage process is:

Stage One: Year One

- Governance and Funding
    - **establish a Federal-State/Territory Steering Committee**, co chaired by the Department of Health, Disability and Ageing and the NAA and its partners, bringing together government, patient groups, clinicians and industry
    - **allocate funding to further develop this Blueprint** and to commence development of the National Action Plan in consultation with stakeholders. The Blueprint will include a detailed economic analysis on costs and returns on investment
    - **assess the Australian policy context** via an environmental scan of Australia's policies affecting people living with neurological conditions
- Initiatives for impact
    - **commence proof of concepts of Neuro Hubs and nationally funded Centres of Expertise** with allocated seed funding from all governments. This will enable a bottom-up approach by clinicians and other experts within a place-based context
- **commission a comprehensive evidence review and national service gap audit** with the Australian Institute of Health and Welfare. This will include the development of a national neurological dataset informed by the NAA national Service Gaps and Innovation Survey (to be conducted late 2025/early 2026) and lived experience focus groups
- **prepare a final, evidenced-based National Action Plan for Neurological Conditions** including recommendations relating to government policy, strategy and initiatives to support better outcomes
- **contribute to neuro nursing curriculum development** with the Australian College of Nursing and others.

Stage Two: Years Two and Three

- **roll-out national awareness campaign**
- **roll-out neuro nursing workforce strategy** including training
- **further expansion of Neuro Hubs / nationally funded Centres of Expertise** with one in each State and Territory
- **launch linked data repository** via the Australian Institute of Health and Welfare
- **funding allocated in 2026-2027 Federal Budget for the Neurological Research Mission** and priorities underway
- **implement integrated care pathways and carer support packages across Australia.**

Stage Three: Years Four and Five

- **fund national expansion of Neuro Hubs** in each State and Territory with number per jurisdiction based on population size
- **embed neurological key performance indicators i**n all relevant Commonwealth and State/Territory agreements (eg National Health Reform Agreement, National Health Information Agreement, Medicare, and others)
- **fund and conduct mid-term independent evaluation** in 2028 and final evaluation in 2031, both with public reporting.

By implementing this three-stage process, it is expected that people with neurological conditions can live better lives with earlier diagnosis, better care when and where they need it, effective treatments driven by research and innovation.

Engagement and Accountability

The NAA advocates that the success of the development and implementation of the National Action Plan is reliant upon bringing together and reflecting voices and insights from across the neurological community. Accountability to the community ensures that the Plan and proposed priority actions lead to tangible, sustained improvements in the lives of people affected by neurological conditions.

Role	Who is involved
Governance group	Federal Department of Health, Disability and Ageing in partnership with NAA including people with lived experience and other interest/stakeholders
Co-production and implementation engagement group	• Whole-of-government engagement across portfolios (Health, Disability and the NDIS, Social Services, Aged Care and Seniors, Women, Indigenous Australians, Multicultural Affairs, Industry and Innovation, Science, Youth, Rural and Regional Health, Mental Health) plus relevant State and Territory government departments and agencies • NAA members, its partners and wider representation from people with lived experience • Neurologists, clinicians, nursing, allied health • Researchers • Industry • relevant professional associations • other relevant peak bodies, eg Carers Australia

Reporting

For continuing transparency and accountability it is suggested that the following reporting mechanisms be implemented:

- the Federal Minister for Health, Disability and Ageing to annually report progress on the National Action Plan to National Cabinet and to the Australian Parliament
- State and Territory Health Ministers to annually report progress to their respective Parliaments
- the Neurological Alliance Australia to report to Department, NAA member organisations and publicly.

Funding

The proposed National Action Plan for Neurological Conditions is for governments to fund and – together with the NAA and others – deliver better outcomes to support Australians living with neurological conditions. The NAA seeks sustained Australian and State/Territory funding to implement new - and scale existing - initiatives, for new and expanded services, and for research. In doing so, a dedicated National Neurological Conditions Fund should be established to pool Australian and State/Territory funding, philanthropic, and others.

This funding request is to be part of a consortium approach where existing funding actions will be aligned to ensure all activities support the Blueprint.

It is estimated the following funding is required to deliver the National Action Plan:

- $30 million a year over 10 years for the Neurological Research Mission
- $34 million seed funding during 2025-2026 for comprehensive evidence review, national gap survey, data work including infrastructure, and Neuro Hubs / nationally funded Centres of Expertise pilots *(detailed costings to be developed)*
- $22 million for each year 2026 to 2031 for awareness campaigns, nursing workforce development initiatives, service delivery including expansion of neuro hubs, data work, research and independent evaluations in 2028 and 2031 (detailed costings to be developed).

