



Spinal Muscular Atrophy
AUSTRALIA INC.



Neurological Alliance Australia

Seeks commitments for the 2019 Federal Election

These are the important ways our politicians can help us...

Neurological Alliance Australia*

DEMENTIA AUSTRALIA

BRAIN INJURY AUSTRALIA

HUNTINGTON'S AUSTRALIA

MOTOR NEURONE DISEASE AUSTRALIA

MJD FOUNDATION

MS AUSTRALIA

MUSCULAR DYSTROPHY AUSTRALIA

MUSCULAR DYSTROPHY FOUNDATION AUSTRALIA

PARKINSON'S AUSTRALIA

SPINAL MUSCULAR ATROPHY AUSTRALIA

LEUKODYSTROPHY AUSTRALIA

POLIO AUSTRALIA

The NAA seeks commitments from candidates from all sides of politics to address the urgent needs of adults and children living with progressive neurological or neuromuscular diseases in Australia.

What do we need?

People with progressive neurological or neuromuscular diseases have two basic needs:

1. A cure
2. Improved support for their treatment, care and management

How many are affected?

The members of the NAA are able to make estimates of the number of people diagnosed with the conditions represented by the Alliance and also the annual cost to the Australian economy through economic impact studies.

Overall, it is estimated that nearly 1.3 million Australians live with a progressive neurological or neuromuscular disease in Australia with an annual cost to the Australian economy of over \$36 billion. Nearly every Australian knows or has a loved one with one of these debilitating diseases.

*The Neurological Alliance Australia is an alliance of national not-for-profit peak organisations with a focus on representing adults and children, their families, friends and carers, living with progressive, degenerative, neurological or neuromuscular conditions in Australia. Collectively we aim to promote shared issues and concerns for the improved quality of life for people living with these conditions and funding to support research into the treatment, better management and ultimately a cure for these conditions.

1. Invest in funding for medical research

What needs to be done?

The NAA represents a group of progressive, degenerative neurological and neuromuscular diseases which are lifelong and for which cures are yet to be found. Doctors and scientists are making discoveries about the treatment and management of these diseases every day, yet significant research investment is needed to progress this work and give hope to the more than 1.3 million affected in Australia.

- A significant investment in medical research to treat, prevent and ultimately to cure these diseases.
- The development of National Guidelines for the management of people with rapidly progressive neurological conditions.

3. Stop young people entering residential aged care

What needs to be done?

More than 6,000 Australians aged under 65 live in aged care facilities. Of those, around 2,000 have joined the NDIS but so far only 2% of these participants receive housing support in their plans. Admissions of young people into residential aged care is not acceptable in 2019 and beyond.

- An investment in dramatically improved specialist accessible accommodation options
- Funding to provide an appropriate level of care within the NDIS
- Integration of the NDIS with the housing and health sectors
- Investment in an appropriately trained disability workforce

2. Address NDIS implementation problems

What needs to be done?

Our communities live with unpredictable, often invisible diseases, full of uncertainty. A commitment to addressing the many issues that have arisen during the implementation of the NDIS will reassure our communities, their families and carers, enabling them to maintain their independence and plan for the future.

- Improve training of NDIA staff especially in knowledge about neurological conditions, improve clarity and consistency in plans, improve flexibility in length of plans, and improve the ease and transparency of the planning review process
- Improve the delivery of the NDIS to Aboriginal and Torres Strait Islander people with disability in remote communities
- Fund specialist disability organisations to support NDIS pre-planning¹
- Address the practical application of those NDIS principles not aligned to the increased needs of those living with degenerative neurological conditions, e.g. cannot apply a policy of reducing Coordination of Support hours as capacity increases - this does not apply to a degenerative condition

¹ "The NDIA should also make better use of expertise from within the industry, including by getting specialist disability organisations or service providers more involved in the planning process", NDIS Costs - Productivity Commission Study Report, Nov 2017, p 28

4. Provide housing options

What needs to be done?