It should be noted that some of elements of the Blueprint are about making sure existing policies and programs are working better for a cohort who is often overlooked. It is acknowledged that the Neurodegenerative, Palliative Care and Rare Diseases Advisory Group of the NDIA has begun taking steps to address this issue.

Monitoring and Evaluation

- establish an Outcomes Framework aligned with WHO IGAP indicators and national health objectives
- embed a Monitoring and Evaluation Framework with key performance indicators (eg waiting times, DALYs averted, hospital admissions) linked to proposed targets under each Objective and Priority Action with a publicly available dashboard to ensure transparency and accountability
- regular reporting to and by the Federal-State/Territory Steering Committee cochaired by the Department of Health, Disability and Ageing and the NAA on progress, effectiveness, and relevant system performance
- standing agenda item for quarterly NAA meetings to review progress and set priorities
- annual reporting by the Australian Health Disability and Ageing Minister to National Cabinet and by the Australian and State/Territory Health Ministers to their respective Parliaments
- independent evaluation at mid-point in 2028 with refresh as identified, and in 2031.

Message to leaders: What’s one thing you’d say to Australia’s Health Minister?

Mr Butler - your party is a party of vision. It delivered the biggest change for people living with a disability ever when it devised and implemented the NDIS.

I think most of us understand the government’s budget is not infinite: that the basic economic concept of opportunity cost means every dollar the government spends on one aspect of society, it can’t spend on another. But while the NDIS partially keeps our feet (or wheels) on the road - the journey - towards much-hoped-for cures, a large chunk of the neuromuscular disease community are still invisible or feel we are somewhat relegated to the shadows.

Taking the Neurological Alliance Australia and prosecuting the case for a more comprehensive, government-wide approach to neuromuscular diseases is critical to ensuring the many of us who live with neurological conditions keep the hope alive and never feel like we are stuck in the shadows but can thrive in the brilliant sunlight of our “lucky country”. – Paul B, diagnosed with Facioscapulohumeral muscular dystrophy.

Priority Action Areas (2025-2031)

Focused on improving health and health systems which should flow through to improving the practical issues that people with neurological conditions experience. Notwithstanding this, there must be policy, process and procedural changes to improve the day-to-day lives of people with neurological conditions.

In alignment with the national and international frameworks, six strategic objectives have been identified. For each Strategic Objective (note not mutually exclusive), the identified priority action areas are below. It must be noted that the Blueprint and its suggested priority action areas is a framework for action, rather than a prescriptive checklist. It is acknowledged that priorities and funding allocations may shift as health, disability and aged care system reform continues, and as new opportunities, risks or data emerge.

Strategic Objective	Suggested Priority Actions	Outcomes	Alignment with existing or emerging policies (inc. reviews)
1. Promote awareness, understanding and health literacy	Launch a national campaign highlighting neurological conditions, early symptoms, modifiable risk factors and culturally appropriate resources	Public awareness, early help-seeking, reduced stigma	*National Preventive Health Strategy 2021-2030, National Strategic Framework for Chronic Conditions 2017 (being reviewed), National Dementia Action Plan 2024–2034*
	Ensure evidence-based, accessible information on neurological conditions and brain health is available for people with lived experience and for all government agencies	Empowered self-management, informed decisions	*Australian Charter of Healthcare Rights, National Digital Health Strategy 2023-2028*
	Fund NAA to develop multilingual consumer information for individuals and families to support informed decision-making and self-management including how to access government services	Health equity, improved access for Culturally and Linguistically Diverse groups	*Multicultural Access and Equity Policy (2025),* National Health Literacy Strategy (being developed)

Strategic Objective	Suggested Priority Actions	Outcomes	Alignment with existing or emerging policies (inc. reviews)
2. Strengthen prevention, early diagnosis, intervention and treatment	Establish and fund Neuro Hubs and nationally funded Centres of Expertise across all States and Territories including Centres of Expertise for rare disease developed bottom-up led by clinicians	National specialist access, equity, rare disease care	*National Strategic Action Plan for Rare Diseases 2020,* National Health and Medical Research Strategy (being developed)
	Implement improved integrated models of care in hospitals and in the home including expanding neurological care access to primary care	Improved care services within different settings with expanded neurological care access	*National Strategic Framework for Chronic Conditions 2017 (being reviewed), Primary Health Care 10-Year Plan 2022-2032, National Strategic Action Plan for Rare Diseases 2020*
	Advocate for and implement universal early screening for relevant genetic neurological conditions such as reproductive carrier screening, Newborn bloodspot screening (either genomic or not), and other population screening	Early diagnosis, targeted support, cost savings	*Australian Genomics Roadmap 2023, National Preventive Health Strategy 2021-2030*
	Reduce specialist waittimes via telehealth and streamlined referral pathways to other specialists and services	Faster access, reduced system pressure	*Strengthening Medicare reports, Primary Health Care 10-Year Plan 2022-2032*
	Improve regional, rural and remote capacity and access to diagnostic and treatment services	Reduced geographic health disparities	*Stronger Rural Health Strategy 2021, MyMedicare, National Digital Health Strategy 2023-2028*
	Expand multidisciplinary and integrated care models including early intervention pathways	Improved patient-centred and coordinated care and support, comorbidity management, improved early intervention	*National Strategic Framework for Chronic Conditions 2017 (being reviewed), Primary Health Care 10-Year Plan 2022-2032,* NDIS and Aged Care reforms

Strategic Objective	Suggested Priority Actions	Outcomes	Alignment with existing or emerging policies (inc. reviews)
3. Guarantee equitable access to lifelong, personcentred care	Develop a National Neuro Nursing Workforce Strategy	Build a specialised workforce for growing neurological care needs and improved patient outcomes, workforce retention and career pathways	National Nursing Workforce Strategy (being developed), *Care and Support Workforce Strategy 2022–2032, National Health Workforce Strategy (2021)*
	Expand Medicare-funded telehealth	Improved timely access to specialist care, reduced rural/remote inequities	*Strengthening Medicare Taskforce Report (2023), National Digital Health Strategy 2023-2028, Primary Health Care 10-Year Plan 2022-2032*
	Ensure seamless transitions between paediatric, adult and aged care services	Continuity of care and support across life stages, reduced care gaps and duplication	NDIS reforms and Participant Service Guarantee, Royal Commission into Aged Care (2021), *National Action Plan for the Health of Children and Young People 2020=2030, National Disability Strategy 2021–2031, youth health frameworks*
	Prioritise women by designing services to be gender-sensitive, developing women-specific supports, encouraging research which focuses on gender differences in neurological disorders, treatment and care, or developing a clinic that specialises in neurological conditions that affect women and improving access to such services	Improved recognition of gender-specific impacts, reduced health inequities	*National Women's Health Strategy 2020–2030, Working for Women: A Strategy for Gender Equality (2024),* carer strategies (state-level)
	Embed culturally appropriate and safe First Nations-led service models	Improved outcomes for First Nations people, greater trust in services, strengthened cultural safety across system	*National Aboriginal and Torres Strait Islander Health Plan 2021–2031,* Closing the Gap targets, First Nations-led Disability Strategy (being developed)

Strategic Objective	Suggested Priority Actions	Outcomes	Alignment with existing or emerging policies (inc. reviews)
	Ensure adequate funding for the NDIS to promptly and equitably meet the needs of people with neurological conditions	Fairer access, timely provision of support and therapies	*NDIS Review Final Report (2023),* NDIS Participant Service Improvement Plan, Disability Royal Commission report (2023)
	Guarantee access to affordable therapies, assistive technologies, and rehabilitation	Earlier access to emerging treatments through clinical trials, greater equity, independence and quality of life, reduced long-term health costs	*Australia's Disability Strategy 2021-31,* Aged Care reform agenda, PBS/HTA Review
	Deliver and expand pre-service education for doctors and nurses on neurological care to reflect the neurological burden as proportion of the population. Deliver targeted training for healthcare professionals to improve diagnosis, treatment, support and prevention (eg carrier screening for genetic diseases)	Improved diagnosis and care quality, earlier intervention and disease management	*NDIS Workforce Capability Framework,* Aged Care Workforce Strategy (being developed), National Allied Health Workforce Strategy (being developed), *Genomics Australia Roadmap 2023, National Care and Support Economy Strategy 2023*, Primary Care reform
	Consolidate professional education by NAA members, together with professional bodies, to be more effective and cost efficient	Reduced duplication and cost, ensure consistent high-quality clinical education, enhance national neuro knowledge	*National Workforce Strategy 2022-27*, Allied Health and specialist College initiatives, Health and Medical Research Workforce reforms