Much of Australia's housing stock is unaffordable or inaccessible, and government policy settings push people with chronic diseases and disability into unsafe and unwanted housing, such as group homes or boarding houses, or even into homelessness and too often are being forced into residential aged care.

- A significant investment in housing to make sure that all people with chronic diseases and disability live in homes that are safe, affordable and accessible, including suitable housing in rural and remote areas
- Accessible housing features to be made mandatory in all new housing
- Accessible housing to be integrated into existing residential communities, including portable housing
- Federal Government to provide financial incentives to make sure our social, public and community housing is accessible

6. Stop excessive levels of out-of-pocket expenses

What needs to be done?

Progressive, degenerative neurological and neuromuscular diseases are very expensive and the burden of out-of-pocket expenses increases year by year, despite mechanisms such as the PBS safety net.

- Review and expand the variety and level of safety net measures to mitigate against the financial hardship of living with a chronic disease.

5. Ensure equal access to assistive technology

What needs to be done?

It is unclear where responsibility lies for addressing the assistive technology needs of older people with a chronic disease or disability. Funding and access is inequitable and confusing. Many people are sacrificing their limited income or falling through the gaps.

- State and Federal Governments must come together to develop a sustainable solution to the equitable provision of assistive technology to all Australians
- Provide funds for assistive technology in addition to Home Care Package funding to ensure that older people who acquire a disability can access the assistive technology they need to maintain their independence, quality of life, communication and community access and to support carer health and well-being

7. Improve the quality of aged care

What needs to be done?

Aged Care services are designed to support people who are frail aged, not people with progressive complex conditions.

This is causing many people to be pushed into financial hardship or residential aged care. Others are added to long waiting lists or are assigned a lower level package that does not meet their needs.

- The introduction of a formal 'fast track' process for automatic access to Level 4 Home Care for those with progressing and complex needs
- Packages for people living with complex and progressive conditions
- If Aged Care is unable to meet the disability needs of older people, the NDIS should develop a safety net model that provides for top-up funding through the NDIS to address needs not met by Aged Care
- Ultimately the NDIS should include all people with disability, regardless of age

9. Introduce care pathways and sector integration

What needs to be done?

Everyone living with a progressive neurological or neuromuscular condition should have access to the right care, in the right place at the right time.

We want to create articulated pathways of care and support, with an emphasis on consumer-directed care. The introduction of policies to bring about mandated integration between the aged care, health care and disability care systems will ensure people with a disability have their needs met, regardless of which system they access. This approach will also bring about efficiencies in the NDIS, through the streamlining of services and support.

- Effective interfaces with allied sectors, particularly health and palliative care, must be developed to ensure a coordinated inter and multidisciplinary approach to care
- The development of National Guidelines for the management of people with rapidly progressive neurological conditions

8. Invest in Neurological (Movement Disorders) Nurse positions

What needs to be done?

Patients with progressive degenerative neurological conditions are often unable to access health professionals who have a good understanding of their condition and best practice management. An investment in the establishment of up to 100 community-based Neurological (Movement Disorders) Nurse positions in rural and regional settings, will:

- Reduce the current burden on the Australian economy from inadequate or delayed health services and the level of government funded services such as the NDIS, Disability Support Pension and aged care services.
- Improve patient quality of life by enabling the individual to remain independent for longer without excessive financial burden and the stress of finding appropriately trained professionals.
- Reduce the rate and/or degree of degenerative symptoms an individual may experience without access to specialised assistance.
- Reduce the burden and workload of GPs and neurologists, reduce presentations to hospital accident and emergency departments, reduce hospital admissions, and reduce length-of-stay in hospital
- Optimise NDIS packages (nursing is excluded from NDIS packages, but packages will be optimised if a NDIS participant is well managed medically)

For more information on these 2019 Federal Election Commitments and the work of the Neurological Alliance Australia:

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