Strategic Objective	Suggested Priority Actions	Outcomes	Alignment with existing or emerging policies (inc. reviews)
4. Provide practical and emotional support for people with neurological conditions and their carers and families	Introduce a national Neurological Support Package (managing through difficult news, respite, counselling, financial support and income protection) co-produced by people with lived experience and carers/family	Holistic wrap-around supports for patients, carers and families	NDIS Review, *National Carer Strategy 2024-2034*, Mental Health reforms
	Fund peer support networks and targeted support initiatives for children and young people	Social connection, resilience, reduced isolation	*Mental Health and Wellbeing Strategy 2023-2027*, State/Territory mental health and children/*youth initiatives*
	Tailor well-being programs to those living with chronic neurological diseases, who are at higher risk of depression, anxiety and social isolation	Social connection, resilience, reduced isolation	*Mental Health and Wellbeing Strategy 2023-2027, Royal Commissions (Aged Care, Disability, Mental Health (Vic)), National Preventive Health Strategy 2021–2030,* youth initiatives (State/Territory)
	Integrate caregiver impact into PBS and service evaluations	Valuing carers, equitable funding decisions re subsidised treatments and services	*Health Technology Assessment (HTA) Review* (underway), *National Carer Strategy 2024-2034, Carer Recognition Act, PBS reform (inc Pharmaceutical Reform Agreement Review 2024),* Productivity Commission reviews (various)
	Involve people with lived experience of neurological conditions and carers/family in the monitoring and evaluation of policies, plans, research and other strategies and services relevant to them	More relevant and responsive policies, plans, strategies and services for people with neurological conditions and their carers and family	National Strategic Framework for Chronic Conditions (review underway), National Preventive Health Strategy 2021-2030, Carer Recognition Act 2010 (Cth), NHMRC Statement on Consumer and Community Involvement in Health and Medical Research (currently under review)

Strategic Objective	Suggested Priority Actions	Outcomes	Alignment with existing or emerging policies (inc. reviews)
5. Drive research, data and assistive technology innovation	Establish a Neurological Research Mission under the Medical Research Future Fund (MRFF) to unite and build on separate research investments in neurological conditions	Long-term investment, cures, innovation, better coordinated action, progress accelerated in neurological health	MRFF Missions Framework, *National Strategic Action Plan for Rare Diseases 2020*, National Health and Medical Research Strategy (being developed)
	Fund further research on modifiable risk factors and neuroprotection	Development of prevention strategies, strengthened evidence base for public health	*National Preventive Health Strategy 2021-2030, MRFF Dementia, Brain Cancer, and Genomics Missions, National Strategic Action Plan for Rare Diseases 2020, National Dementia Action Plan 2024–2034*
	Streamline the neurological clinical trials pipeline and implement the National One Stop Shop for Clinical Trials	Faster trial approvals, broader patient access	National One Stop Shop for Clinical Trials (underway), *National Clinical Trials Governance Framework 2022*, National Health and Medical Research Strategy (being developed)
	Reform the PBS and implement the HTA Review to ensure faster and fairer access for Australians to innovative medicines and treatments	Faster and fairer access to therapies, better support for rare/complex neurological conditions	HTA Review (underway), National Medicines Policy (2022), National Strategic Action Plan for Rare Diseases 2020
	Fund collaborative clinical trials and research projects targeting causes, modifiable risk factors, treatments, and cures for neurological diseases, and world-best care models	Prevention, treatment breakthroughs	MRFF Trials Programs, HTA Review (underway)
	Fund AIHW to develop and maintain a linked Neurological Data Repository with dashboards	Evidence for planning, equity, performance	AIHW Strategy, National Disability Data Asset, Reform Agreements
	Incentivise AI-driven precision therapies, next-generation tools and local manufacture of assistive technology.	Innovation, precision medicine, local jobs	*Digital Economy Strategy 2030*, HTA Review (underway), Economic Reform Roundtable (Aug 2025)

Strategic Objective	Suggested Priority Actions	Outcomes	Alignment with existing or emerging policies (inc. reviews)
6. Strengthen health system integration	Support the Federal Government’s portfolio integration across the health, aged care, and disability to improve outcomes for people with neurological conditions (eg NDIS support workers being able to support a client admitted to hospital)	Seamless care, reduced fragmentation	NDIS Review, Royal Commissions, *Primary Health Care 10 Year Plan 2022–2032*
	Mandate neuro-informed training for NDIS, agedcare and hospital staff	Better recognition and management across sectors	NDIS Workforce Framework, Aged Care Standards, Health Workforce Strategy
	Pilot cross-sector Neuro Navigation Teams to coordinate care across health, disability and aged care	Coordinated care, reduced system burden for families	Care Finder model, Primary Health Network multidisciplinary trials, NDIS Review
	Embed neurological indicators in national performance reporting.	Accountability, better planning and equity	AIHW, *Report on Government Services* (Productivity Commission), National Disability Data Asset, Aged Care Quality and Safety Commission data

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“I wholeheartedly endorse the Blueprint for a National Action Plan for Neurological Conditions 2025–2031 developed by the Neurological Alliance Australia. This Blueprint sets out a clear and practical pathway to ensure that the millions of Australians living with neurological conditions, including multiple sclerosis, have fair access to the care, treatments, and support they deserve. By investing in integrated, forward-looking, and sustainable solutions, Australia can improve lives now while building a stronger future. The Blueprint is firmly aligned with the WHO Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders, showing leadership in translating global commitments into national action. Its impact will extend far beyond Australia, providing a model that can inspire countries around the world to prioritise neurological health.”

— Lydia Makaroff, Chief Executive, Multiple Sclerosis International Federation

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